



Royal College  
of Physicians

# Why asthma still kills

## The National Review of Asthma Deaths (NRAD)

Confidential Enquiry report  
**May 2014**

Commissioned by:

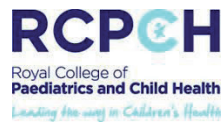
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**HQIP**

Healthcare Quality  
Improvement Partnership

**Supported by:**



**Eastern Region Confidential Enquiry of Asthma Deaths**





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**Confidential Enquiry report (May 2014)**

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**The National Review of Asthma Deaths (NRAD)**

The National Review of Asthma Deaths (NRAD) is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England, NHS Wales, the Health and Social Care Division of the Scottish Government, and the Northern Ireland Department of Health, Social Services and Public Safety (DHSSPS). The NRAD is delivered by the Clinical Effectiveness and Evaluation Unit (CEEU) of the Clinical Standards Department at the Royal College of Physicians (RCP).

**Healthcare Quality Improvement Partnership (HQIP) and the Clinical Outcome Review Programmes (CORP)**

The Healthcare Quality Improvement Partnership (HQIP) is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing (RCN) and National Voices. HQIP's aim is to increase the impact that clinical audit has on healthcare quality and stimulate improvement in safety and effectiveness by systematically enabling clinicians, managers and policy-makers to learn from adverse events and other relevant data.

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## Foreword

### Why asthma still kills

It is a great honour to be asked to write the foreword to this report of the National Review of Asthma Deaths (NRAD) Confidential Enquiry. It represents an immense amount of work, expertly led, executed with immense attention to detail and involving very large numbers of people freely offering their time to ensure the validity of the results.

When the establishment of a confidential enquiry was being considered 3–4 years ago, concern was expressed that it may not tell us anything new, and that previous local audits over three or four decades had shown depressingly similar findings. Some of the findings reported here are undoubtedly new, some have been emphasised for over 40 years; however, they are highlighted now, at a time when we potentially have new systems to address them (eg computerised prescribing), and some results should unequivocally lead to a shake-up, more training and monitoring, and an end to the complacency that has arisen regarding this common condition.

When I first became involved in trying to improve care for those with asthma, there were no guidelines, less choice of medications, very few nurse specialists and little information or support available for those with the condition. Much has improved since then but, as this report shows, complacency must be tackled. The very heterogeneity of the condition may have contributed to the complacency; however, as the report shows, it is not just those with severe asthma who die. Whilst one appreciates the diversity of medical conditions looked after in primary care, and indeed the diversity of respiratory illnesses looked after by chest physicians and paediatricians, some of our failings with regards to asthma care represent a general failing to change systems and approaches to accommodate the new health burdens, which are no longer acute, but long term. If our patients do not always take medication as we advise, is that their fault or our failure to involve them in a process of shared decision making? If the patient fails to attend for review or to collect a repeat prescription, is it because our processes, methods of follow-up or their convenience was suboptimal, or indeed was it the quality of the consultation and the expertise experienced that failed to impress? Our continued failure to provide meaningful support as patients self-manage their condition needs to be rectified, and where this needs to be modified to address issues of literacy or psychological comorbidity, we need to do so to ensure that good care is equally available to all.

As you read this report, do not forget that it concerns people who have died, many needlessly and many prematurely, leaving anguish and heartbreak for their loved ones. The best result from this report would be that its recommendations are implemented and a further review of asthma deaths will not be required, because fewer people die from the disease.

**Martyn R Partridge**  
Professor of respiratory medicine, Imperial College London

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## Who is this report for?

This report is intended for use by a wide range of audiences, including:

- NHS service managers
- pharmacists
- primary healthcare settings: GP practices, practice nurses, out-of-hours services, first responders, paramedics
- secondary healthcare settings: hospitals, urgent care centres (UCCs), emergency departments (accident and emergency)
- patients and carers
- policy-makers: health departments of England, Northern Ireland, Scotland and Wales
- commissioners
- professional and patient organisations: royal colleges, specialist societies and organisations representing patients.

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## Executive summary

Advancements in drug treatments, applied research and the development of evidence-based clinical guidelines have contributed to the reduction of deaths from asthma over the past 50 years.

Previous confidential enquiries have suggested that avoidable factors play a part in as many as three-quarters of cases of asthma death. These studies have often been small, conducted locally and undertaken at a considerable time after death. The National Review of Asthma Deaths (NRAD), reported here, is the first national investigation of asthma deaths in the UK and the largest study worldwide to date. Work on the NRAD was undertaken over a 3-year period and was one element of the Department of Health in England's Respiratory Programme. The primary aim of the NRAD was to understand the circumstances surrounding asthma deaths in the UK in order to identify avoidable factors and make recommendations to improve care and reduce the number of deaths.

Asthma deaths occurring between February 2012 and January 2013 were identified through the Office for National Statistics (ONS) for England and Wales, the Northern Ireland Statistics and Research Agency (NISRA) and the National Records of Scotland (NRS). Extensive information about each death was sought from multiple sources, including primary, secondary and tertiary care, as well as ambulance, paramedic and out-of-hours care providers. 374 local coordinators were appointed in 297 hospitals across the NHS to collect and submit information to the project team, and 174 expert clinical assessors were recruited from primary, secondary and tertiary care throughout the UK to join expert panels that reviewed data. Each assessor participated in one or more expert panels, during which all information gathered on each death, including post-mortem reports, was reviewed by two assessors in detail, and this was followed by discussion and a consensus agreement of avoidable factors and recommendations by the whole panel.

Data were available for analysis on 195 people who were thought to have died from asthma during the review period and the key findings relate to this group. Denominators vary according to where data were missing.

### Key findings

#### Use of NHS services

- 1 During the final attack of asthma, 87 (45%) of the 195 people were known to have died without seeking medical assistance or before emergency medical care could be provided.
- 2 The majority of people who died from asthma (112, 57%) were not recorded as being under specialist supervision during the 12 months prior to death. Only 83 (43%) were managed in secondary or tertiary care during this period.

- 3 There was a history of previous hospital admission for asthma in 47% (90 of 190).
- 4 Nineteen (10%) of the 195 died within 28 days of discharge from hospital after treatment for asthma.
- 5 At least 40 (21%) of the 195 people who died had attended a hospital emergency department with asthma at least once in the previous year and, of these, 23 had attended twice or more.

### **Medical and professional care**

- 1 Personal asthma action plans (PAAPs), acknowledged to improve asthma care, were known to be provided to only 44 (23%) of the 195 people who died from asthma.
- 2 There was no evidence that an asthma review had taken place in general practice in the last year before death for 84 (43%) of the 195 people who died.
- 3 Exacerbating factors, or triggers, were documented in the records of almost half (95) of patients; they included drugs, viral infections and allergy. A trigger was not documented in the other half.
- 4 Of 155 patients for whom severity could be estimated, 61 (39%) appeared to have severe asthma. Fourteen (9%) were being treated for mild asthma and 76 (49%) for moderate asthma. It is likely that many patients who were treated as having mild or moderate asthma had poorly controlled undertreated asthma, rather than truly mild or moderate disease.
- 5 The expert panels identified factors that could have avoided death in relation to the health professional's implementation of asthma guidelines in 89 (46%) of the 195 deaths, including lack of specific asthma expertise in 34 (17%) and lack of knowledge of the UK asthma guidelines in 48 (25%).

### **Prescribing and medicines use**

- 1 There was evidence of excessive prescribing of reliever medication. Among 189 patients who were on short-acting relievers at the time of death, the number of prescriptions was known for 165, and 65 of these (39%) had been prescribed more than 12 short-acting reliever inhalers in the year before they died, while six (4%) had been prescribed more than 50 reliever inhalers. Those prescribed more than 12 reliever inhalers were likely to have had poorly controlled asthma.
- 2 There was evidence of under-prescribing of preventer medication. To comply with recommendations, most patients would usually need at least 12 preventer prescriptions per year. Among 168 patients on preventer inhalers at the time of death, either as stand-alone or in combination, the number of prescriptions was known for 128, and 49 of these (38%) were known to have been issued with fewer than four and 103 (80%) issued with fewer than 12 preventer inhalers in the previous year.
- 3 There was evidence of inappropriate prescribing of long-acting beta agonist (LABA) bronchodilator inhalers. From available data, 27 (14%) of those who died were prescribed a single-component LABA bronchodilator at the time of death. At least five (3%) patients were on LABA monotherapy without inhaled corticosteroid preventer treatment.

### **Patient factors and perception of risk of poor control**

- 1 The expert panels identified factors that could have avoided the death related to patients, their families and the environment in 126 (65%) of those who died. These included current tobacco smoking in 37 (19%), exposure to second-hand smoke in the home, non-adherence to medical advice and non-attendance at review appointments.
- 2 Particularly in children and young people, poor recognition of risk of adverse outcome was found to be an important avoidable factor in 7/10 (70%) children and 15/18 (83%) young people in primary care, and in 2/7 (29%) children and 3/9 (33%) young people in secondary care.

- 3 The median age at the time of the initial diagnosis of asthma was 37 years. Most people who died, and for whom this information was available, were diagnosed in adulthood, with 70/102 (69%) diagnosed after the age of 15 years.
- 4 Psychosocial factors contributing to the risk of asthma death and its perception were identified by panels in 51 (26%) of those who died, and included depression and mental health issues in 32 (16%) and substance misuse in 12 (6%).

## Key recommendations

### Organisation of NHS services

- 1 Every NHS hospital and general practice should have a designated, named clinical lead for asthma services, responsible for formal training in the management of acute asthma.
- 2 Patients with asthma must be referred to a specialist asthma service if they have required more than two courses of systemic corticosteroids, oral or injected, in the previous 12 months or require management using British Thoracic Society (BTS) stepwise treatment 4 or 5 to achieve control.<sup>1</sup>
- 3 Follow-up arrangements must be made after every attendance at an emergency department or out-of-hours service for an asthma attack. Secondary care follow-up should be arranged after every hospital admission for asthma, and for patients who have attended the emergency department two or more times with an asthma attack in the previous 12 months.
- 4 A standard national asthma template should be developed to facilitate a structured, thorough asthma review. This should improve the documentation of reviews in medical records and form the basis of local audit of asthma care.
- 5 Electronic surveillance of prescribing in primary care should be introduced as a matter of urgency to alert clinicians to patients being prescribed excessive quantities of short-acting reliever inhalers, or too few preventer inhalers.
- 6 A national ongoing audit of asthma should be established, which would help clinicians, commissioners and patient organisations to work together to improve asthma care.

### Medical and professional care

- 1 All people with asthma should be provided with written guidance in the form of a personal asthma action plan (PAAP) that details their own triggers and current treatment, and specifies how to prevent relapse and when and how to seek help in an emergency.
- 2 People with asthma should have a structured review by a healthcare professional with specialist training in asthma, at least annually. People at high risk of severe asthma attacks should be monitored more closely, ensuring that their personal asthma action plans (PAAPs) are reviewed and updated at each review.
- 3 Factors that trigger or exacerbate asthma must be elicited routinely and documented in the medical records and personal asthma action plans (PAAPs) of all people with asthma, so that measures can be taken to reduce their impact.
- 4 An assessment of recent asthma control should be undertaken at every asthma review. Where loss of control is identified, immediate action is required, including escalation of responsibility, treatment change and arrangements for follow-up.
- 5 Health professionals must be aware of the factors that increase the risk of asthma attacks and death, including the significance of concurrent psychological and mental health issues.

### **Prescribing and medicines use**

- 1 All asthma patients who have been prescribed more than 12 short-acting reliever inhalers in the previous 12 months should be invited for urgent review of their asthma control, with the aim of improving their asthma through education and change of treatment if required.
- 2 An assessment of inhaler technique to ensure effectiveness should be routinely undertaken and formally documented at annual review, and also checked by the pharmacist when a new device is dispensed.
- 3 Non-adherence to preventer inhaled corticosteroids is associated with increased risk of poor asthma control and should be continually monitored.
- 4 The use of combination inhalers should be encouraged. Where long-acting beta agonist (LABA) bronchodilators are prescribed for people with asthma, they should be prescribed with an inhaled corticosteroid in a single combination inhaler.

### **Patient factors and perception of risk**

- 1 Patient self-management should be encouraged to reflect their known triggers, eg increasing medication before the start of the hay-fever season, avoiding non-steroidal anti-inflammatory drugs or by the early use of oral corticosteroids with viral- or allergic-induced exacerbations.
- 2 A history of smoking and/or exposure to second-hand smoke should be documented in the medical records of all people with asthma. Current smokers should be offered referral to a smoking-cessation service.
- 3 Parents and children, and those who care for or teach them, should be educated about managing asthma. This should include emphasis on 'how', 'why' and 'when' they should use their asthma medications, recognising when asthma is not controlled and knowing when and how to seek emergency advice.
- 4 Efforts to minimise exposure to allergens and second-hand smoke should be emphasised, especially in young people with asthma.

# Recommendations matrix

Recommendation	NHS service managers	Pharmacists	Primary healthcare settings: GP practices, practice nurses, out-of-hours services, first responders, paramedics	Secondary healthcare settings: hospitals, urgent care centres (UCCs), emergency departments (accident and emergency)	Patients and carers	Policy-makers: health departments of England, Northern Ireland, Scotland and Wales	Commissioners	Professional and patient organisations: royal colleges, specialist societies and organisations representing patients
<b>Organisation of NHS services</b>								
Every NHS hospital and general practice should have a designated, named clinical lead for asthma services, responsible for formal training in the management of acute asthma	✓		✓	✓		✓	✓	
Patients with asthma must be referred to a specialist asthma service if they have required more than two courses of systemic corticosteroids, oral or injected, in the previous 12 months or require management using British Thoracic Society (BTS) stepwise treatment 4 or 5 to achieve control <sup>1</sup>			✓	✓			✓	

Recommendation	NHS service managers	Pharmacists	Primary healthcare settings: GP practices, practice nurses, out-of-hours services, first responders, paramedics	Secondary healthcare settings: hospitals, urgent care centres (UCCs), emergency departments (accident and emergency)	Patients and carers	Policy-makers: health departments of England, Northern Ireland, Scotland and Wales	Commissioners	Professional and patient organisations: royal colleges, specialist societies and organisations representing patients
Follow-up arrangements must be made after every attendance at an emergency department or out-of-hours service for an asthma attack. Secondary care follow-up should be arranged after every hospital admission for asthma, and for patients who have attended the emergency department two or more times with an asthma attack in the previous 12 months	✓		✓	✓			✓	
A standard national asthma template should be developed to facilitate a structured, thorough asthma review. This should improve the documentation of reviews in medical records and form the basis of local audit of asthma care	✓		✓			✓	✓	





Recommendation	NHS service managers	Pharmacists	Primary healthcare settings: GP practices, practice nurses, out-of-hours services, first responders, paramedics	Secondary healthcare settings: hospitals, urgent care centres (UCCs), emergency departments (accident and emergency)	Patients and carers	Policy-makers: health departments of England, Northern Ireland, Scotland and Wales	Commissioners	Professional and patient organisations: royal colleges, specialist societies and organisations representing patients
<b>Medical and professional care</b>								
All people with asthma should be provided with written guidance in the form of a personal asthma action plan (PAAP) that details their own triggers and current treatment, and specifies how to prevent relapse and when and how to seek help in an emergency			✓	✓	✓		✓	✓
People with asthma should have a structured review by a healthcare professional with specialist training in asthma, at least annually. People at high risk of severe asthma attacks should be monitored more closely, ensuring that their personal asthma action plans (PAAPs) are reviewed and updated at each review			✓	✓			✓	

Factors that trigger or exacerbate asthma must be elicited routinely and documented in the medical records and personal asthma action plans (PAAPs) of all people with asthma, so that measures can be taken to reduce their impact			✓
An assessment of recent asthma control should be undertaken at every asthma review. Where loss of control is identified, immediate action is required, including escalation of responsibility, treatment change and arrangements for follow-up	✓		
Health professionals must be aware of the features that increase the risk of asthma attacks and death, including the significance of concurrent psychological and mental health issues			
✓	✓		✓
✓	✓		✓
	✓		✓

Recommendation	NHS service managers	Pharmacists	Primary healthcare settings: GP practices, practice nurses, out-of-hours services, first responders, paramedics	Secondary healthcare settings: hospitals, urgent care centres (UCCs), emergency departments (accident and emergency)	Patients and carers	Policy-makers: health departments of England, Northern Ireland, Scotland and Wales	Commissioners	Professional and patient organisations: royal colleges, specialist societies and organisations representing patients
<b>Prescribing and medicines use</b>								
All asthma patients who have been prescribed more than 12 short-acting reliever inhalers in the previous 12 months should be invited for urgent review of their asthma control, with the aim of improving their asthma through education and change of treatment if required		✓	✓	✓	✓	✓	✓	✓
An assessment of inhaler technique to ensure effectiveness should be routinely undertaken and formally documented at annual review, and also checked by the pharmacist when a new device is dispensed		✓	✓					



Recommendation	NHS service managers	Pharmacists	Primary healthcare settings: GP practices, practice nurses, out-of-hours services, first responders, paramedics	Secondary healthcare settings: hospitals, urgent care centres (UCCs), emergency departments (accident and emergency)	Patients and carers	Policy-makers: health departments of England, Northern Ireland, Scotland and Wales	Commissioners	Professional and patient organisations: royal colleges, specialist societies and organisations representing patients
<b>Patient factors and perception of risk</b>								
Patient self-management should be encouraged to reflect their known triggers, eg increasing medication before the start of the hay-fever season, avoiding non-steroidal anti-inflammatory drugs or by the early use of oral corticosteroids with viral or allergic-induced exacerbations		✓	✓	✓	✓			✓
A history of smoking and/or exposure to second-hand smoke should be documented in the medical records of all people with asthma. Current smokers should be offered referral to a smoking-cessation service	✓		✓	✓	✓			✓

<p>Parents and children, and those who care for or teach them, should be educated about managing asthma. This should include emphasis on 'how', 'why' and 'when' they should use their asthma medications, recognising when asthma is not controlled and knowing when and how to seek emergency advice</p>	✓									
	✓									
	✓									
	✓									
	✓									
	✓									
	✓									
	✓									
	✓									
<p>Efforts to minimise exposure to allergens and second-hand smoke should be emphasised, especially in young people with asthma</p>	✓									
<b>Research recommendation</b>										
<p>Further research is required to confirm whether late-onset asthma is a risk factor for asthma death</p>	✓									

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# Chapter 1 – Introduction

## Features of asthma

Asthma is a common, multifactorial and often chronic (long-term) respiratory illness that can result in episodic or persistent symptoms and in episodes of suddenly worsening wheezing (asthma attacks, or exacerbations) that can prove fatal. The British Thoracic Society/Scottish Intercollegiate Guidelines Network (BTS/SIGN) asthma guideline highlights that the diagnosis of asthma is based on clinical features with support from objective findings; there is no standardised definition of the type, severity or frequency of symptoms, nor of any investigation findings, which can be variable.<sup>1</sup> The absence of a ‘gold standard’ test makes it difficult to confirm or refute the diagnosis of asthma. Therefore, asthma diagnosis is usually based on one or more typical features, including: respiratory symptoms; evidence of variable airflow obstruction using lung function tests; and the person’s response to asthma medication. Symptoms of asthma include the intermittent presence of wheeze, breathlessness, chest tightness and cough. Airflow obstruction results from airway hyper-responsiveness (or twitchiness of the muscles in the airways), and inflammation resulting in swelling of the airway walls as well as accumulation of secretions within. Symptoms are usually episodic and may vary over time. Asthma is triggered by many factors, including: viral infections; exercise; substances (called allergens) that cause allergic reactions, either aero-allergens (such as house dust mites, pollens, fungal spores or animal dander) or oral allergens (such as eggs, fish, milk or nuts). Other triggers include medicines including aspirin and non-steroidal anti-inflammatory drugs (NSAIDs), eg ibuprofen and naproxen, and environmental factors such as tobacco smoke, dust and fumes, and air pollutants, as well as climatic variation.

The underlying pathological process resulting in the features of asthma vary between individuals. Hence, each person’s asthma has different characteristics and pattern of triggers and their response to treatment may also vary. People with asthma also experience uncontrolled episodes or attacks that too can vary between and within individuals. These asthma attacks at their worst can be life threatening or, more rarely, fatal. In order to ensure that people with asthma are free from symptoms and attacks and are able to lead a normal, active life, each patient should have their asthma triggers identified and treatment tailored to their needs.

## Psychosocial aspects

There is a well-recognised link between asthma and psychosocial problems; the prevalences of anxiety, depression and panic disorder are much higher in people with asthma than in matched controls and are associated with poor outcomes.<sup>1,2</sup> The association between impaired psychological health status and

asthma outcomes, including mortality (death), has been known by researchers for many years. Furthermore, disadvantaged socio-economic and ethnic groups have particularly poor outcomes. For example, those with asthma who also have depression or anxiety experience more asthma symptoms and have worse outcomes in terms of higher use of healthcare resources, less successful emergency treatment and more frequent admission to hospital. Adherence to preventative treatment is reduced in people with psychological dysfunction.

## Epidemiology of asthma in the UK

The number of people affected by asthma in the UK is amongst the highest in the world. According to Asthma UK and other sources, up to 5.4 million people in the UK are currently receiving treatment for asthma.<sup>3–5</sup> It accounts for high numbers of consultations in primary care, out-of-hours services and hospital emergency departments. During 2011–2, there were over 65,000 hospital admissions for asthma in the UK (Table 1.1).

**Table 1.1 Number of hospital admissions for asthma in the UK (2011–2)**

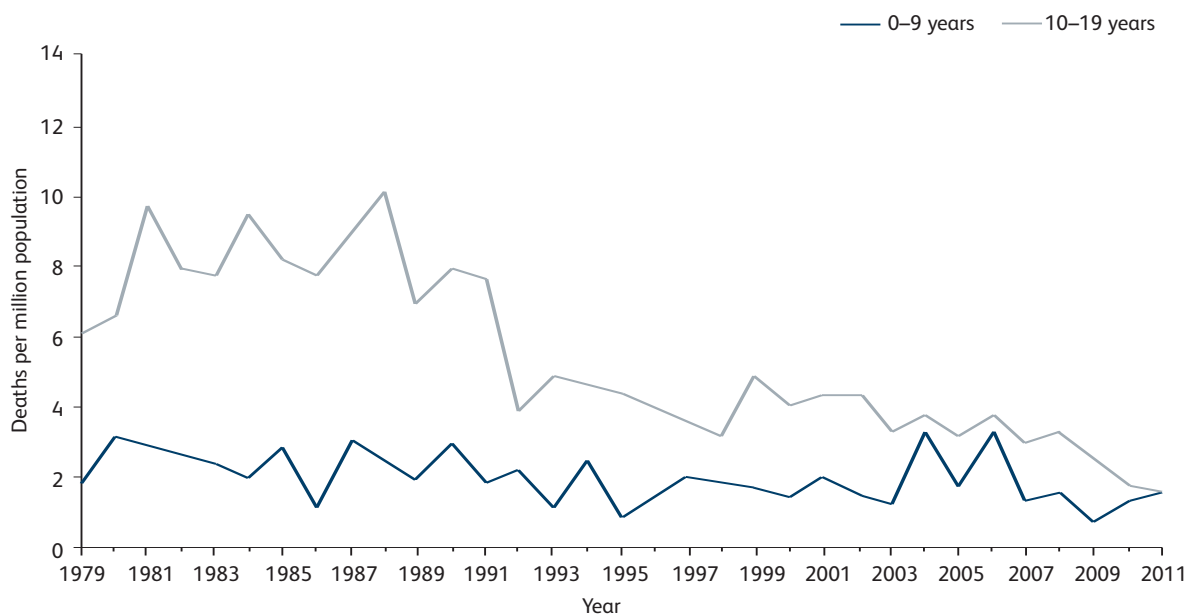
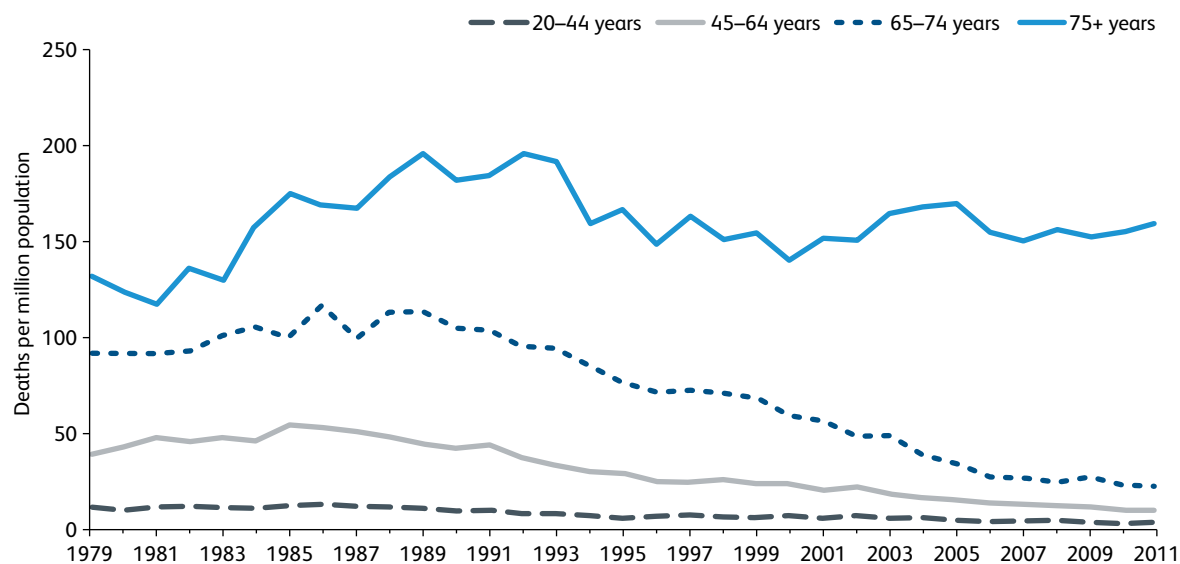
	All ages	Age 0–14 years	Age 15+ years
<b>UK</b>	65,316	25,073	40,243
<b>England</b>	54,789	21,319	33,470
<b>Wales</b>	3,349	1,231	2,118
<b>Scotland</b>	5,694	1,886	3,808
<b>Northern Ireland</b>	1,484	637	847

Sources: **Scotland:** Scottish Morbidity Record, Information Services Division, NHS Scotland; **England:** Hospital Episode Statistics, Health & Social Care Information Centre; **Wales:** Health Services Wales; **Northern Ireland:** Hospital Inpatient System, Northern Ireland Department of Health, Social Services and Public Safety

## Asthma deaths in the UK

The number of deaths from asthma in the UK has fluctuated over the past 50 years. A peak during the 1960s affected all age groups, although most noticeably younger people, and was attributed to avoidable medical factors, particularly the introduction of unselective beta agonist bronchodilator reliever inhalers, which had adverse cardiovascular effects.<sup>6,7</sup> An unexplained increase in the number of deaths occurred in the early 1980s, peaking in 1998, this time affecting older age groups (Fig 1.1 and 1.2).

The number of reported asthma deaths in the UK remains amongst the highest in Europe.<sup>8,9</sup> Comparisons of international asthma death rates for 5- to 34-year-olds during 2001–10 show that the UK asthma mortality is one of the highest in Europe, and comparable with those for Australia, New Zealand and the USA.

**Fig 1.1 Deaths attributed to asthma. Males and females combined, 0–19 years, UK 1979–2011****Fig 1.2 Deaths attributed to asthma. Males and females combined, 20+ years, UK 1979–2011**

### Previous studies on asthma deaths

Since the 1960s, several investigations into the circumstances of deaths from asthma have been completed. These included confidential enquiries (based on asthma deaths only) and case-control studies (in which there was a comparison group of non-fatal asthma controls).<sup>10-19</sup> These studies have tended to be limited to younger age groups, and considered cases have been spread over a number of years. Furthermore, most of these investigations were undertaken retrospectively, with a considerable interval between the deaths and the enquiries; one notable exception is the currently ongoing confidential enquiry in the Eastern region of the UK into asthma deaths.<sup>10</sup>

In the early 1980s, the British Thoracic Association (BTA), now known as the British Thoracic Society (BTS), raised awareness of asthma deaths both in the UK and internationally by publishing its confidential enquiry into 90 people who died from asthma in 1979, in two regions of England.<sup>15</sup> The authors concluded that there were avoidable factors in 79% of the deaths, including poor recognition of severity by both patients and healthcare professionals as well as undertreatment. An international task force on asthma death and a publication highlighting problems related to hospital management of acute asthma attacks in the late 1980s resulted in the formulation of British and subsequently international guidelines on the management of asthma.<sup>20,21</sup> Sadly, subsequent regional asthma death confidential enquiries have repeatedly identified potentially avoidable factors that preceded most asthma deaths. Examples of avoidable factors related to asthma deaths include: long-term undertreatment of asthma; under-assessment of asthma severity; problems with routine management with a failure to follow guidelines and delays in referral to specialists; failure to follow up people after severe asthma attacks; and lack of patient education and provision of personal asthma action plans (PAAPs). Previous studies also identified that many people who die from asthma fail to adhere to medical advice, particularly related to attending routine review appointments and taking regular preventer medication for asthma (Appendix 9 – Literature review of key findings in asthma death confidential enquiries and studies).

The most recent publication by the ongoing Eastern Region Confidential Enquiry (2012) reported some additional factors that were deemed to have contributed to deaths from asthma.<sup>22</sup> These include:

- a summer seasonal peak of deaths, particularly in those aged below 40 years
- some evidence of clustering of deaths around thunderstorms in late summer
- allergic factors such as pet ownership in children
- intolerance to non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen, in patients with severe late-onset non-allergic asthma (ie that developed later in life).

## **The National Review of Asthma Deaths (NRAD)**

The Royal College of Physicians (RCP) was commissioned to deliver the National Review of Asthma Deaths (NRAD) by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England, NHS Wales, the Health and Social Care Division of the Scottish Government and the Northern Ireland Department of Health, Social Services and Public Safety (DHSSPS). The review was delivered under the auspices of the Clinical Effectiveness and Evaluation Unit (CEEU) within the Clinical Standards Department at the RCP.

While other asthma confidential enquiries have been undertaken regionally, the NRAD was the first UK-wide investigation of asthma deaths, and the largest worldwide study of this kind to date. Data were derived from multiple sources, including primary, secondary and tertiary care, as well as ambulance paramedic and out-of-hours care providers.

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## Chapter 2 – Aim and objectives

The aim and objectives were developed by a multidisciplinary steering group, which included asthma clinicians from primary and secondary care, statisticians, allergists, epidemiologists, government representatives, patient organisations, pathologists and national leads in respiratory disease. The NRAD was undertaken over a 3-year period from May 2011 to May 2014. It reviewed information on all certified asthma and anaphylaxis deaths occurring in the UK between February 2012 and January 2013.

### Aim

The aim of the NRAD was to understand the circumstances surrounding asthma deaths in the UK, in order to identify avoidable factors and make recommendations for changes to improve asthma care as well as patient self-management.

### Objectives

- 1 Conduct a multidisciplinary, confidential enquiry to investigate the circumstances and clarify the cause of death in those people meeting the study inclusion criteria.
- 2 Examine the effectiveness of the management of asthma by reviewing the quality of care during the fatal attack, as well as previous treatment, against standards derived principally from the British Thoracic Society/Scottish Intercollegiate Guidelines Network (BTS/SIGN) *British Guideline on the Management of Asthma* (2012).<sup>1</sup>
- 3 Identify potentially avoidable factors related to the circumstances of those asthma deaths.
- 4 Make recommendations for changes in clinical management in order to reduce the number of preventable deaths from asthma in the future.
- 5 Understand the effect of asthma and death from asthma on families and carers of people with asthma by interviewing bereaved relatives on their experiences of the care provided to the family member who died.

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## Chapter 3 – Method and data collection

### Standards, data collection and databases

The NRAD steering group agreed protocols for the confidential enquiry and family interviews. Notification and data collection forms for clinicians and emergency services were developed and tested for usability by steering group members, by a GP with recent experience of an asthma death in her practice and by a number of secondary care clinicians and members of the NRAD implementation group.

A family interview schedule was developed and agreed by contacting the bereaved families working group. Advice line specialist nurses working for Asthma UK were trained to pilot and subsequently conduct the interviews.

A modified DELPHI method was used to develop 25 indicators of quality of asthma care to be used by the NRAD enquiry panels, together with the BTS/SIGN *British Guideline on the Management of Asthma* (2012), for the evaluation of the cases that they were asked to review. These indicators are shown in Table 3.1.<sup>1,23</sup>

**Table 3.1 NRAD indicators of quality of asthma care**

Past medical history
1 Patients diagnosed with asthma should have at least one annual review by a health professional competent to do so.
2 An asthma review should include assessment of control, medication review and adjustment if necessary; education, and issue, review or modification of a written asthma action plan, inhaler technique checking, discussion around adherence and prescription filling and allergies (actions should be recorded).
3 Patients with diagnosed asthma should have an entry in the medical record that the patient has been given a written personal asthma action plan (PAAP).
4 Patients with severe asthma should be under the care of a specialist.
5 Patients should attend their planned review consultations for their asthma.
6 Patients with acute or deteriorating asthma should obtain access to medical attention within 24 hours.
7 For patients with severe asthma, there should be evidence in the record of a review of the patient's adherence to medication.



Table 3.1 *continued*

8	Patients prescribed more than six reliever inhalers in the previous 12 months should be on preventer treatment as well.
9	Patients with severe or life-threatening asthma attacks should have evidence of initial, and ongoing and repeated observations of recorded vital signs pre and post treatment, including SpO <sub>2</sub> /arterial blood gases and lung function (with reasons stated if not measured).
10	The initial assessment of a patient presenting with an asthma exacerbation should include information on previous attacks (including previous life-threatening attacks and intensive therapy unit (ITU) admissions).
11	When a patient with asthma presents with new or worsening respiratory symptoms, the medical records should include a note of the presenting symptoms, response to medication given or taken, and the current medication.
12	Assessment of patients presenting acutely with new or worsening respiratory symptoms should include: pulse; respiratory rate; pulse oximetry; lung function (peak expiratory flow (PEF) or spirometry); auscultation of the chest; and blood pressure (BP) measurement.
13	Patients attending a GP surgery, out-of-hours centre or hospital department with an asthma attack should be seen and initially treated with bronchodilators within half an hour.
14	Patients with life-threatening asthma attacks should be treated with oxygen-driven nebulised bronchodilators.
15	Patients treated in hospital for life-threatening or severe acute asthma should be treated with systemic steroids within 1 hour of arrival (if not administered before reaching hospital).
16	Patients treated for a severe or life-threatening asthma attack should be prescribed systemic steroids.
17	Patients should be treated according to guidelines.
<b>Management of previous attacks</b>	
18	There should be evidence of a structured discharge plan (to include medication, education and follow-up) following hospital admission for an asthma attack.
19	Patients should be provided with a new or updated personal asthma action plan (PAAP) immediately following treatment or within 48 hours after an asthma attack.
20	Inhaler technique: there should be a record of assessment of inhaler technique when patients are evaluated following an asthma attack.
21	Hospital staff should inform the GP of follow-up plan and management within 48 hours of discharge of patients following an asthma attack.
22	Hospital discharge letters following an asthma attack should detail presenting history, treatment, post-discharge treatment and follow-up plans.
23	There should be evidence that a structured management plan (to include medication, education and follow-up) has been given to the patient following treatment in primary care or accident and emergency for acute asthma.
24	Patients who have been treated for an asthma attack should be prescribed regular inhaled corticosteroids.
25	Adult patients admitted with acute asthma should not be discharged ideally until peak expiratory flow (PEF) >70 % best or predicted (if no previous record of PEF).

## Death certification

The inclusion or exclusion of cases in the NRAD was determined by death certificate entries and subsequent review of medical records. Death certificates, also known as Medical Certificates of Cause of Death (MCCDs), are completed as a statutory duty of the doctor who last attended the patient. In accordance with World Health Organization (WHO) recommendations in the *International Statistical Classification of Diseases and Related Health Problems 10th revision (ICD-10)*, the death certificate comprises two parts:<sup>24,25</sup>

- Part I, which comprises three subsections and captures information as follows:
  - Ia, the disease or condition leading directly to death
  - Ib, other disease or condition, if any, leading to Ia
  - Ic, other disease or condition, if any, leading to Ib.
- Part II, which captures information where there were other significant conditions, contributing to death, but not related to the disease or condition causing it.

The MCCD is used by national statistics departments to determine the ‘underlying cause of death’, also known as the ‘underlying cause mortality’.<sup>24,25</sup> In the UK, the responsible departments are the Office for National Statistics (ONS) for England and Wales, the Northern Ireland Statistics and Research Agency (NISRA) and the National Records of Scotland (NRS).

## NRAD inclusion and exclusion criteria

### Included:

- people who died between 1 February 2012 and 31 January 2013
- people under 75 years old, and whose underlying cause of death was classified by national data-recording agencies of the four nations (ONS, NISRA or NRS) as asthma or anaphylaxis (ie ICD-10U – J45–J46, T78.2); or
- people aged 75 years or more who had asthma or anaphylaxis in Part I of the MCCD or where asthma death was confirmed by post-mortem.

### Excluded:

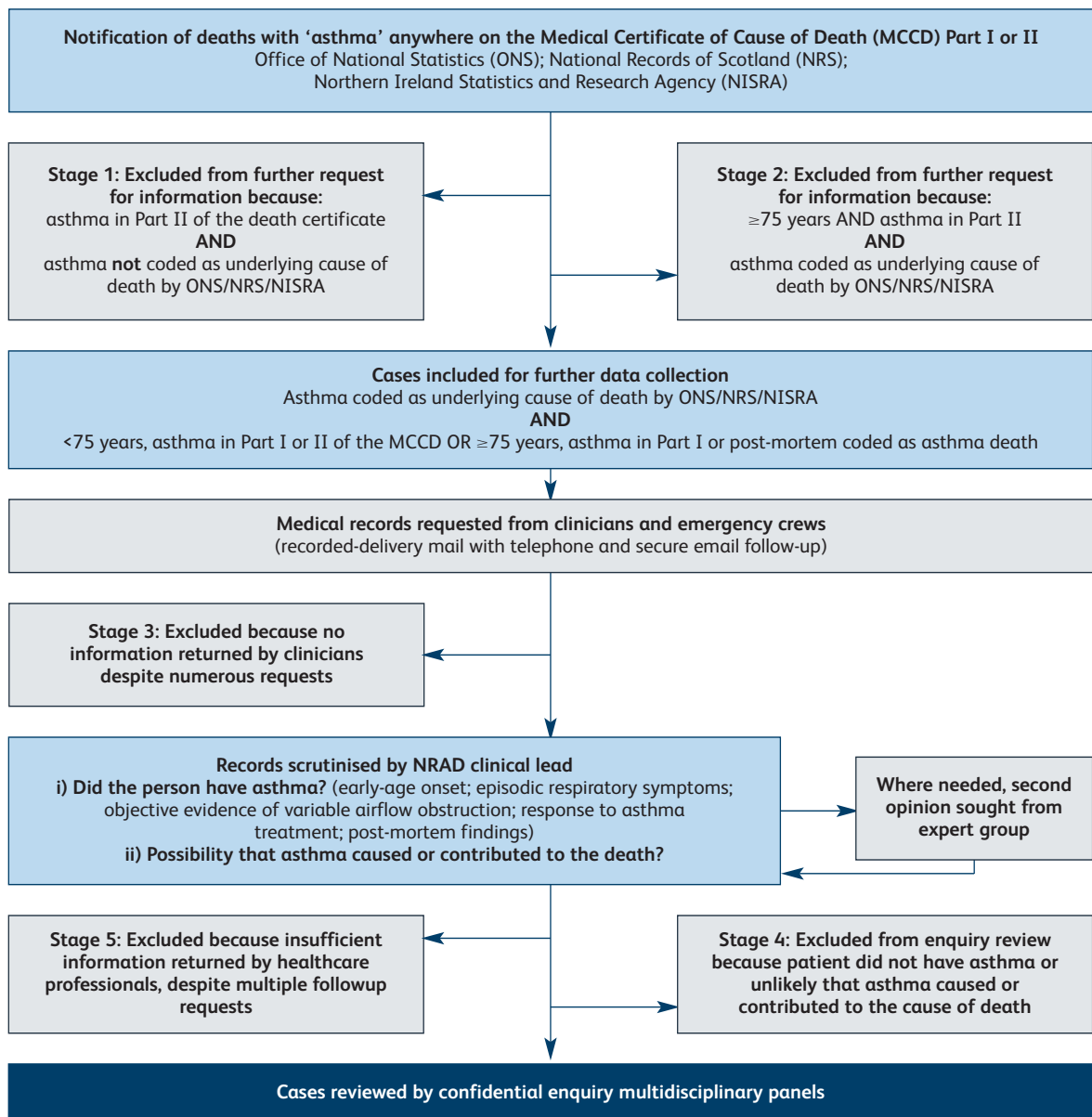
- people aged 75 years or more, who had asthma in Part II of the MCCD that was classified as the underlying cause of death.

The steering group excluded this cohort because the likelihood of a ‘true’ asthma death was low and resources did not permit detailed assessment of every case. It is likely that some of these did include deaths from asthma. However, the NRAD was not an epidemiological study.

## Notification and screening

The national organisations (ONS, NISRA and NRS) notified the project team of asthma deaths on a monthly basis, but some notifications also came directly from health professionals, coroners, families and others aware of the enquiry. This included 374 local coordinators who were appointed in 297 hospitals. Those cases that met the NRAD criteria were selected for further consideration by the NRAD.

Fig 3.1 NRAD notification and screening consort



## Data sources

Medical records and other information were requested from general practices, hospitals, emergency services and coroners' offices on all deaths meeting the inclusion criteria, including:

- a summary of details related to the person's asthma and copies of records pertaining to the final attack
- 2 years of prescribing information, consultation records and copy of correspondence(s) between specialists and GPs
- specific details of management of previous asthma attacks in primary and secondary care in the last 12 months (Appendices 3 and 5 – Forms A2 and B2)

- organisational details of primary care practices that cared for included cases
- copies of any local critical incident reviews on the deceased patients.

A letter from the NRAD clinical lead and the chair of Council of the Royal College of General Practitioners (RCGP) accompanied all requests for information to encourage cooperation and emphasise professional responsibility to participate in confidential enquiries.

Upon receipt of medical records and other information from colleagues, the NRAD clinical lead, supported by a screening panel comprising retired asthma experts, selected cases for review by the confidential enquiry panels. Cases were included based on the probability that:

- i) the patient had asthma (such as early age of onset of symptoms; episodic respiratory symptoms; objective evidence of variable airflow obstruction on lung function testing; response to asthma treatment; and post-mortem findings)
- ii) asthma possibly caused or contributed to the death. Cases were excluded if it was clear, either in the records or from correspondence from the clinician managing the case before death, that asthma was unlikely or there was a high probability that the patient did not die from asthma (Stage 4, Fig 4.1). All children and young persons (under 20 years old) were included.

## Environmental data

Environmental data were obtained by geographical location (postcodes) of all cases included for consideration by the NRAD panels. In addition, weather data for the date of each death (day of death, and the six preceding days) and the corresponding date 1 year previously for comparison were obtained. These were supplied by the Met Office, the UK's national weather service, and included:

- pollen concentrations (all available species)
- temperatures
- relative humidity
- concentrations of nitric oxide, nitrogen dioxide, ozone, PM10 particulate matter, sulphur dioxide and carbon monoxide.

Fungal spore data were only available from one centre in Derbyshire and were provided courtesy of the Institute for Lung Health at the University of Leicester. These data were used to provide an approximation of fungal spore levels nationally.

## Data validation

The monthly notifications of deaths from ONS and NRS, along with death certification data, were recorded on a central NRAD database. Data from Northern Ireland were processed separately before uploading to the database in order to comply with information governance regulations. Data from cases not meeting the NRAD entry criteria were not uploaded to the database.

Three separate inter-rater agreement/reliability (IRR) analyses were undertaken:

- a random 10% sample of 50 of the first 500 cases screened was selected for repeat screening for suitability for inclusion by the clinical expert panel

- a random 10% sample of all cases that had been selected for panel reviews were resubmitted for a second review by a panel comprising different members who met on a different date
- one independent pathologist with expertise in the coronial process reviewed all available post-mortem reports and a second reviewed alternate cases.

For full details of these analyses see Appendix 12 – Inter-rater reliability (IRR) report for NRAD.

### Multidisciplinary confidential enquiry panels

Multidisciplinary confidential enquiry panels were convened to review the included cases and complete the panel assessment tool (Appendix 6 – Panel assessment form). Members of the panels reviewed:

- the reliability of the diagnosis of asthma
- whether asthma caused or contributed to the death
- whether any potentially preventable or avoidable factors of the deaths were evident in the records. This included an analysis related to the asthma care both immediately preceding death and in the past
- the overall clinical management, rated against:
  - i) the BTS/SIGN asthma guideline<sup>1</sup>
  - ii) the NRAD indicators of quality of care developed for this purpose (Table 3.1).

Data resulting from the panel deliberations are shown in Chapter 6.

174 volunteer clinical assessors were recruited from primary, secondary and tertiary care throughout the UK (Table 3.2) and each participated in one or more panels. Assessors were currently (or within 5 years of being) in clinical practice in an NHS organisation, professional body or patient organisation and all were clinical experts in asthma care. All were invited to attend a training session before their first panel meeting; 89 assessors participated.

**Table 3.2 NRAD Confidential Enquiry panel clinical assessors by profession**

Expertise	Number
Paediatricians (general, respiratory, allergy, intensive care and emergency paediatrics) <sup>a</sup>	21
Adult physicians (general, respiratory, allergy, intensive care and emergency medicine)	67
GPs	34
Pharmacists	2
Primary care nurses (specialist asthma and respiratory)	25
Secondary care nurses (consultants, paediatric nurses, specialist adult and paediatric asthma and respiratory nurses)	24
Clinical lecturers	1
<b>Total</b>	<b>174</b>

<sup>a</sup>Paediatric panels were composed mostly of paediatricians

Thirty-seven panel meetings were convened in various locations across the UK. On average, a panel comprised 10 clinical assessors, with nine anonymised cases being presented and discussed per meeting. Pre-panel preparation material was sent to assessors. On the day of the meeting, each case was presented in detail by two clinical assessors, independent of each other. Issues were identified and discussed by the entire panel prior to agreement on the cause of death and conclusions on care provided.

## Data analysis

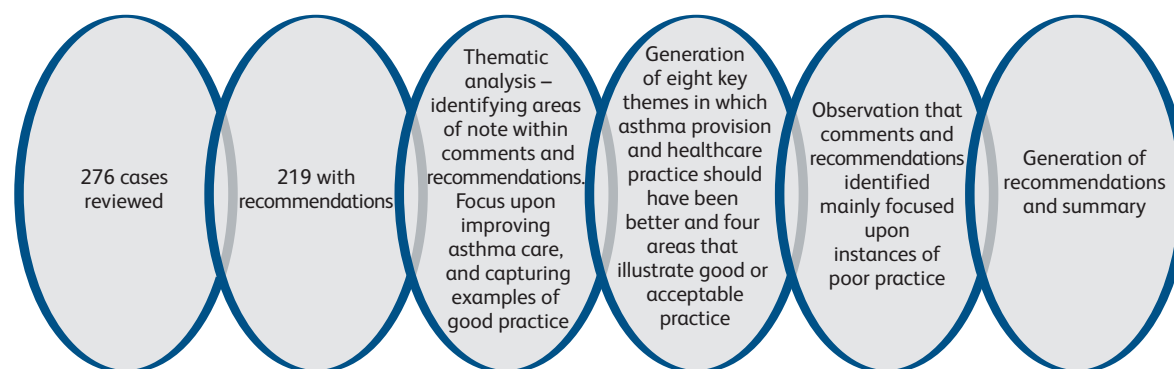
### Quantitative

Statistical analysis was carried out using Stata version 12. Results are presented as percentages for binary and categorical data. Continuous data are presented as medians and interquartile ranges (IQRs). Inter-rater agreement was measured using Cohen's kappa statistic.

### Qualitative

276 cases were reviewed by the expert panels. The majority, 219 (79%), of these cases resulted in exactly 1,000 recommendations or comments where care could have been improved. Recommendations and comments (free text) were transcribed verbatim from the panel assessment form into a spreadsheet prior to coding and thematic analysis to generate themes (Fig 3.2).<sup>26–30</sup> Additionally, examples of good practice were identified, similarly analysed and reported (Appendix 10 – Summary of qualitative analysis of free text recommendations and comments by panel assessors).

**Fig 3.2 Qualitative data-analysis process**



## Ethics and confidentiality

Approval was obtained from the National Information Governance Board (NIGB) under section 251 of the NHS Act (2006) to collect patient-identifiable information without consent (approval reference: ECC 8-02(FT2)/2011). Approval to conduct family interviews was obtained from the National Research Ethics Service committee (NRES) reference 1522/NOCI/2012; however, local research and development (R&D) permission was also required and was only achieved from 66 (28%) of the 238 R&D departments approached nationally.

All steering group members and assessors complied with RCP information and security policies, data protection legislation and guidelines. All records were fully anonymised. Clinical assessors were allocated cases from areas that were geographically remote from their base locations. All information relating to the NRAD, including death data and panel conclusions, was logged onto the central NRAD database, which has its own specific system-level security policy in place. Anonymised information from sources in Northern Ireland was returned to and entered by the NRAD satellite team in Belfast to comply with local data-protection regulations.

A cause for concern policy was developed and implemented to address cases (38/276, 14%) that panellists unanimously agreed should be followed up with specific local action (Appendix 6 – Panel assessment form).

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## Chapter 4 – Data returns and demographics

### Screening process results

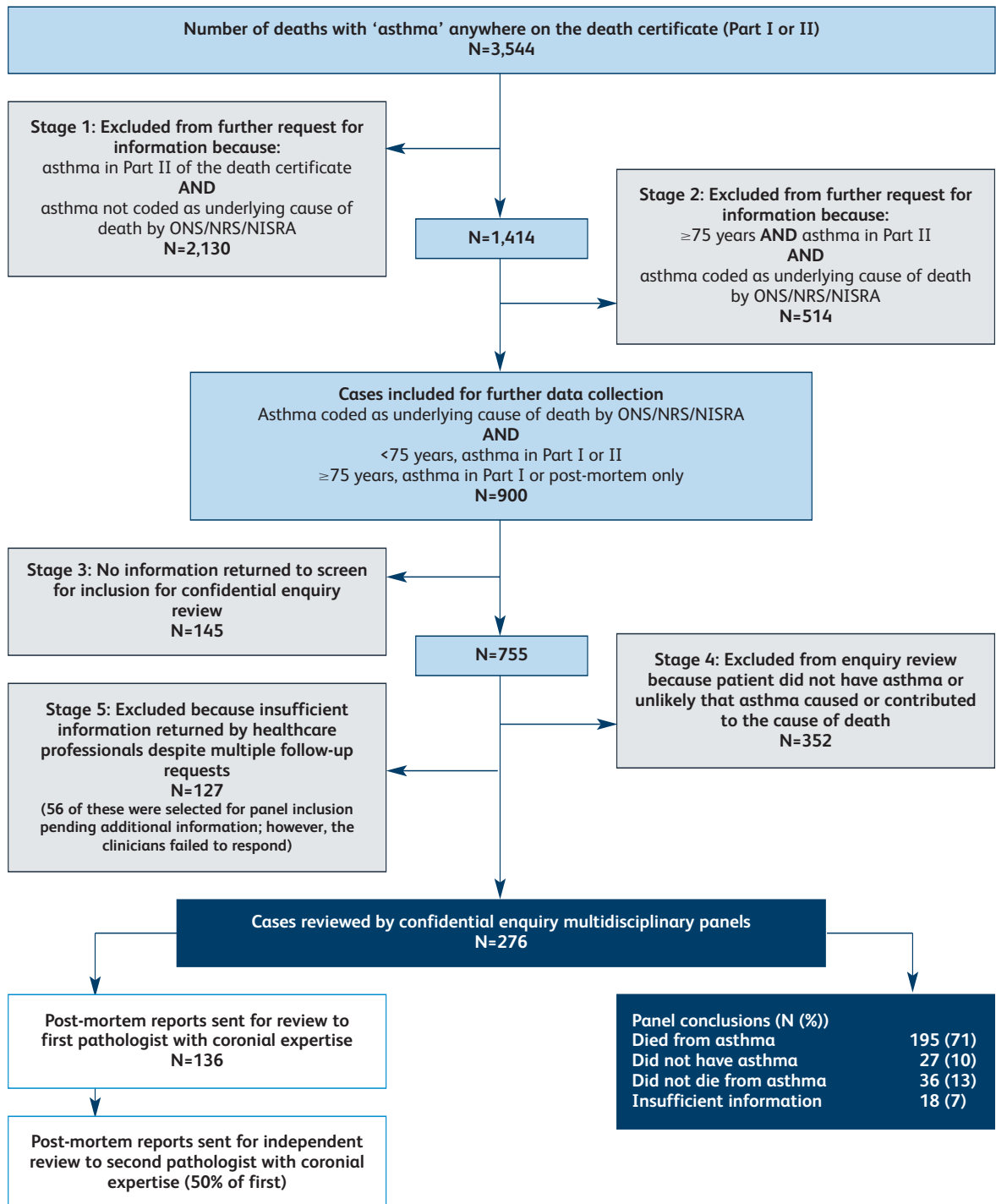
During the study year, 900 of the 3,544 people in the UK with a mention of the word asthma on their death certificates met the overarching inclusion criteria for the NRAD; these were screened for consideration by the confidential enquiry panels. The details are shown in Table 4.1 and Fig 4.1. Owing to the inclusion and exclusion criteria used for the NRAD, the cases selected do not represent all of the asthma deaths in the study period. Therefore, the NRAD does not provide an accurate figure for the total number of asthma deaths in the UK during the period of this review. The process for deciding whether to include or exclude cases for the confidential enquiry is described in Chapter 3.

**Table 4.1** Number (%) of cases included in and excluded from the NRAD Confidential Enquiry

Included and excluded cases	Frequency n (%)
<b>Included:</b> Asthma coded as the underlying cause of death by ONS/NRS/NISRA <b>AND</b> <75 years with asthma in Part I or II of the MCCD ≥75 years with asthma in Part I of the MCCD only	900 (25)
<b>Excluded:</b> ≥75 years with asthma in Part II of the MCCD and coded as the underlying cause of death	514 (15)
<b>Excluded:</b> cases (all ages) with asthma in Part II of the MCCD and not coded as the underlying cause of death	2,130 (60)
<b>Total</b>	<b>3,544</b>



Fig 4.1 NRAD consort diagram showing the numbers of cases with a mention<sup>a</sup> of asthma on the Medical Certificate of Cause of Death (MCCD), those meeting NRAD eligibility criteria and the medical case notes returned



<sup>a</sup>Data from the Office for National Statistics (ONS) for England and Wales, the Northern Ireland Statistics and Research Agency (NISRA) and the National Records of Scotland (NRS)

The following groups were excluded from the enquiry.

- 2,130/3,544 (60%) people (all ages) with asthma listed in Part II of the MCCD where this was not coded as the underlying cause of death (Table 4.2).
  - 184/2,130 (9%) of these exclusions had deaths attributed to respiratory diseases other than asthma (Table 4.3).
- 514/3,544 (15%) were aged 75 years and older with asthma recorded in Part II of the death certificate and in whom asthma was coded as an underlying cause of death. Those with post-mortem confirmation of asthma death were included (Table 4.3.1). It was decided by the NRAD steering group to exclude these cases from the enquiry on the grounds of limited resources and because the attending doctors had recorded asthma in Part II of the death certificates.

**Table 4.2 Underlying cause of death in excluded cases where asthma was not coded as the underlying cause of death (Stage 1, Fig 4.1)**

Underlying cause of death (ONS, ICD-10U)	N=2,130 n (%)
(I00–I99) Diseases of the circulatory system	751 (35)
(C00–C99) Neoplasms	484 (23)
(K00–K93) Diseases of the digestive system	192 (9)
<b>(J00–J99) Diseases of the respiratory system</b> (Table 4.3 details these cases)	<b>184 (9)</b>
(F00–F99) Mental and behavioural disorders	136 (6)
(G00–G99) Diseases of the nervous system	80 (4)
(V01–Y98) External causes of morbidity and mortality	72 (3)
(E00–E99) Endocrine, nutritional and metabolic diseases	60 (3)
(N00–N99) Diseases of the genitourinary system	50 (2)
(A00–A99) Certain infectious and parasitic diseases	35 (2)
(M00–M99) Diseases of the musculoskeletal system and connective tissue	32 (2)
(D00–D99) Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	25 (1)
(L00–L99) Diseases of the skin and subcutaneous tissue	14 (1)
(B00–B99) Certain infectious and parasitic diseases	8 (0.4)
(Q00–Q99) Congenital malformations, deformations and chromosomal abnormalities	4 (0.2)
(R00–R99) Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	3 (0.1)

**Table 4.3 Description of respiratory ICD-10U codes (ICD-10U codes J00–J99) in 184 excluded cases where asthma was entered in Part II of the MCCD and not coded as the underlying cause of death in Part I (Stage 1, Fig 4.1)**

Description of code	ICD-10U code	N=184 n (%)
COPD	J440, J448, J441	72 (39)
Pneumonitis due to food and vomit	J690	34 (18)
Influenza and pneumonia	J09, J111, J13, J14, J180, J181, J189	24 (13)
Bronchiectasis	J47	21 (11)
Other interstitial pulmonary diseases with fibrosis	J841	16 (9)
Emphysema, unspecified	J439	5 (3)
Interstitial pulmonary disease, unspecified	J849	3 (2)
Paralysis of vocal cords and larynx (incl laryngoplegia, paralysis of glottis)	J380	1 (1)
Other diseases of vocal cords (incl abscess, cellulitis, granuloma, leukokeratosis, leukoplakia)	J383	1 (1)
Stenosis of larynx	J386	1 (1)
Other diseases of larynx (abscess, cellulitis, disease NOS, necrosis, pachyderma, perichondritis, ulcer)	J387	1 (1)
Bronchitis, not specified as acute or chronic	J40	1 (1)
Hypersensitivity pneumonitis due to unspecified organic dust	J679	1 (1)
Pulmonary collapse	J981	1 (1)
Other disorders of lung	J984	1 (1)
Other specified respiratory disorders	J988	1 (1)

COPD, chronic obstructive pulmonary disease; NOS, not otherwise specified

Tables 4.3.1 and 4.3.2 illustrate the overall variation in the type and quality of information included in death certificates for those aged 75 years and over with asthma recorded in Part II of the MCCD and coded as the underlying cause of death (Stage 2, Fig 4.1). These MCCD entries should reflect the cause of death and the factors directly contributing to the deaths. The majority of entries in Part Ia of the MCCD were for pneumonia or chest infections (401/514, 78%).

In Part II of 132 of these 514 certificates, only the single term ‘asthma’ was recorded, while the Part II entries of the other 382 contained a composite list of medical conditions from which people had suffered during their lifetimes, which may or may not have contributed to their deaths. Examples of these entries are shown in Fig 4.3.2.

**Table 4.3.1 Description of the medical disease terms entered in Parts I and II of the MCCD for 514 people over the age of 75 years and excluded from the NRAD process, where asthma was entered in Part II of the MCCD and coded as the underlying cause of death (Stage 2, Fig 4.1)**

Medical Certificate of Cause of Death (MCCD) entry <sup>a</sup>	Part Ia	Part Ib	Part Ic	Part II
Acute renal failure	6	1		
Asthma				132
Asthma and other medical conditions (listed in the field on the MCCD) <sup>b</sup>				382
Cardiac arrest/cardiac failure	9	1		
Cerebrovascular accident	2			
Dementia			1	
Hypertension/aortic valve disease			2	
GI problem (eg cholecystitis, paralytic ileus, gallstones, pancreatitis)		2	1	
Hypoglycaemia	1			
Multi-organ failure	15	3		
Old age/immobility	61	7		
Other respiratory (eg pulmonary emboli, lung effusion, pneumothorax)	3			
Pneumonia/chest infection	401	60	11	
Respiratory failure	10			
Septicaemia	6	7		
<b>Total entries</b>	<b>514</b>	<b>81</b>	<b>15</b>	<b>514</b>

<sup>a</sup>These disease terms have been combined and grouped from the original terms for brevity

<sup>b</sup>See Table 4.3.2

GI, gastrointestinal

## Coding of underlying cause of death in older people

Older people often have multiple health conditions that may or may not contribute to their death; many are entered on death certificates, therefore the ‘true’ underlying cause of death may not be clear.<sup>25</sup> For example, if the word ‘asthma’ appears anywhere on the death certificate, this may be classified as the underlying cause of death, irrespective of where on the certificate the word was entered; as a result, death certification and subsequent assignment of underlying cause of death vary considerably.<sup>31–33</sup> This results from the application of the complex rules of the WHO for classifying diseases to determine the underlying cause of death. Table 4.3.2 shows some examples of the entries by the doctors completing the MCCDs, where asthma was assigned as the underlying cause of death by the authorities.

According to the complex rules of the WHO for classifying diseases, the underlying cause of death was coded as asthma (ie ICD-10U J149).<sup>24</sup>

**Table 4.3.2 Examples of MCCDs from the 382 of the 514 people aged 75 years and over who were excluded from the NRAD process, where asthma was entered in Part II of the MCCD and coded as the underlying cause of death but where other medical conditions were also entered in Part II**

Part Ia	Part Ib	Part II
Sepsis		Chronic kidney disease stage 4; obesity; ischaemic heart disease; hypertension; diabetes mellitus; asthma
Bronchopneumonia		Recurrent intestinal obstruction due to volvulus; chronic asthma
Old age		Chest infection; cancer of breast; asthma; COPD; long-term oxygen therapy
Pneumonia		Asthma; previous myocardial infarction; COPD
Bronchopneumonia		Asthma; diverticular disease; venous leg ulcers; atrial fibrillation

COPD, chronic obstructive pulmonary disease

## Screening of cases for inclusion criteria

Most of the clinical records of the 755 cases returned by general practices and hospitals (Fig 4.1) were screened for panel inclusion by a single clinician (NRAD clinical lead), with advice on some from an expert group of retired asthma specialists. These experts reassessed a random sample of 50 selected from these 755 cases by way of validation; there was good agreement at the screening phase, with a high kappa score of 0.79. This is very encouraging in terms of the utility of the method to include/exclude cases suitable for panel review (Appendix 12 – Inter-rater reliability report for NRAD). Sufficient information was obtained for 276 deaths to allow detailed discussion at confidential enquiry panel meetings (Fig 4.1 summarises the selection process and Chapter 6 details the panel conclusions).

Clinicians failed to contribute any, or sufficient, information on 272 cases and so assessment for inclusion could not be completed and these cases were excluded. This occurred despite repeated requests for information, endorsement of the NRAD by all relevant royal colleges and guidance from the General Medical Council (GMC) stating that UK-registered doctors have a duty to contribute to confidential enquiries in order to help keep patients safe.<sup>34</sup> While there may have been good reasons for non-participation by health professionals, the clinicians treating 145 (16%) of the 900 cases failed to provide any explanation at all for their non-participation (Fig 4.1).

The remainder of this report is restricted to deaths that were due to asthma. Death due to asthma was defined as a death where the panel had concluded that asthma had definitely/probably/possibly contributed to or caused death. Of the 276 deaths that went to panel, 195 (71%) were due to asthma.

## Demographics

Characteristics of those who died from asthma (N=195) are shown in Table 4.4.1 and Table 5.3. Three-quarters of the people reviewed by the panels and who died from asthma were over 40 years old. Ethnicity data, available for 188 (96%) of those people who died from asthma, indicated that they comprised 158 (84%) white individuals, nine (5%) of mixed race, 14 (7%) Asian and one (0.5%) black, and six (3%) whose origin was not known.

**Table 4.4.1 Demographic and personal characteristics of 195 people who, the panels concluded, died from asthma<sup>a</sup>**

		n (%)
Gender	Male/female	80 (41)/115 (59)
Age at death, years (N=193)	Minimum–maximum; median (IQR)	4–97; 58 (40–74)
Age group, years	<10	10 (5)
	10–19	18 (9)
	20–44	33 (17)
	45–64	50 (26)
	65–74	35 (18)
	75+	47 (24)
Latest BMI, kg/m <sup>2</sup> (N=121)	Minimum–maximum; median (IQR)	13.3–56.9; 27 (22–31)
	<20	21 (17)
	20–24.9	32 (26)
	25–29.9 (overweight)	30 (25)
	30+ (obese or very obese)	38 (31)
Psychosocial and learning disability factors (N=190)	Depression	29 (15)
	Anxiety	33 (17)
	Psychiatric treatment in the last 12 months	16 (8)
	Drug or alcohol abuse	11 (6)
	Deliberate self-harm	4 (2)
	Learning disability	4 (2)
	Social isolation/lives alone	14 (7)
	Other	43 (23)
	One or more of the above specified	84 (44)
If child aged <18 years (N=28)	Known to social services and documented in medical records	4 (14)
Smoking status (N=193)	Non-smoker	100 (52)
	Smoker	39 (20)
	Ex-smoker (stopped over 12 months ago)	42 (22)
	Ex-smoker (stopped during past 12 months)	5 (3)
	Not known from records	7 (4)
Excluding current smokers (N=154), exposure to second-hand smoke	At home	15 (10)
	At work	1 (1)
Location of death	Home (private address)	80 (41)
	Nursing/residential home	5 (3)
	Hospital, pre-hospital arrest	45 (23)
	Hospital, arrest in hospital	59 (30)
	Holiday	4 (2)
	Other	2 (1)
The person died before seeking medical assistance or before medical assistance was provided		87 (45)

<sup>a</sup>These data were either provided by a combination of responses from the GP or by extraction from GP records by an experienced respiratory clinician. Denominators for the percentages were 195 unless otherwise stated

Nearly half (41%) died at home, one-quarter (23%) on the way to hospital and one-third (30%) in hospital.

Forty-five per cent (87/195) died from asthma without any medical assistance during the final episode; for 65 of these cases, there was no record of them seeking medical assistance, and for 22 cases (11%), there was a record of the patient trying to get help but dying before medical treatment could be administered. In children, the panels found that 8/10 (80%) of those under 10 years, and 13/18 (72%) of those aged 10–19 years, died before they reached hospital. It was not clear from the information provided by the clinicians why the 65 cases did not call for assistance in time, or why care was not provided for the 22 cases who did call for help. There was a record of 11 (17%) of the 65 and eight (36%) of the 22 cases being provided with a PAAP.

Obesity and exposure to cigarette smoke are both known to increase the risk of people having asthma attacks.<sup>35,36</sup> Body mass index (BMI) data were available for 121 of the 195 and, of these, 30 (25%) were overweight (BMI 25–29.9) and 38 (31%) were obese or very obese (BMI 30+). Thirty-nine of the 195 (20%) who died from asthma were recorded as active smokers (just below the average for the UK). Of patients where active smoking status was not documented, 16 were known to be exposed to second-hand smoke. No details were obtained on the proportion of these people who were offered smoking-cessation advice.

**Key finding:** During the final attack of asthma, 87 (45%) people died without seeking medical assistance or before emergency medical care could be provided.

**Recommendation:** All people with asthma should be provided with written guidance in the form of a personal asthma action plan (PAAP) that details their own triggers and current treatment, and specifies how to prevent relapse and when and how to seek help in an emergency.

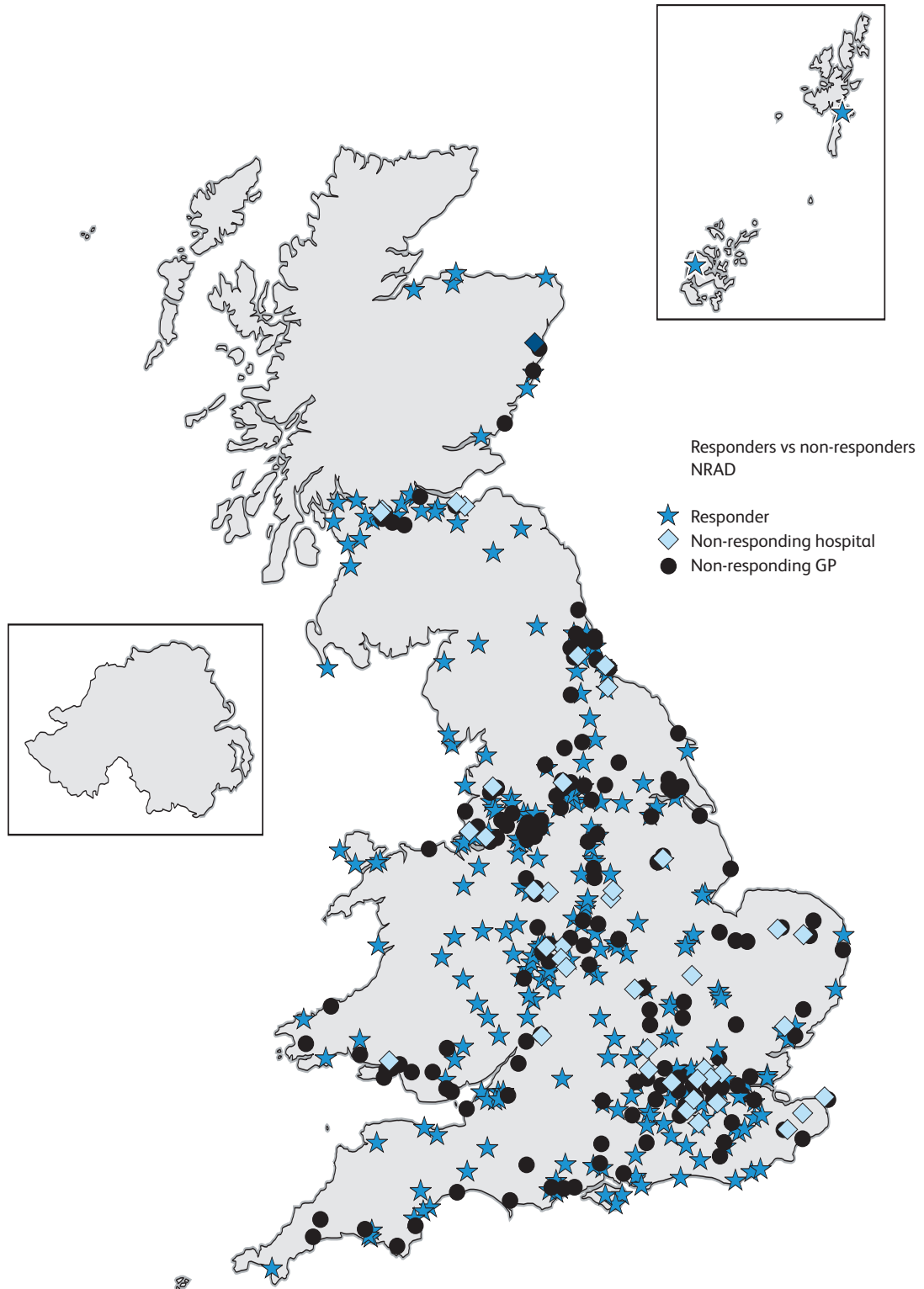
**Target audiences:** Primary healthcare setting, secondary healthcare setting, patients and carers, commissioners and professional and patient organisations.

**Key finding:** Fifty-five (28%) of the 195 people who died from asthma were current smokers (39) or exposed to second-hand smoke (16).

**Recommendation:** A history of smoking and/or exposure to second-hand smoke should be documented in the medical records of all people with asthma. Current smokers should be offered referral to a smoking-cessation service.<sup>1</sup>

**Target audiences:** NHS service managers, primary healthcare setting, secondary healthcare setting, patients and carers and professional and patient organisations.

Fig 4.2 Geographical locations of where deaths occurred across the country



Three groups are displayed: (1) 403 responses from GPs and hospitals on the 276 cases that went to panel – blue stars, (2) 193 non-responding GPs – black dots, (3) 59 non-responding hospitals – light blue diamonds. The non-responders highlighted are organisations with case information outstanding at the end of the data submission period (31 August 2013); responses may have been received to previous case requests. Owing to information governance regulations, Northern Ireland organisations cannot be portrayed on this map.



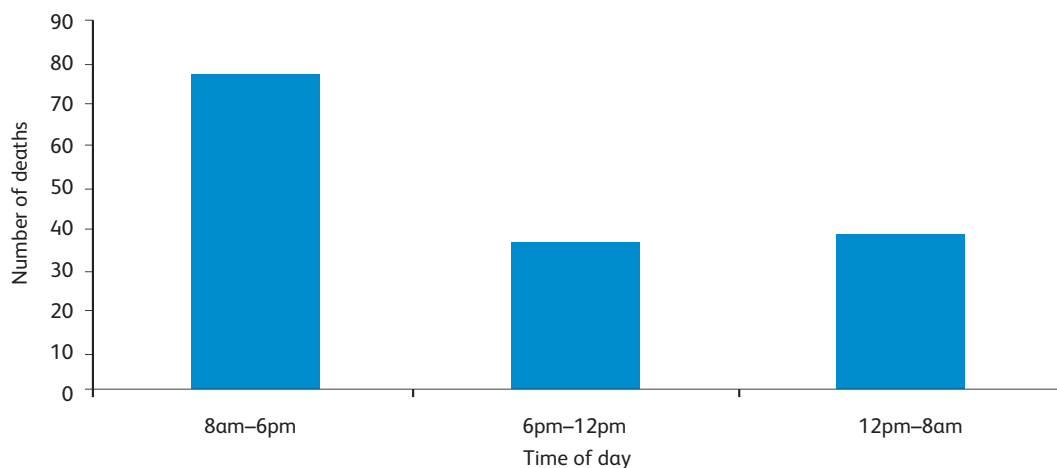
From Fig 4.2, these three groups of data appear fairly evenly distributed, suggesting that the NRAD received a geographically representative sample of information on those cases considered eligible for the panels.

Fig 4.3.1–4.3.4 show demographic data on the time of day, day of the week and month when the deaths from asthma occurred; in Fig 4.3.2, the day of the week among asthma deaths was compared against all those who were selected for the NRAD.

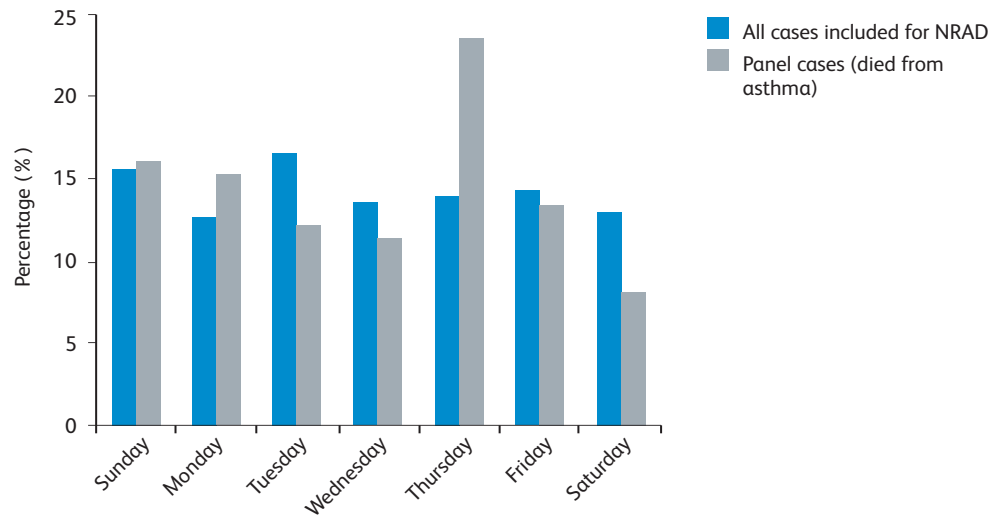
The number of asthma deaths was greatest in March, with 30 deaths. Deaths occurring in other months ranged between 12 and 17 deaths per month. In the 28 children and young people, 4/10 (40%) aged under 10 years and 14/18 (78%) aged 10–19 years died between March and September inclusive.

Panels were asked specifically whether they agreed with the official coding of asthma as the underlying cause of death. Figure 4.3.5 shows that the proportion of cases where the panels agreed with this decreased with the age of the case.

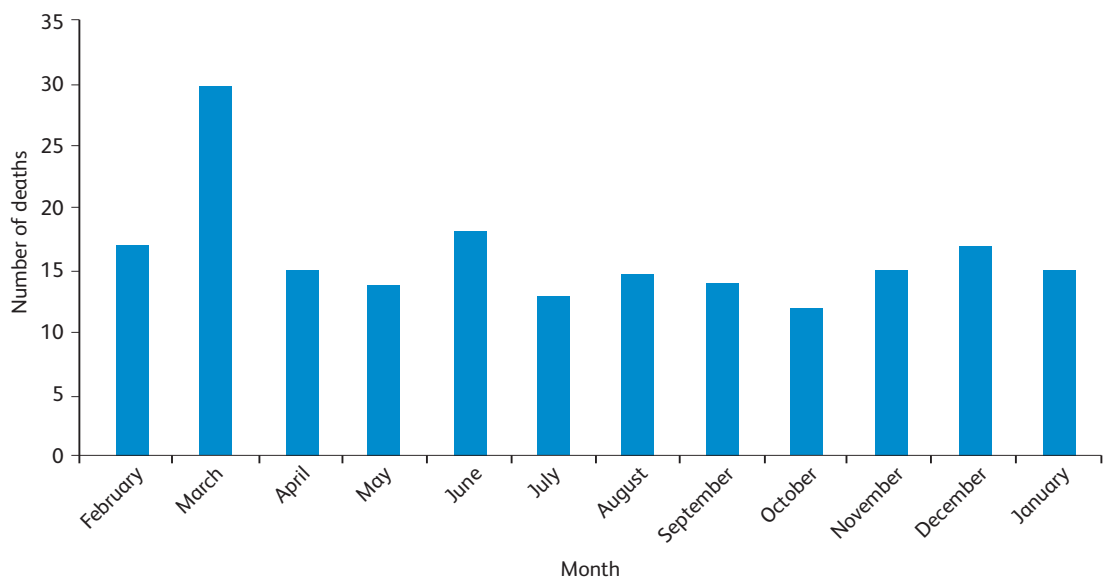
**Fig 4.3.1 Time of day that death occurred** (for 153 of 195 who died from asthma, where the time of death was recorded)



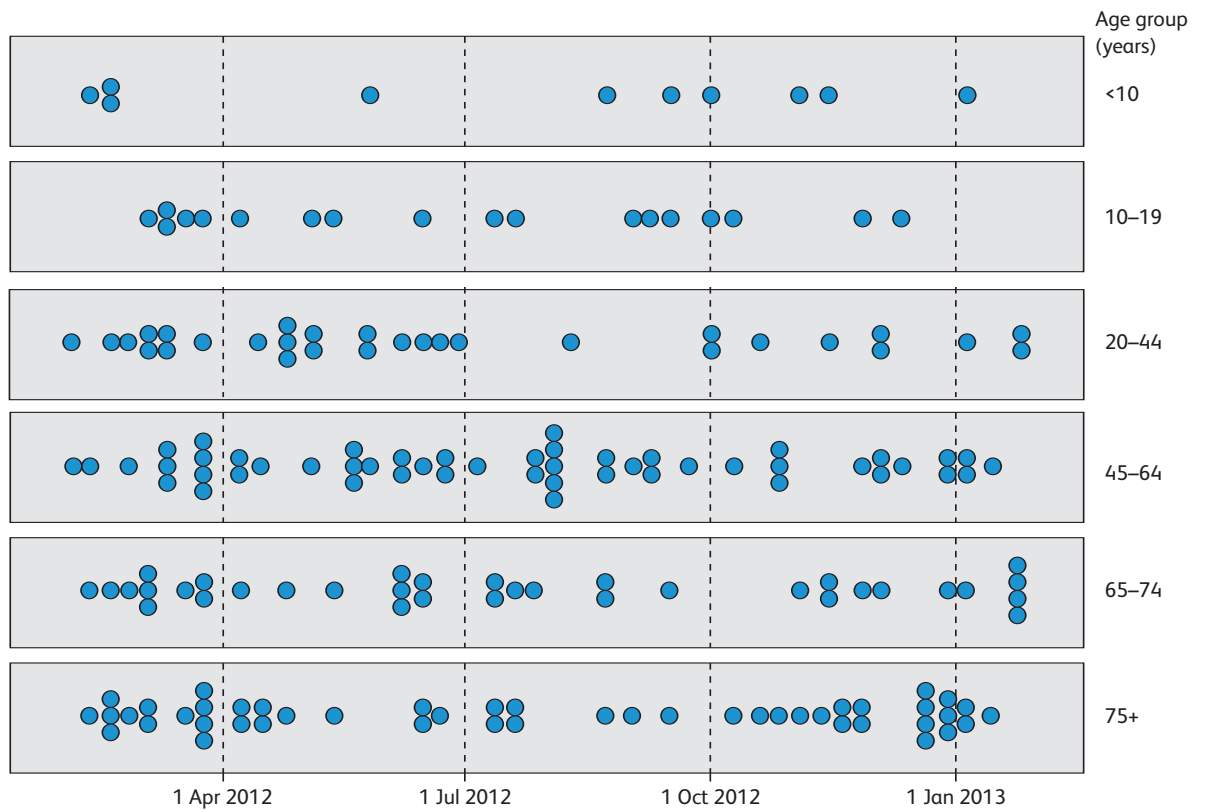
**Fig 4.3.2 Day of the week that death occurred** (for 195 who died from asthma, and 890 of all 900 included for the NRAD)



**Fig 4.3.3 Month that death occurred** (for 195 who died from asthma)

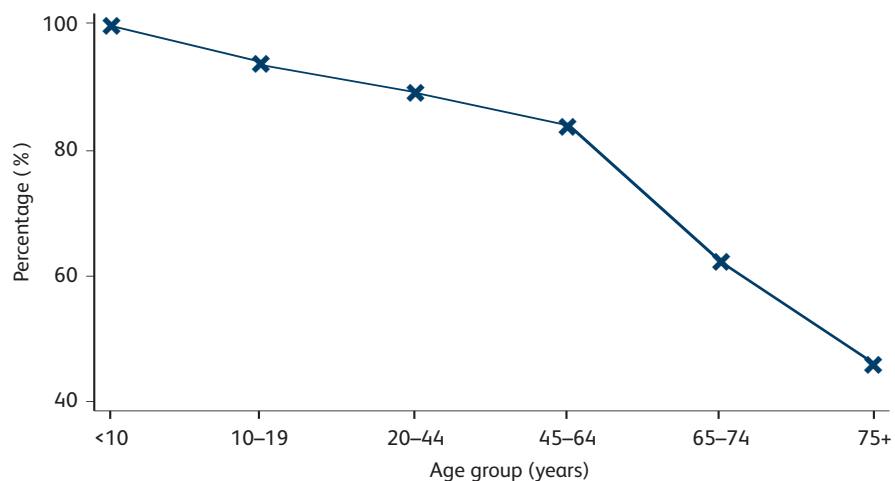


**Fig 4.3.4 Asthma deaths over time by age group (N=193<sup>a</sup>)**



<sup>a</sup>Date of birth was missing in two cases, so for these cases age could not be calculated

**Fig 4.3.5 Percentage of cases by age group where the panel agreed<sup>a</sup> that the clinical findings matched the coding of asthma as the underlying cause of death by the Office for National Statistics (ONS) for England and Wales, the Northern Ireland Statistics and Research Agency (NISRA) or the National Records of Scotland (NRS) (N=259)**



<sup>a</sup>Cases where the panel selected that they definitely/probably/possibly agreed that ONS/NISRA/NRS matched the clinical findings. Excluded cases were those where this question was deemed not applicable by the panel (N=3), where there was insufficient information to decide (N=13) or where information was missing (N=1)

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## Chapter 5 – Clinical care and patient characteristics

### General practice care

Practice details were returned for 138 (71%) of the 195 patients who died from asthma. Denominators vary according to where data were missing.

#### Practice details

Practices had a median of four doctors (IQR 3–5, N=131), and cared for a median 9,500 patients (IQR 6,250–12,000, N=134). Thirteen (10%) of 131 practices had only one full-time doctor, and nine of these also employed between one and six part-time doctors.

#### Skill mix in the practices

Thirty-eight (28%) of 135 practices had a doctor with a special interest in respiratory diseases. One hundred (81%) of 124 practices were known to have employed at least one nurse with an asthma diploma. Fifty-seven (41%) of 138 practices provided student teaching and GP postgraduate training, and 15 (11%) of these were research practices.

#### Quality and Outcomes Framework (QOF)

GPs who perform asthma reviews can claim payment for their work under the UK Quality and Outcomes Framework (QOF). QOF is a voluntary annual reward and incentive programme for all GP practices. QOF scores were recorded by the GPs for 89/138 (64%) of the 195 people who died from asthma; full points (ie 45 points) were attained by 74 (83%) of the 89 practices.<sup>37,38</sup>

#### Routine asthma reviews in primary care

Good asthma care includes regular clinical review. This should be a structured review at least annually, but more frequently in people with poor asthma control or at high risk of severe attacks. A review should include an assessment of asthma control, identification of risk factors, a check of inhaler technique, optimisation of treatment and provision or update of an agreed PAAP for patients.<sup>1,2</sup>

Asthma reviews were performed by GPs in 78 (57%) of 136 practices, by GPs with an interest in respiratory diseases in three (2%), by nurses with an asthma diploma in 82 (60%) and by 'general' practice nurses in 62 (46%), with multiple options possible (Appendix 2 – Form A1, section 6). Practices

were asked to list their usual procedures when doing an asthma review to qualify for claiming QOF payments, and these are shown in Table 5.1.

**Table 5.1 Processes and assessments undertaken in 135 general practices during an asthma review<sup>a</sup>**

		n (%)
Practice staff perform a review of medication		132 (98)
Practice staff assess patients' adherence to medication		122 (90)
Practice staff increase dose of medication when appropriate		129 (96)
Practice staff decrease dose of medication when appropriate		126 (93)
Practice staff issue a personal asthma action plan (PAAP) (if not done before)		85 (63)
Practice staff record assessment of asthma control		115 (85)
Methods used for assessing asthma control in the practices (N=77)	RCP three questions <sup>1</sup>	63/77 (82)
	Asthma Control Test (ACT) <sup>1</sup>	5/77 (6)
	Another control tool	9/77 (12)

<sup>a</sup>Three practices did not respond to any of these questions and were therefore excluded

Of the 195 patients who died from asthma, 135 (69%) had their last asthma review in primary care recorded, of which 132 (98%) were face to face, two were by telephone and one was not known. The median time to death since the last asthma review in primary care was 121 days (IQR 30–306 days). Among the 135 cases where the last asthma review was recorded in primary care, only 37 (27%) had an assessment of asthma control, 57 (42%) an assessment of medication use, 96 (71%) an assessment of inhaler technique and only 33 (24%) had been provided with a PAAP. In 111 (57%) of the 195 cases, there was evidence that a routine asthma review was performed in the last year before death.

Forty-two patients (22%) missed a routine asthma appointment in the year before they died. Practices attempted to follow up 23 (55%) of these; in 19 (45%), there was no record of contact being made to encourage attendance. There was no information available on the provision or timing of appointments offered for patients (Table 5.2).

### Personal asthma action plans (PAAPs)

There is strong research evidence of the effectiveness of PAAPs. In only 44 (23%) of the 195 patients who died was there a record of them having been provided with a PAAP in either primary or secondary care.

For 65 of the 195 patients who died (33%), there was no record of them seeking medical assistance during the final attack; 11 (17%) of these had been provided with a PAAP. A further 22 patients sought medical assistance but died before treatment could be administered, of whom eight (36%) had been provided with a PAAP. This suggests a need for improved advice for patients on the recognition and emergency self-management of asthma attacks. Wider use of PAAPs has the potential to prevent death from asthma by increasing the number of people who take appropriate action and seek help.

**Table 5.2 Details of current management of 195 patients who died from asthma**

		n (%)
Who cared for this patient's asthma in the 12 months before death? (N=195)	Primary care only: GP only	49 (25)
	Primary care only: nurse (with no GP input in the 2 years before death)	4 (2)
	Primary care only: GP and nurse	43 (22)
	Secondary care only	19 (10)
	Primary and secondary care	64 (33)
	No one recorded	16 (8)
Asthma review in primary care	Patient was reviewed (N=195)	135 (69)
	Evidence of routine primary care review in the last year (N=195)	111 (57)
	Time to death since last review in days, median (IQR) (N=128)	121 (30–306)
Asthma review in secondary care	Patient was reviewed (N=83) <sup>a</sup>	29 (35)
	Evidence of routine secondary care review in the last year (N=83)	28 (34)
	Time to death since last review in days, median (IQR) (N=26)	62 (26–96)
Reviews recorded in both primary and secondary care (N=195)		22 (11)
Missed routine GP asthma appointment in last 12 months recorded (N=195)		42 (22)
Time from last routine appointment missed to death in days, median (IQR) (N=41)		79 (58–212)
Where appointments were missed, was any action taken to try to contact the patient? (N=42) <sup>b</sup>	Letter	20 (48)
	Phone call	6 (14)
	Nurse/doctor visit	5 (12)
	Other/not known	19 (45)
Recorded assessments performed in the last 12 months		
Peak flow; spirometry	Primary care (N=195)	105 (54); 40 (21)
	Secondary care (N=83) <sup>a</sup>	15 (18); 17 (20)
Inhaler technique checked	Primary care (N=195)	96 (49)
	Secondary care (N=83) <sup>a</sup>	14 (17)
Assessment of asthma control using the RCP three questions during the last review <sup>42</sup>	Primary care (195)	37 (19)
	Secondary care (N=83) <sup>a</sup>	5 (6)
Assessment of the person's adherence to medical advice during the last asthma review	Primary care (N=195)	57 (29)
	Secondary care (N=83) <sup>a</sup>	9 (11)
Provided with a personal asthma action plan (ever)	Primary care (N=195)	33 (17)
	Secondary care (N=83) <sup>a</sup>	12 (14)
	Primary or secondary care (N=195)	44 (23)

<sup>a</sup>In those 83 people treated in secondary care in the previous 12 months

<sup>b</sup>More than one item may have been selected, accounting for the higher totals

## Inhaler technique

Asthma sufferers who are unable to use their inhaler correctly are at increased risk of poor asthma control, potentially resulting in an attack.<sup>39–41</sup> Inhaler technique was recorded as good in 65 (68%) of the 96 cases checked in primary care.

**Key finding:** Among the 135 cases where the last asthma review was recorded in primary care, only 37 of these (27%) had an assessment of asthma control, 57 (42%) an assessment of medication use and 96 (71%) an assessment of inhaler technique, and only 33 (24%) had been provided with a personal asthma action plan (PAAP). In 111 (57%) of the 195 cases, there was evidence that a routine asthma review was performed in the last year before death.

**Recommendation:** A standard national asthma template should be developed to facilitate a structured, thorough asthma review. This should improve the documentation of reviews in medical records and form the basis of local audit of asthma care.

**Target audiences:** NHS service managers, primary healthcare settings, commissioners and policy-makers.

## Specialist hospital care

Eighty-three (43%) of the 195 patients had a record of receiving specialist secondary care, but only 28 (34%) of these had been reviewed in specialist secondary care in the 12 months prior to death: the median time since the last asthma review was 62 days (IQR 26–96 days). Inhaler technique was known to have been checked in seven (8%) of these 83 patients.

Twenty-eight (14%) of the 195 deaths were in children and young people under the age of 20 years. Sixteen of these (57%) had been receiving specialist secondary care.

**Key finding:** Of the 195 patients who died, 60 (31%) had no record of an asthma review in primary care in the previous 12 months.

**Key finding:** Of the 83 patients who died and were under specialist supervision, 54 (65%) had no record of an asthma review in secondary care in the previous 12 months.

**Recommendation:** People with asthma should have a structured review by a healthcare professional with specialist training in asthma, at least annually. People at high risk of severe asthma attacks should be monitored more closely, ensuring that their personal asthma actions plans (PAAPs) are reviewed and updated at each review (National Standards set for the four UK nations).<sup>1,2,43–47</sup>

**Target audiences:** Primary healthcare setting, secondary healthcare setting and commissioners.

**Key finding:** Of the 195 patients who died from asthma, 112 (57%) were not recorded as being under specialist secondary care supervision.

**Recommendation:** Patients with asthma must be referred to a specialist asthma service if they have required more than two courses of systemic corticosteroids, oral or injected, in the previous 12 months or require management using British Thoracic Society (BTS) stepwise treatment 4 or 5 to achieve control.<sup>1</sup>

**Target audiences:** Primary healthcare setting, secondary healthcare setting and commissioners.

## Clinical characteristics of 195 patients who died from asthma

Summary information was obtained from data submitted by clinicians or extracted from copies of clinical records by the NRAD clinicians (Appendices 2–5 – Forms A1, A2 and B1, B2).

### Duration of asthma and ages

Age at death ranged from 4 to 97 years. Those who died had suffered from asthma for between 1 and 62 years (median 11 years, IQR 5–20 years).

Age at diagnosis was available for 102 patients. Asthma was first diagnosed between the ages of 10 months and 90 years, with the median age at diagnosis being 37 years (IQR 9–61 years). Seventy patients (69%) were diagnosed after the age of 15 years, suggesting that most were diagnosed in adulthood and had late-onset asthma.

This may be a new and important finding because most asthma is considered to start in childhood.<sup>2</sup>

**Key finding:** Median age at diagnosis for the 102 patients in whom it was known was 37 years (IQR 9–61 years); 70 (69%) were diagnosed after the age of 15 years. This implies that most were diagnosed in adulthood (late-onset asthma).

**Research recommendation:** Further research is required to confirm whether late-onset asthma is a risk factor for asthma death.

**Target audiences:** NHS service managers and policy-makers.

## Diagnosis

According to UK national standards, there should be a record of the rationale for diagnosing asthma in the medical notes.<sup>43–47</sup> One hundred (51%) of the 195 patients who died were diagnosed on the basis of recurrent symptoms, 34 (17%) on physiological measurement of lung function, and 66 (34%) on the response to asthma medication. The basis for diagnosing asthma was not detailed in 64 (33%).



## Asthma triggers

In any individual with asthma, triggers are generally consistent and often predictable. Exacerbating factors or triggers for asthma should be elicited and documented so that measures can be taken to reduce their impact. Exacerbating factors or triggers were recorded in only 95/188 (51%). Respiratory tract infections were the most common triggers of attacks, followed by hay fever and other allergic factors. No trigger was documented in 93/188 (49%) of those who died (Table 5.3).

## Asthma control and severity

Severity and control of asthma are often misunderstood or confused. Severity is assessed by the amount of medication required to control the disease, whereas control is related to the presence of asthma-related symptoms.<sup>1,2,48</sup>

One of the best predictors of future asthma attacks is the level of symptom control.<sup>1,2</sup> In this review, the NRAD requested information about the method used to determine asthma control, but evidence on the level of control in each case was not available. The NRAD defined severe asthma as present in those patients receiving treatment at BTS steps 4 and 5 and/or the additional criteria of hospital admissions and asthma attacks recorded in the previous year (Table 5.3, and Appendices 2 and 4 – Form A1 and B1, item 4.2).

Of the 155 patients for whom severity could be estimated, 61 (39%) had asthma that was classified as severe.<sup>1</sup> Fourteen (9%) were treated as mild cases (BTS step 1) and 76 (49%) as moderate cases (BTS steps 2 and 3). It is likely that many cases that were treated as mild or moderate (BTS steps 1–3) had poorly controlled, undertreated asthma rather than truly mild or moderate disease. In the remaining four patients, the first attack was the final attack and therefore a severity was not assigned.

**Key finding:** In patients who died from asthma, exacerbating factors or triggers were recorded in only 95/195 (49%). Documented triggers included respiratory tract infections, allergy and drugs.

**Recommendation:** Factors that trigger or exacerbate asthma must be elicited routinely and documented in the medical records and personal asthma action plans (PAAPs) of all people with asthma, so that measures can be taken to reduce their impact.

**Target audiences:** Primary healthcare setting and secondary healthcare setting.

## Previous hospitalisation

Ninety patients (47%) of the 190 for whom information was available had, at some time in the past, been admitted to hospital owing to asthma; 27/181 (15%) had been admitted to an intensive care unit (ICU). Forty patients (34%) of 117 had attended an emergency department (23 of them on two or more occasions) in the previous year because of asthma. There may have been more emergency department attendances, because data were missing in a further 78 cases.

Nineteen (10%) of the 195 patients died within 28 days of being treated in hospital for an asthma attack.

**Table 5.3 Overall asthma and allergy characteristics of 195 patients who died from asthma**

		n (%)
Duration of asthma in years (N=104)	Minimum–maximum; median (IQR)	0–62; 11 (5–20)
Age at diagnosis of asthma, in years unless stated (N=102)	Minimum–maximum; median (IQR)	10 months–90; 37 (9–61)
History of allergy (N=193)		80 (41)
Evidence of blood test results for eosinophilia in records (N=175)		27 (15)
History of anaphylaxis (N=193)		6 (3)
Patients with known exacerbation factor(s) (N=188)		95 (51)
Which factors triggered asthma exacerbations? (N=188)	Food allergy	6 (3)
	Animal allergy	13 (7)
	Hay fever/allergic rhinitis	30 (15)
	Virus infection/URTI	52 (28)
	Drugs (NSAIDs, aspirin or beta blockers)	4 (2)
	Exercise	14 (7)
	Factor not specified	16 (8)
How was asthma diagnosed? (multiple options have been selected) (N=195)	Recurrent symptoms	100 (51)
	Response to asthma medication	66 (34)
	Variable airflow obstruction <sup>a</sup>	34 (17)
	Other	23 (12)
	Not specified	64 (33)
Type of asthma (multiple options may have been selected) (N=195)	Allergic asthma	34 (17)
	Late-onset asthma	78 (40)
	Brittle asthma	26 (13)
	Aspirin-sensitive asthma	1 (1)
	Occupational asthma	2 (1)
	Seasonal asthma	8 (4)
	Other	46 (24)
	Not specified	34 (17)
Severity of asthma in the 12 months prior to death (N=155) <sup>b</sup>	No history of asthma	4 (3)
	Mild	14 (9)
	Moderate	76 (49)
	Severe	61 (39)
Accident and emergency department treatment in the 12 months before death (N=117)	Attended accident and emergency	40 (34)
Previous admission(s) due to asthma	Hospital, ever (N=190)	90 (47)
	Intensive care, ever (N=181)	27 (15)
	Required ventilation, ever (N=143)	10 (7)

<sup>a</sup>Airflow obstruction was tested by peak expiratory flow (PEF) or spirometry; clinicians completed a tick box stating how asthma was diagnosed (Appendices 2 and 4 – forms A1 and B1)

<sup>b</sup>Severity was defined as follows: BTS/SIGN treatment steps 1 and 2 were used as surrogate for mild and moderate severity; those who were prescribed four asthma medications and those who had been admitted to hospital in the past year, needed oral corticosteroids daily or had two or more prescriptions for systemic corticosteroids in the past year were classified as severe

NSAIDs, non-steroidal anti-inflammatory drugs (eg ibuprofen and naproxen); URTI, upper respiratory tract infection

## Medication: prescriptions issued by GPs

In general practice, repeat-prescribing systems enable patients to request and collect an agreed number of medications for a specified period of time without the need for consultation. These are recorded on GP records, but it is left to patients to order and collect prescriptions themselves. Practices usually invite patients to attend for an asthma review when they have requested the maximum number of approved prescriptions or have passed the date set for review of medication.

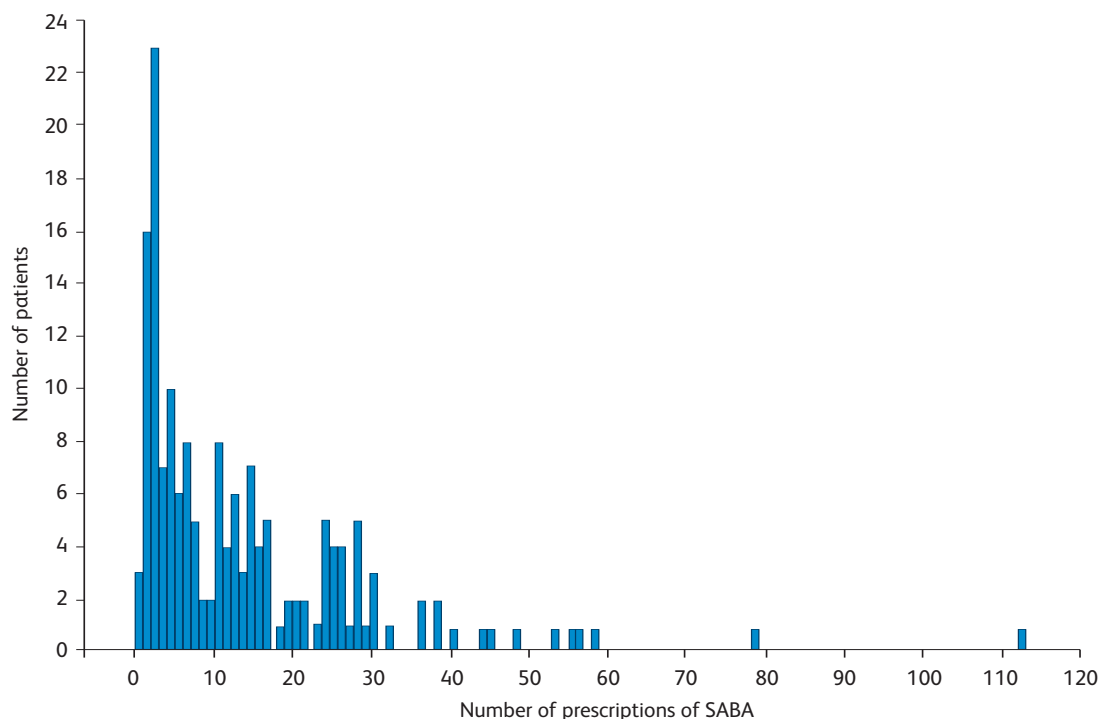
The medication prescription data for the past 12 months in those dying from asthma are shown in Table 5.4 and Fig 5.1–5.3.

### Short-acting beta agonist (SABA) bronchodilators (Fig 5.1 and Table 5.4)

Well-controlled asthma is associated with little or no need for short-acting bronchodilator (SABA or reliever) inhalers, so the need for excess SABA inhalers is a signal that asthma is poorly controlled. National guidelines state that those regularly using SABA inhalers more than three times a week should be prescribed regular corticosteroid (preventer or inhaled corticosteroid) inhalers.

From information on 194 of the 195 people who died, 189 (97%) were prescribed SABAs at the time of death. The number of SABA inhalers issued was recorded in 165; only three did not have any SABA prescription in the year before death. For these 165 patients, the number of prescribed inhalers ranged from 0 to 112, with a median of 10 (IQR 2–21), per year. Ninety-two (56%) of the 165 were prescribed

**Fig 5.1** Frequencies of SABA prescriptions issued for patients in the 12 months before death from asthma (data available for 165 patients)



**Table 5.4 Current medication of 195 patients who died from asthma**

Drug		n (%)
Short-acting beta agonist (SABA) bronchodilators	Prescribed (N=194) <sup>a</sup>	189 (97)
	Prescriptions per patient (N=165): minimum–maximum; median (IQR)	0–112; 10 (2, 21)
Single-component ICS inhalers	Prescribed (N=192) <sup>a</sup>	79 (41)
	Prescriptions per patient (N=63): minimum–maximum; median (IQR)	0–23; 3 (1–7)
Combined ICS/LABA inhalers	Prescribed (N=191) <sup>a</sup>	111 (58)
	Prescriptions per patient (N=88): minimum–maximum; median (IQR)	0–52; 5 (2–8)
LABA inhalers as a single component	Prescribed <sup>a</sup> as stand-alone inhaler (N=183)	27 (15)

<sup>a</sup>Prescribed on repeat prescription. Note that more than one item may have been prescribed  
ICS, inhaled corticosteroids; LABA, long-acting beta agonist; SABA, short-acting beta agonist

more than six and 65 (39%) more than 12 SABA inhalers in the year before they died. Six patients (4%) had been prescribed more than 50 SABA inhalers in the previous year.

Those prescribed multiple SABA (reliever) inhalers were likely to have poorly controlled asthma.

Further details of the 27 LABA inhalers as a single component are given in Table 5.4.1.

**Table 5.4.1 LABA inhalers as a single component**

LABA as single component	ICS as single component	ICS/LABA combination	n
Yes	Yes	No	12
Yes	Yes	Yes	7
Yes	No	Yes	5
Yes	No	No	2
Yes	Not known	Yes	1

### Inhaled corticosteroids (ICS)

Inhaled corticosteroid (ICS or preventer) inhalers are the cornerstone of management of people with asthma with persistent symptoms and those at risk of attacks. Good control is usually achieved with the regular use of preventer medication.<sup>1</sup> However, previous research has consistently reported that many people take less ICS than recommended by their clinician ('non-adherence'), and this has been associated with poor outcomes, including death.<sup>49,50</sup> ICS medication is currently available either as inhalers containing ICS alone ('stand-alone' ICS inhalers) or in combination with a long-acting beta agonist (LABA) bronchodilator as 'combination' inhalers. Co-administration of ICS and LABA can also be achieved by using two separate single drug inhalers.

### Patients prescribed any ICS preventer medication (Fig 5.2 and Table 5.4)

From available information, 168 (86%) of the 195 patients were prescribed preventer inhalers containing inhaled corticosteroids, either as ‘stand-alone’ ICS and/or as combination inhalers, at the time of death.

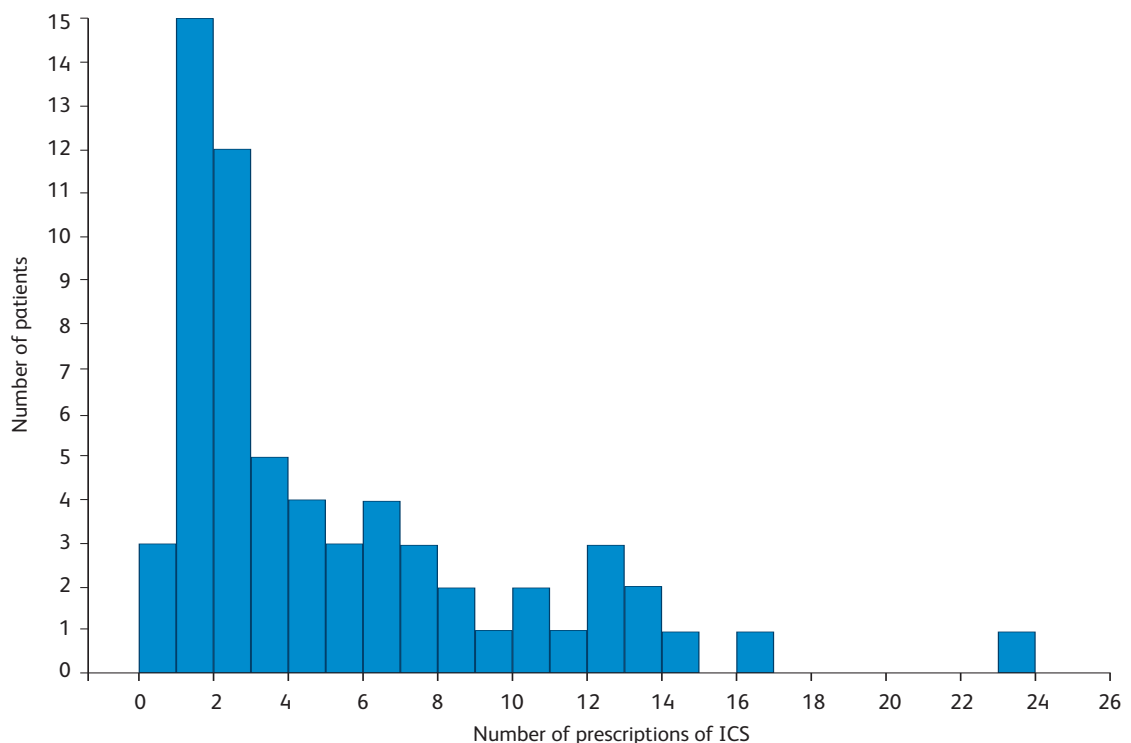
Depending on the dose of preventer medication and the inhalers prescribed, in order to adhere to advice on daily medication use, patients would normally need at least 12 preventer inhalers (‘stand-alone’ ICS or combination devices) per year. For 128 of the 168 patients, the numbers of prescribed preventer inhalers in the year before they died are known. These 128 patients were issued between one and 54 inhalers (median 5, IQR 2–10) in the previous year. Forty-nine (38%) of the 128 had been issued with fewer than four inhalers and 103 (80%) had been issued with fewer than 12 in the previous year.

### Patients prescribed ICS as a single component (Fig 5.2 and Table 5.4)

From available information on 192 patients, 79 (41%) were recorded as having ‘stand-alone’ ICS inhalers prescribed at the time of death. Of these, the number of prescriptions issued in the previous year was known for 63 patients, for whom between zero and 23 prescriptions were issued (median 3, IQR 1–7). Thirty-five (56%) of the 63 patients were prescribed fewer than four inhalers, and 55 (87%) were prescribed fewer than 12 inhalers.

Since most ICS inhalers last for 1 month at standard doses, the majority of patients taking ICS inhalers were probably undertreated (Fig 5.2).

**Fig 5.2** Frequencies of ICS prescriptions issued for cases in the 12 months before death from asthma (data available for 63 patients)



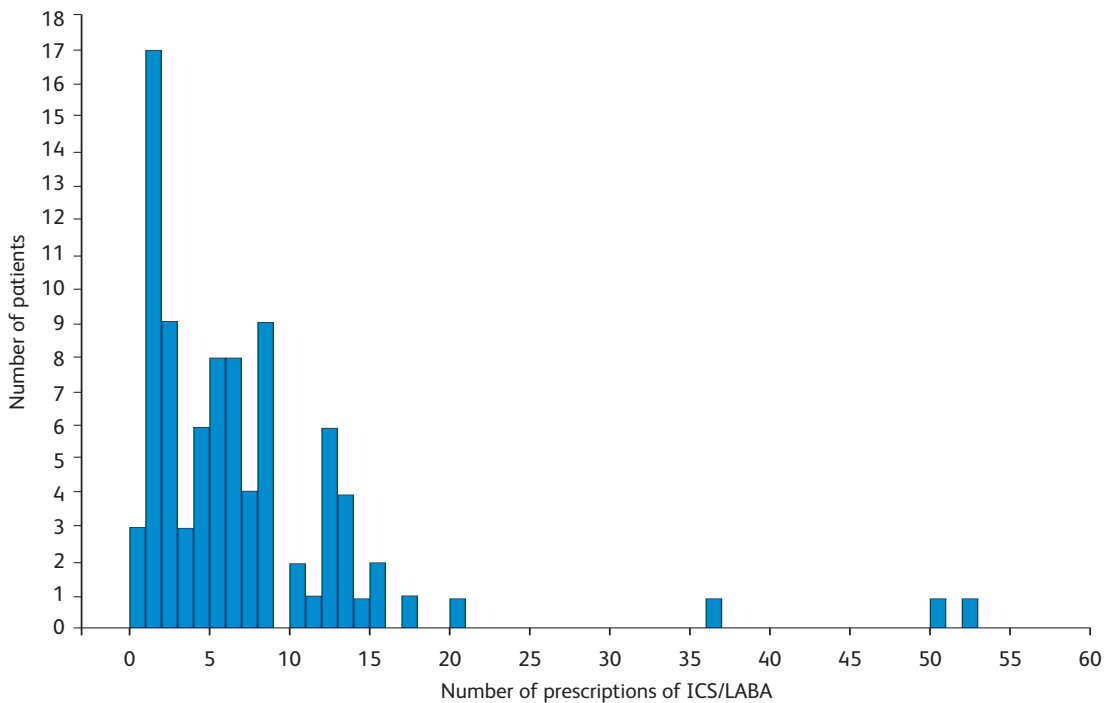
**Patients prescribed ICS/LABA in combination inhalers (Table 5.4 and Fig 5.3)**

From available information on 191 patients, 111 (58%) were recorded as having combination ICS/LABA inhalers prescribed at the time of death. The number of prescriptions issued was known in 88 who had been prescribed between zero and 52 inhalers (median 5, IQR 2–8) in the previous year. Thirty-two (36%) of the 88 patients had been prescribed fewer than four inhalers and 70 (80%) had been prescribed fewer than 12 in the previous year.

Since most ICS/LABA inhalers last for 1 month at standard doses, the majority of patients prescribed combination inhalers were probably undertreated (Fig 5.3).

Twenty-seven patients were prescribed long-acting beta agonist (LABA) bronchodilators as a single device. Of these patients, two were not prescribed ICS inhalers (as a single device or in combination) at the time of death. Twenty-five patients were prescribed ICS inhalers; however, three of these patients were known to have stopped collecting their prescriptions. This means that at least five of the 195 (3%) patients who died from asthma were on LABA monotherapy without ICS preventer treatment, putting them at greater risk of a severe asthma attack.

**Fig 5.3** Frequencies of ICS/LABA prescriptions issued for patients in the 12 months before death from asthma (data available for 88 patients)



**Key finding:** There is evidence of overuse of or over-reliance on SABA (reliever) inhalers. From prescribing data on 165 patients, 92 (56%) were prescribed more than six and 65 (39%) more than 12 SABA inhalers in the year before they died. Six patients (4%) had been prescribed more than 50 SABA inhalers in the previous year.

**Recommendation:** All asthma patients who have been prescribed more than 12 short-acting reliever inhalers in the previous 12 months should be invited for urgent review of their asthma control, with the aim of improving their asthma through education and change of treatment if required.

**Target audiences:** Pharmacists, primary healthcare setting, secondary healthcare setting, patients and carers, policy-makers, commissioners and professional and patient organisations.

**Recommendation:** Electronic surveillance of prescribing in primary care should be introduced as a matter of urgency to alert clinicians to patients being prescribed excessive quantities of short-acting reliever inhalers, or too few preventer inhalers.

**Target audiences:** NHS service managers, pharmacists, primary healthcare setting and commissioners.

## LABA monotherapy

There have been major concerns over the prescription of LABA inhalers without ICS (ie LABA monotherapy), a treatment that has been associated in controlled trials with increased mortality and is without a licence or guideline endorsement.<sup>51–53</sup> LABAs can be provided either as part of a single ICS/LABA combination inhaler, which ensures that LABA therapy cannot be prescribed as monotherapy without ICS, or as a LABA inhaler, which allows the possibility of differential adherence to ICS and LABA components. Of those who died from asthma, 27 were prescribed LABA as a single-component inhaler device. The panels reported that, in eight cases, LABA therapy without concomitant ICS was a factor in the asthma death. However, on closer scrutiny, only five (Table 6.4.2) were actually on LABA monotherapy (ie without ICS); two of the others were prescribed combined ICS/LABA and the third had not been prescribed either.

**Key finding:** There was evidence of widespread underuse of preventer medication. Overall compliance with preventer inhaled corticosteroid (ICS) was poor, with low repeat prescription fill rates both for patients treated with ICS alone and for those treated with ICS in combination with a long-acting beta agonist (LABA).

**Recommendation:** Non-adherence to preventer inhaled corticosteroids is associated with increased risk of poor asthma control and should be continually monitored.

**Target audiences:** Pharmacists, primary healthcare setting and secondary healthcare setting.

**Key finding:** At least five (3%) patients who died were on LABA monotherapy without inhaled corticosteroid preventer treatment.

**Recommendation:** The use of combination inhalers should be encouraged. Where long-acting beta agonist (LABA) bronchodilators are prescribed for people with asthma, they should be prescribed with an inhaled corticosteroid in a single combination inhaler.

**Target audiences:** NHS service managers, pharmacists, primary healthcare setting and secondary healthcare setting.



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## Chapter 6 – Confidential enquiry panel conclusions

Of the 900 cases that met the NRAD entry criteria, 276 were considered in detail by the confidential enquiry panels; the panels concluded that 195 (71%) people died from asthma (Table 6.1). The other 81 people did not have asthma, had asthma but did not die from it, or there were insufficient data to make a decision.

**Table 6.1 Main conclusions of expert multidisciplinary panels on 276 cases**

Main conclusions	n (%)
People who died from asthma <sup>a</sup>	195 (71)
People who did not have asthma	27 (10)
People who had asthma but did not die from it	36 (13)
Insufficient information:	
to decide whether the person had asthma	14 (5)
to decide whether the person died from asthma	4 (1)

<sup>a</sup>Panels considered that 171/195 (88%) patients definitely, probably or possibly died from asthma and that asthma definitely, probably or possibly contributed significantly to 24/195 (12%) deaths (Appendix 6 – Panel assessment form)

Forty-two (22%) of the 195 cases judged by the panels to have died from asthma were considered by their own clinicians to have chronic obstructive pulmonary disease (COPD) as well as asthma. COPD has overlapping features with asthma but is treated differently and, during the NRAD review process, it became clear that some asthma deaths might have been miscoded as COPD. In discussion with respiratory experts, a new Read code was requested to facilitate a computerised record of 'chronic asthma with fixed airflow obstruction'. This new code (H335) was created in June 2013 and is available for recording in UK primary care computerised records.

**Key finding:** In 27 (10%) of the 276 cases where the Medical Certificate of Cause of Death (MCCD) identified asthma as the cause of death, expert multidisciplinary panels concluded that the patients did not have asthma.

**Recommendation:** There is a need for improved guidance for doctors completing Medical Certificates of Cause of Death (MCCDs).

**Target audiences:** NHS service managers, primary healthcare setting, secondary healthcare setting and policy-makers.

## Overall quality of care

The expert multidisciplinary panels were asked to judge the quality of care provided against the standards set by the NRAD (Table 3.1) and the BTS/SIGN asthma guideline.<sup>1</sup> Quality of care was categorised into adequate or inadequate, with adequate defined as the level of care that the panel assessors would accept for themselves or a family member.

The panels concluded that the overall standard of asthma care was inadequate, with several aspects of care well below the expected standard, for 51 (26%) of those who died. The overall standard of care for children and young people was inadequate (with several aspects of care well below the expected standard) in 13/28 (46%).

**Table 6.2 Expert multidisciplinary panel conclusions on the quality of care for patients who died from asthma**

Main conclusions	Died from asthma at any age (N=195) n (%)	Died from asthma aged <20 years (N=28) n (%)
<b>a) Quality of care: routine/chronic management</b>		
Adequate	56 (29)	2 (7)
Inadequate	121 (62)	26 (93)
Not applicable, insufficient information or missing data	18 (9)	0
<b>b) Quality of care: management of attacks in the past</b>		
Adequate	69 (35)	8 (29)
Inadequate	70 (36)	13 (46)
Not applicable, insufficient information or missing data	56 (29)	7 (25)
<b>c) Quality of care: management of the final attack</b>		
Adequate	66 (34)	13 (46)
Inadequate	49 (25)	8 (29)
Not applicable, insufficient information or missing data	80 (41)	7 (25)
<b>d) Overall standard of asthma care</b>		
Good practice	31 (16)	1 (4)
Room for improvement – aspects of clinical care	51 (26)	8 (29)
Room for improvement – aspects of organisational care	6 (3)	2 (7)
Room for improvement – aspects of clinical and organisational care	45 (23)	3 (11)
Less than satisfactory; several aspects of clinical and/or organisational care were well below the expected standard	51 (26)	13 (46)
Insufficient information or missing data	11 (6)	1 (4)

**Key finding:** Several aspects of asthma care fell well below expected standards for 51 (26%) of those who died and the management of the fatal asthma attack was inadequate for 49 (25%) of them.

**Recommendation:** A national ongoing audit of asthma should be established, which would help clinicians, commissioners and patient organisations to work together to improve asthma care.

**Target audiences:** Healthcare departments of England, Northern Ireland, Scotland and Wales.

## Asthma guidelines

Panels identified potentially avoidable factors in the year before death in 89 (46%) of the 195 deaths, where alternative management could reasonably be expected to have affected outcome. These included apparent lack of specific asthma expertise by attending clinicians in 34 (17%) and lack of implementation of the BTS/SIGN asthma guideline in 48 (25%) cases.

**Key finding:** There were potentially avoidable factors related to the implementation of national guidelines in 89 (46%) of the 195 deaths.

**Recommendation:** A standard national asthma template should be developed to improve documentation and allow for a more complete and structured asthma review. This should form the basis of a local audit of asthma care.

**Target audiences:** NHS service managers, primary healthcare setting, policy-makers and commissioners.

## Panel conclusions: potentially avoidable factors in the asthma deaths

The panels identified 130 (67%) cases of the 195 who died from asthma that had at least one major potential avoidable factor. The major factors that were selected most frequently are listed in Table 6.2.1.

**Table 6.2.1 Potentially avoidable factors identified by panels**

Question in the panel form	Major factors	Number
b5	Clinicians apparently did not recognise high-risk status	21
b13	Clinicians appeared to lack specific asthma expertise	17
b1	Adequate asthma review not performed	16
b7	Clinician did not refer to another appropriate team member when this seemed to have been indicated	16
a1	Patients apparently did not take prescribed medication in the month before death	15
a2	Patients apparently did not take prescribed medication in the year before death	13
b1	Patients overprescribed short-acting beta agonist (reliever) inhalers	13
c2	Poor or inadequate implementation of policy/pathway/protocol	13
b13	Lack of knowledge of guidelines	12
A2	Patient apparently did not adhere to medical advice	10

## Patients, their families and their environment

In 126 (65%) of the 195 deaths, panels identified potentially avoidable factors that may have been influenced by patients, their families or the environment during the 12 months before death (Table 6.3.1). Apparently poor adherence to medical advice was identified in 94 (48%) cases. Sixty-six (34%) did not seem to be taking appropriate medication despite this being prescribed, and 43 (22%) failed to attend for asthma reviews. Thirty-seven (19%) of those who died were smokers and 12 (6%) were exposed to second-hand smoke.

**Table 6.3.1 Avoidable factors related to the patient or family and their environment**

Factors	All ages (N=195)	Under 10 years (N=10)	10–19 years (N=18)
	n (%)	n (%)	n (%)
<b>One or more avoidable factor</b>	<b>126 (65)</b>	<b>9 (90)</b>	<b>17 (94)</b>
<b>Poor adherence to medical advice</b>	<b>94 (48)</b>	<b>9 (90)</b>	<b>13 (72)</b>
Did not adhere to medical advice	54 (28)	3 (30)	10 (56)
Did not attend asthma reviews	43 (22)	3 (30)	5 (28)
Delay/failure in seeking medical advice	36 (18)	5 (50)	7 (39)
Delay/failure in responding to symptoms	39 (20)	8 (80)	9 (50)
Failure to take appropriate medication	66 (34)	4 (40)	13 (72)
<b>Psychosocial factors</b>	<b>51 (26)</b>	<b>3 (30)</b>	<b>4 (22)</b>
Psychological factors	32 (16)	1 (10)	1 (6)
Substance misuse	12 (6)	0 (0)	0 (0)
Social factors	29 (15)	2 (20)	4 (22)
<b>Smoker or exposed to second-hand smoke</b>	<b>47 (24)</b>	<b>3 (30)</b>	<b>7 (39)</b>
Smoker	37 (19)	1 (10)	0 (0)
Exposed to second-hand smoke	12 (6)	3 (30)	7 (39)
<b>Allergy</b>	<b>23 (12)</b>	<b>2 (20)</b>	<b>7 (39)</b>
Allergy to animals	8 (4)	0 (0)	2 (11)
Food allergy	4 (2)	0 (0)	2 (11)
Seasonal allergy	17 (9)	2 (20)	6 (33)
Drug induced	4 (2)	0 (0)	0 (0)
Other	10 (5)	0 (0)	0 (0)

In children and young people, there were potentially avoidable factors related to patients, their families or the environment in nine (90%) of those under 10 years and in 17 (94%) of those between 10 and 19 years. Seven of 18 (39%) young people between the ages of 10 and 19 years were exposed to second-hand smoke and seven (39%) had allergies.

Of the 28 children and young people, four (40%) of those aged under 10 years and 14 (78%) of those aged 10–19 years died between March and September, which supports previous research findings that children and young people are more likely to die during the summer months than the rest of the year.<sup>22</sup>

**Key finding:** In children and young people, apparent lack of adherence to medical advice was common. Seven (39%) of those aged 10–19 years were exposed to second-hand smoke. Allergy, especially seasonal allergy, was evident in patients under 20 years.

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

**Target audiences:** NHS service managers, pharmacists, primary healthcare setting, secondary healthcare setting and patients and carers.

**Recommendation:** Efforts to minimise exposure to allergens and second-hand smoke should be emphasised, especially in young people with asthma.

**Target audiences:** NHS service managers, primary healthcare setting, secondary healthcare setting and policy-makers.

**Key finding:** There were potentially avoidable factors related to patients and their families in 126 of 195 (65%) deaths, including inadequate information, education and advice on managing asthma.

**Recommendation:** Patient self-management should be encouraged to reflect their known triggers, eg increasing medication before the start of the hay-fever season, avoiding non-steroidal anti-inflammatory drugs or by the early use of oral corticosteroids with viral- or allergic-induced exacerbations.

**Target audiences:** Pharmacists, primary healthcare setting, secondary healthcare setting, patients and carers, and professional and patient organisations.

## Routine medical care and ongoing clinical supervision and monitoring

Good routine medical care of asthma includes optimisation of treatment, usually by prescribing preventer medication in those with poor control, checking inhaler technique and provision of a PAAP. There were potentially avoidable factors related to routine care, supervision and monitoring in primary care in 137 (70%) patients and in 24/83 (29%) of those managed in secondary/tertiary care in the year before death.

**Table 6.3.2 Potentially avoidable factors identified by panels in routine medical care and ongoing supervision and monitoring in primary and secondary care in the 12 months before death**

Patients (%) with potentially avoidable factor(s) during routine medical care and ongoing supervision and monitoring in primary and secondary care	All ages		Under 10 years		10–19 years		10–19 years	
	Primary care (N=195) n (%)	Secondary care <sup>b</sup> (N=83) n (%)	Primary care (N=10) n (%)	Secondary care <sup>b</sup> (N=7) n (%)	Primary care (N=18) n (%)	Secondary care <sup>b</sup> (N=9) n (%)	Primary care (N=18) n (%)	Secondary care <sup>b</sup> (N=9) n (%)
<b>One or more avoidable factor</b>	<b>137 (70)</b>	<b>24 (29)</b>	<b>8 (80)</b>	<b>4 (57)</b>	<b>16 (89)</b>	<b>4 (44)</b>	<b>16 (89)</b>	<b>4 (44)</b>
<b>Avoidable prescribing factor<sup>a</sup></b>	<b>92 (47)</b>	<b>12 (14)</b>	<b>2 (20)</b>	<b>1 (14)</b>	<b>12 (67)</b>	<b>2 (22)</b>	<b>12 (67)</b>	<b>2 (22)</b>
Did not prescribe the appropriate medication	29 (15)	2 (2)	0 (0)	0 (0)	4 (22)	0 (0)	4 (22)	0 (0)
Did not prescribe in accordance with guidelines	51 (26)	6 (7)	1 (10)	0 (0)	7 (39)	0 (0)	7 (39)	0 (0)
Overprescribed short-acting beta agonist bronchodilators	47 (24)	1 (1)	0 (0)	0 (0)	5 (28)	0 (0)	5 (28)	0 (0)
Prescribed long-acting beta agonist bronchodilator as monotherapy	8 (4)	0 (0)	1 (10)	0 (0)	1 (6)	0 (0)	1 (6)	0 (0)
Prescribed inappropriate dose of oral inhaled steroids	32 (16)	7 (8)	0 (0)	1 (14)	7 (39)	2 (22)	7 (39)	2 (22)
Prescribed inappropriate dose of other medicines	6 (3)	1 (1)	0 (0)	0 (0)	2 (11)	0 (0)	2 (11)	0 (0)
Did not offer preventative treatment	20 (10)	4 (5)	0 (0)	0 (0)	0 (0)	1 (11)	0 (0)	1 (11)
Did not check inhaler technique	44 (23)	10 (12)	3 (30)	2 (29)	2 (11)	2 (22)	2 (11)	2 (22)
<b>Lack of adherence to guidelines<sup>a</sup></b>	<b>115 (59)</b>	<b>19 (23)</b>	<b>7 (70)</b>	<b>4 (57)</b>	<b>14 (78)</b>	<b>3 (33)</b>	<b>14 (78)</b>	<b>3 (33)</b>
Did not review the patient according to guidelines	61 (31)	7 (8)	5 (50)	1 (14)	2 (11)	0 (0)	2 (11)	0 (0)
Did not identify potential triggers for asthma, eg allergies and NSAIDs	24 (12)	6 (7)	0 (0)	1 (14)	6 (33)	2 (22)	6 (33)	2 (22)
Did not perform adequate asthma review	81 (42)	10 (12)	4 (40)	2 (29)	10 (56)	3 (33)	10 (56)	3 (33)
Did not give personal asthma action plan	89 (46)	12 (14)	5 (50)	3 (43)	11 (61)	2 (22)	11 (61)	2 (22)

<sup>a</sup>More than one item could be selected

<sup>b</sup>Among patients whose care was managed by secondary/tertiary care NSAID, non-steroidal anti-inflammatory drug

**Key finding:** The panels identified potentially avoidable factors related to routine asthma care, ongoing supervision and monitoring in 137/195 (70%) cases in primary and 24/83 (29%) cases in secondary care in the year before death from asthma.

**Recommendation:** Health professionals must be aware of the features that increase the risk of asthma attacks and death, including the significance of concurrent psychological and mental health issues.

**Target audiences:** Primary healthcare setting, secondary healthcare setting, commissioners and professional and patient organisations.

**Recommendation:** Non-adherence to corticosteroid (preventer) therapy is associated with increased risk and should be continually monitored.

**Target audiences:** Pharmacists, primary healthcare setting and secondary healthcare setting.

**Recommendation:** An assessment of recent asthma control should be undertaken at every asthma review. Where loss of control is identified, immediate action is required, including escalation of responsibility, treatment change and arrangements for follow-up.

**Target audiences:** NHS service managers, primary healthcare setting, secondary healthcare setting and commissioners.

**Recommendation:** An assessment of inhaler technique to ensure effectiveness should be routinely undertaken and formally documented at annual review, and also checked by the pharmacist when a new device is dispensed.<sup>1,2,43–47</sup>

**Target audiences:** Pharmacists, primary healthcare setting and secondary healthcare setting.

## Clinical supervision or delegation of care

For the majority of deaths, care had been provided by a professional appropriate for the patient's presenting complaint. In both primary and secondary care, the panels identified avoidable factors related to referral to a specialist in 38 (19%) patients, including delays or failure of referral for specialist opinion. In particular, primary care health professionals did not refer 32 of these patients to secondary care colleagues when this seemed clinically indicated.

The panels identified potentially avoidable factors related to supervision or delegation of care in 29 (15%) of those who died (Appendix 6 – Panel assessment form, section B12, page 28), including inappropriate delegation of care in seven (4%).

## Assessment and recognition of risk status

The panels identified avoidable factors related to assessment and recognition of risk status by professionals in primary care in 99/195 (51%) cases, and in 23/83 (28%) of those seen in secondary care.

**Table 6.3.3 Potentially avoidable factors identified by the panels on the assessment of patients and recognition of their risk status in primary and secondary care**

Patients (%) with avoidable factor(s) related to the assessment and recognition of risk status in primary and secondary care (more than one could be selected by the panels)	All ages		Under 10 years		10–19 years		10–19 years	
	Primary care (N=195) n (%)	Secondary care <sup>b</sup> (N=83) n (%)	Primary care (N=10) n (%)	Secondary care <sup>b</sup> (N=7) n (%)	Primary care (N=18) n (%)	Secondary care <sup>b</sup> (N=9) n (%)	Primary care (N=18) n (%)	Secondary care <sup>b</sup> (N=9) n (%)
<b>One or more avoidable factor</b>	<b>99 (51)</b>	<b>23 (28)</b>	<b>7 (70)</b>	<b>2 (29)</b>	<b>15 (83)</b>	<b>3 (33)</b>	<b>15 (83)</b>	<b>3 (33)</b>
Incorrect diagnosis	12 (6)	3 (4)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
<b>Delay in recognition of risk status<sup>a</sup></b>	<b>49 (25)</b>	<b>10 (12)</b>	<b>5 (50)</b>	<b>0 (0)</b>	<b>9 (50)</b>	<b>2 (22)</b>	<b>9 (50)</b>	<b>2 (22)</b>
Delay in assessment or evaluation of patient	15 (8)	2 (2)	2 (20)	0 (0)	3 (17)	0 (0)	3 (17)	0 (0)
Delay in recognising abnormal clinical signs	7 (4)	3 (4)	1 (10)	0 (0)	2 (11)	1 (11)	2 (11)	1 (11)
Delay in recognising the problem or its severity	29 (15)	4 (5)	2 (20)	0 (0)	5 (28)	0 (0)	5 (28)	0 (0)
Delay in diagnosing or recognising high-risk status	25 (13)	5 (6)	3 (30)	0 (0)	6 (33)	1 (11)	6 (33)	1 (11)
Other delay	3 (2)	1 (1)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
<b>Quality of assessment<sup>a</sup></b>	<b>80 (41)</b>	<b>16 (19)</b>	<b>6 (60)</b>	<b>2 (29)</b>	<b>14 (78)</b>	<b>1 (11)</b>	<b>14 (78)</b>	<b>1 (11)</b>
Did not assess or evaluate the patient properly	43 (22)	6 (7)	3 (30)	0 (0)	6 (33)	1 (11)	6 (33)	1 (11)
Did not record clinical signs	21 (11)	3 (4)	1 (10)	0 (0)	4 (22)	0 (0)	4 (22)	0 (0)
Did not recognise abnormal clinical signs	16 (8)	1 (1)	3 (30)	0 (0)	2 (11)	0 (0)	2 (11)	0 (0)
Did not recognise the problem or its severity	57 (29)	8 (10)	5 (50)	0 (0)	10 (56)	0 (0)	10 (56)	0 (0)
Did not diagnose or recognise high-risk status	60 (31)	11 (13)	5 (50)	2 (29)	13 (72)	1 (11)	13 (72)	1 (11)
Other assessment issue	4 (2)	1 (1)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)

<sup>a</sup>More than one item could be selected

<sup>b</sup>Among patients whose care was managed by secondary/tertiary care



These included delays in recognising risk status in 49/195 (25%) cases in primary care and 10/83 (12%) cases in secondary care, and inadequate assessment in 80/195 (41%) cases in primary care and 16/83 (19%) cases in secondary care.

### Assessment and management of final attack in primary and secondary care

Of the 195 people who died from asthma, 65 (33%) died without seeking medical assistance and a further 22 (11%) called for help but died before they saw a healthcare professional (Table 4.4.1). Sufficient information was available for analysis on 38 patients whose final attack was assessed and treated in primary care and 59 whose final attack was treated in secondary care.

For the 38 (19%) patients treated in primary care during their final, fatal asthma attack, there were potentially avoidable factors in 13 (34%) of these deaths related to assessment of the attack and access to care by professionals in primary care. For the 59 patients who were treated for their final attack in secondary care, there were potentially avoidable factors related to assessment of the attack and access to care by professionals in 20 (34%).

Deficiencies in the quality of the assessment were found in 12 (32%) patients in primary care and 14 (24%) in secondary care. Failures to perform physiological measures of lung function occurred in eight (21%) cases in primary care and five (8%) cases in secondary care.

**Table 6.3.4 Potentially avoidable factors during assessment of final attack and access to care in primary and secondary care**

Patients (%) with avoidable factor(s) relating to assessment of final attack and access to care in primary and secondary care (more than one could be selected by the panels)	All ages	All ages	Under 10 years	10–19 years
	Primary care (N=38) n (%)	Secondary care (N=59) n (%)	Secondary care (N=2) n (%)	Secondary care (N=5) n (%)
<b>One or more avoidable factor</b>	<b>13 (34)</b>	<b>20 (34)</b>	<b>1 (50)</b>	<b>1 (20)</b>
<b>Access to appropriate care was delayed<sup>a</sup></b>	<b>6 (16)</b>	<b>11 (19)</b>	<b>1 (50)</b>	<b>0 (0)</b>
Access to appropriate care was delayed/not possible	3 (8)	5 (8)	0 (0)	0 (0)
Delay in getting adequate medical history	2 (5)	0 (0)	0 (0)	0 (0)
Delay in assessment or evaluation of patient	4 (11)	6 (10)	0 (0)	0 (0)
Delay in taking appropriate physiological measurements during the attack	4 (11)	3 (5)	1 (50)	0 (0)
Delay in recognising abnormal vital signs	4 (11)	7 (12)	1 (50)	0 (0)
<b>Quality of assessment<sup>a</sup></b>	<b>12 (32)</b>	<b>14 (24)</b>	<b>1 (50)</b>	<b>1 (20)</b>
Did not get an adequate medical history	2 (5)	1 (2)	0 (0)	0 (0)
Did not assess or evaluate the patient properly	8 (21)	5 (8)	0 (0)	0 (0)
Did not take appropriate physiological measurements during the attack	8 (21)	5 (8)	1 (50)	0 (0)
Did not recognise abnormal vital signs	7 (18)	6 (10)	1 (50)	0 (0)
Other assessment issue	1 (3)	6 (10)	0 (0)	1 (20)

<sup>a</sup>More than one item could be selected. No avoidable factors for patients aged under 20 years were identified for primary care

## Management of final attack

In an acute asthma attack, treatment with reliever bronchodilators and corticosteroids should be administered as soon as possible. Administration of reliever bronchodilator therapy is recognised as an essential and potentially life-saving treatment in acute severe asthma. In the 49 people recorded as being treated with bronchodilator reliever therapy, timing was only noted in 25 (51%); in these 25 cases, emergency reliever treatment was not given to eight (32%) within 30 minutes of being seen by a doctor.

## Primary care management of final attack

The panels identified avoidable factors related to the management of the final attack by professionals in 12 (32%) of those cases treated in primary care and 20 (34%) treated in secondary care.

These details are shown in Table 6.3.5.

**Key finding:** Twelve of 38 patients who had their fatal attack treated in primary care had avoidable factors related to referral by a professional in primary care to a specialist in secondary care.

**Key finding:** Twenty of 59 patients who died in hospital had an avoidable factor related to referral by a professional in secondary care to a specialist.

**Recommendation:** Every NHS hospital and general practice should have a designated, named clinical lead for asthma services, responsible for formal training in the management of acute asthma.

**Target audiences:** NHS service managers, primary healthcare setting, secondary healthcare setting, policy-makers and commissioners.

## Discharge from hospital

Nineteen (10%) of those who died did so within 28 days of being treated in hospital for an asthma attack. In 13 (68%) of these patients, the panels identified potentially avoidable factors in relation to both their discharge into the community and follow-up arrangements. At least 40 (21%) of those who died had attended an emergency department with an asthma attack in the previous year and, of these, 23 had attended on at least two occasions.

According to national standards, people admitted to hospital with an acute exacerbation of asthma should have a structured review by a member of a specialist respiratory team before discharge.<sup>1,2,43–47</sup>

**Table 6.3.5 Potentially avoidable factors related to management or treatment of final attack in primary and secondary care (38 attacks treated in primary care; 59 attacks treated in secondary care)**

Patients (%) with avoidable factor(s) relating to management of final attack in primary and secondary care (more than one could be selected by the panels)	All ages		Under 10 years		10–19 years		10–19 years	
	Primary care (N=38) n (%)	Secondary care (N=59) n (%)	Primary care (N=1) n (%)	Secondary care (N=2) n (%)	Primary care (N=1) n (%)	Secondary care (N=5) n (%)	Primary care (N=1) n (%)	Secondary care (N=5) n (%)
<b>One or more avoidable factors</b>	<b>12 (32)</b>	<b>20 (34)</b>	<b>0 (0)</b>	<b>1 (50)</b>	<b>1 (100)</b>	<b>2 (40)</b>	<b>1 (100)</b>	<b>2 (40)</b>
<b>Delay in management/treatment/following guidelines</b>	<b>4 (11)</b>	<b>8 (14)</b>	<b>0 (0)</b>	<b>0 (0)</b>	<b>0 (0)</b>	<b>2 (40)</b>	<b>0 (0)</b>	<b>2 (40)</b>
Delay in implementing appropriate monitoring	0 (0)	1 (2)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Delay in initiating treatment	2 (5)	6 (10)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Delay in following guidelines	2 (5)	2 (3)	0 (0)	0 (0)	0 (0)	1 (20)	0 (0)	1 (20)
Other delay	0 (0)	1 (2)	0 (0)	0 (0)	0 (0)	1 (20)	0 (0)	1 (20)
<b>Management issue</b>	<b>11 (29)</b>	<b>13 (22)</b>	<b>0 (0)</b>	<b>1 (50)</b>	<b>1 (100)</b>	<b>0 (0)</b>	<b>1 (100)</b>	<b>0 (0)</b>
Did not implement appropriate monitoring	3 (8)	4 (7)	0 (0)	1 (50)	0 (0)	0 (0)	0 (0)	0 (0)
Did not initiate treatment	6 (16)	5 (8)	0 (0)	1 (50)	1 (100)	0 (0)	1 (100)	0 (0)
Did not follow guidelines	9 (24)	3 (5)	0 (0)	1 (50)	1 (100)	0 (0)	1 (100)	0 (0)
Other failure	4 (11)	7 (12)	0 (0)	1 (50)	0 (0)	0 (0)	0 (0)	0 (0)

**Key finding:** Nineteen (10%) of those who died did so within 28 days of being treated in hospital for an asthma attack. In 13 (68%) of these, there were potentially avoidable factors in relation to both their discharge into the community and follow-up arrangements.

**Recommendation:** The use of patient-held 'rescue' medications including oral corticosteroid and self-administered adrenaline (in people prone to anaphylaxis), as part of a written self-management plan, should be considered for all patients who have had a life-threatening asthma attack or a near-fatal episode.

**Target audiences:** Pharmacists, primary healthcare setting, secondary healthcare setting, patients and carers, commissioners, and professional and patient organisations.

**Key finding:** At least 40 (21%) of those who died had attended an emergency department with an asthma attack in the previous year and, of these, 23 had attended on at least two occasions.

**Recommendation:** Follow-up arrangements must be made after every attendance at an emergency department or out-of-hours service for an asthma attack. Secondary care follow-up should be arranged after every hospital admission for asthma, and for patients who have attended the emergency department two or more times with an asthma attack in the previous 12 months.

**Target audiences:** NHS service managers, primary healthcare setting, secondary healthcare setting and commissioners.

## Local reviews

Following the unexpected death of a patient, a structured local review or critical event analysis (CEA) by health professionals can provide an opportunity for reflection and learning. In children, Child Death Overview Panel (CDOP) processes should be followed.<sup>54</sup> Health professionals were asked to submit copies of any local reviews on their patients selected for the NRAD, but copies of such reports were received for only 24 (12%) of the 195 people who died from asthma. These included 12 of the 28 (43%) children and young people and 12 of 118 (10%) of those aged 20–74 years. No information on any reviews was provided for any patient aged over 74 years. The confidential enquiry panels concluded that nine of 24 (38%) reviews were of adequate quality for learning as a reflection on practice or the care provided for these people.

**Key finding:** Information on local reviews was received on only 24 (12%) of the 195 people who died from asthma.

**Recommendation:** In all cases where asthma is considered to be the cause of death, there should be a structured local critical incident review in primary care (to include secondary care if appropriate) with help from a clinician with relevant expertise.<sup>55</sup>

**Target audiences:** NHS service managers, pharmacists, primary healthcare setting, secondary healthcare setting, policy-makers, commissioners and professional and patient organisations.

### Family interviews

Within the NRAD methodological design, it was envisaged that contact with bereaved family members regarding their experiences and thoughts concerning aspects of the deceased's asthma care would be informative and enlightening. To achieve this, a limited number of telephone interviews were planned with bereaved family members from across the UK. Recorded semi-structured telephone interviews were to be conducted by a registered nurse (Appendix 8 – Bereaved family member interview form). Significant methodological issues were subsequently encountered, including delays in securing appropriate approval from local ethics committees and unforeseen practical difficulties contacting family practitioners and families. As a result, insufficient numbers of interviews were conducted to obtain meaningful, generalisable information. The methodological challenges in this approach will be explored in a subsequent publication.

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## Chapter 7 – Environmental data analysis (weather, pollen and fungal spores)

A number of studies on asthma deaths have reported an increase in seasonal summer death rates in those aged under 45 years. However, in the summer of 2012, the NRAD did not find any clusters or peaks in asthma deaths either during the grass pollen season in May and June or during the fungal spore season in July–September. However, environmental factors are thought to be responsible for the previously reported clusters of deaths in summer. Therefore, weather, pollen and pollution data were obtained from the Met Office (the UK's national weather service) for the date and location of each death, the six preceding days and the corresponding date 1 year previously for comparison. Mean counts per cubic metre of air were provided for fungal spore data for Leicestershire and Derby by the Institute for Lung Health, University of Leicester, for all days in January–November 2011 and March–November 2012. Data were obtained from just one site in the Midlands because fungal spore data are not available for different regions of the UK. Although it is not known exactly how counts from different geographical regions compare, literature suggests a lag phase for fungal spores and so it was assumed that levels from a single central site should be representative.

Data on fungal spore and grass pollen levels were thus available for both 2011 and 2012, but data on the number of asthma deaths were only available for 2012. This proved to be a major limitation and hampered the ability to correlate fungal spore counts and asthma deaths owing to a lack of data on asthma deaths in 2011. Therefore, it was not possible to compare death rates between two seasons with different seasonal aero-allergen levels. In 2012, *Alternaria* and *Cladosporium* counts were considerably lower than in 2011 (Fig 7.1), whilst for some other spores the counts were generally higher in 2012 than in 2011 (notably *Sporobolomyces*, *Tilletiopsis*, *Didymella*, *Leptosphaeria*, *Botrytis*, ascospores, hyaline basidiospores and total fungal spores). Levels of grass pollen were comparable between the two seasons. Therefore, NRAD data on deaths in 2012 remain consistent with the hypothesis that *Alternaria* and *Cladosporium* (both known allergenic seasonal fungal spores) are responsible for the summer peak in asthma deaths seen in some years (but not in 2012) and reported by previous studies. However, in the absence of data on asthma deaths in 2011, no conclusions on causality can be drawn. A more detailed analysis of the data will be undertaken in a separate publication.

Fig 7.1 Median daily counts of *Alternaria* and *Cladosporium*

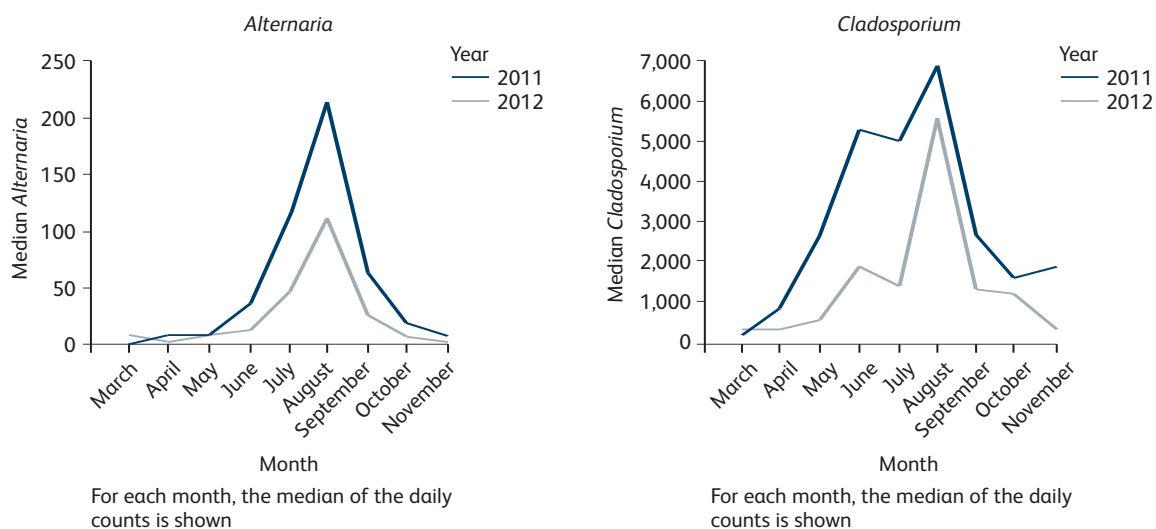


Table 7.1 Data analysed: weather, pollen, fungal spores

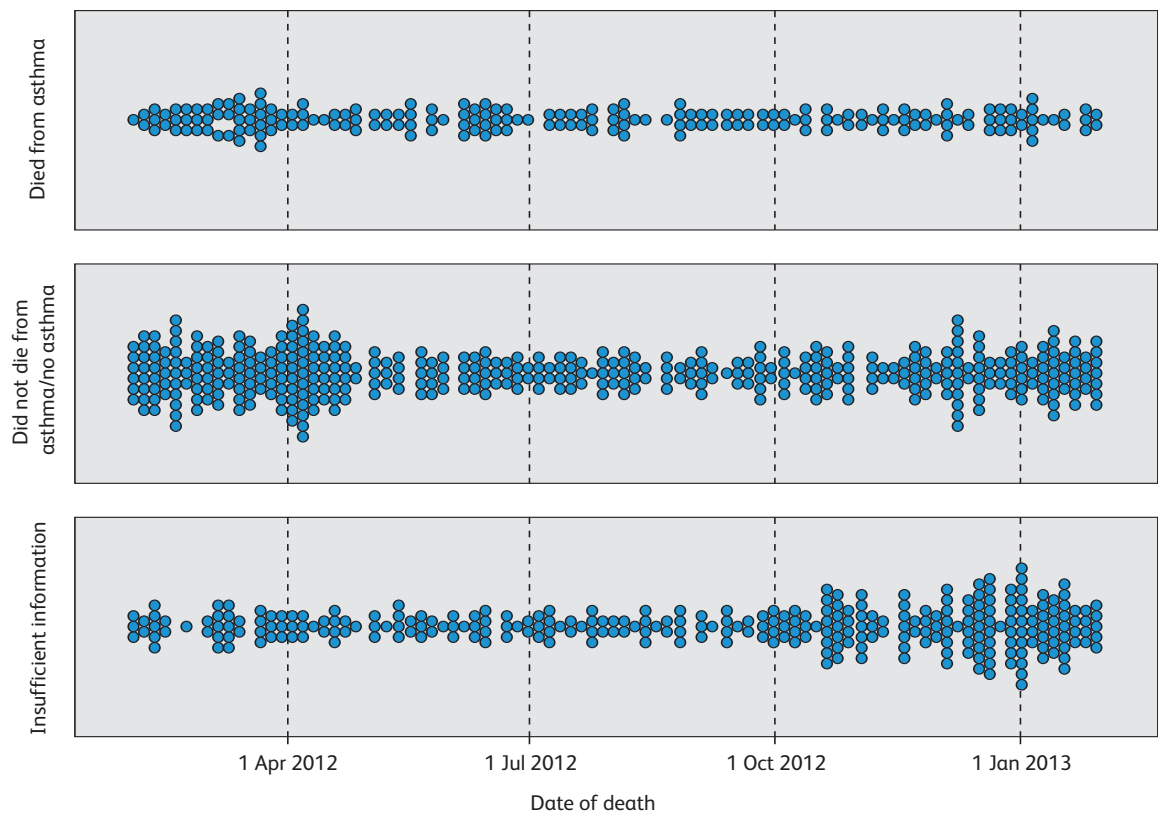
Weather <sup>a</sup> (µg/m <sup>3</sup> unless stated)	Pollen <sup>a</sup> (median count/cm <sup>3</sup> )	Fungal spores <sup>b</sup> (mean count/m <sup>3</sup> of air)
Minimum temperature (Celsius)	<i>Corylus</i> (hazel)	<i>Alternaria</i>
Mean temperature (Celsius)	<i>Alnus</i> (alder)	<i>Cladosporium</i>
Maximum temperature (Celsius)	<i>Salix</i> (willow)	<i>Sporobolomyces</i>
Mean relative humidity (%)	<i>Betula</i> (birch)	<i>Tilletiopsis</i>
Mean carbon monoxide concentration	<i>Fraxinus</i> (ash)	<i>Didymella</i>
Mean nitric oxide concentration	<i>Ulmus</i> (elm)	<i>Leptosphaeria</i>
Mean nitrogen dioxide concentration	<i>Quercus</i> (oak)	<i>Ustilago</i>
Mean ozone concentration	<i>Platanus</i> (plane)	<i>Botrytis</i>
Mean PM10 particulate matter concentration	Poaceae (grass)	<i>Ganoderma</i>
Mean sulphur dioxide concentration	<i>Urtica</i> (nettle)	<i>Epicoccum</i>
	<i>Artemisia</i> (mugwort)	<i>Aspergillus</i> ( <i>Penicillium</i> type)
	<i>Ambrosia</i> (ragweed)	Ascospores
		Coloured basidiospores
		Hyaline basidiospores
		Total fungal spores (sum of above plus others)

Source: <sup>a</sup>Met Office; <sup>b</sup>Dr Catherine Pashley, Institute for Lung Health, University of Leicester

## Temperature, relative humidity and air pollution

For the temperature variables (mean, minimum, maximum), there was a consistent, statistically significant difference between years 2011 and 2012, with 2012 colder by nearly a degree on average. For relative humidity, any differences were less apparent and no UK-wide data could be found. Air-quality data were only available from mid-June 2011 to mid-July 2012 and thus provided little opportunity to compare between years 2011 and 2012.

**Fig 7.2** Distribution of deaths across the seasons for the NRAD cases





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## Chapter 8 – Key findings and advice for patients and carers, and recommendations for primary care organisations

### Key findings and advice for patients and carers by Asthma UK

Prepared by David Hiles, Head of Health Promotion, Asthma UK, London  
Emily Humphreys, Head of Policy and Public Affairs, Asthma UK, London

This report highlights some common factors that contributed to people dying from asthma. However, there are many things that you can do to reduce the risk of having a potentially fatal asthma attack. In fact, of the asthma deaths examined in this report, 65% had major factors that could have been avoided. This section highlights the key findings from the report, and suggests some ways that you can reduce your, or your child's, risk of having a serious asthma attack.

**Key advice:** Know your risk of having an asthma attack.

**Key evidence:** At least 50% of people who died were being treated for mild or moderate asthma.

Asthma does not kill only people who have severe asthma. This report highlights, from available data, that 58% of people who died were being treated for either mild or moderate asthma. So it is really important to understand that asthma does kill, even if you think that you only have mild asthma. There are many factors that can increase your risk of having an asthma attack. One quick thing that you can do is take the Triple A: Avoid Asthma Attacks online test. It asks you a few questions, such as how many times you take your inhalers, and then it gives you a result to show whether you may be at an increased risk of having an asthma attack. The most important thing about the test is that it gives you some great advice about how you can reduce your risk of a future attack. Take the test at [www.asthma.org.uk/triple-a](http://www.asthma.org.uk/triple-a).

You can also take the Asthma Control Test, which looks at how well your asthma is being controlled. You can download the test at [www.asthmacontroltest.com](http://www.asthmacontroltest.com). Talk to your GP or asthma nurse about the results of this test at your next appointment.

**Key advice:** Using a written personal asthma action plan and attending your annual asthma review are vital.

**Key evidence:** Only 23% of people who died had a personal asthma action plan. Twenty-two per cent of people who died missed a review appointment with their GP in the year before they died. Forty-five per cent died before seeking medical assistance, or before medical assistance was provided during the attack that caused their death.

If you have asthma, you are entitled to have a review with your asthma nurse or GP at least once a year. A review is your chance to tell your GP or asthma nurse how your asthma is affecting you. You can then agree a plan of action together to reduce your risk and get on top of your asthma.

At the review, you should ask for your own written personal asthma action plan to be completed. This is a written plan that is personal to you and lets you know how to spot when your symptoms are getting worse, what to do when your symptoms get worse, what to do in an emergency and when to call for medical help. We know that many people leave it too late to call for help when their asthma is really troubling them. Using a personal asthma action plan can help you to avoid these emergencies. You can download an asthma action plan from [www.asthma.org.uk/adultactionplan](http://www.asthma.org.uk/adultactionplan) and you can take it to your GP or asthma nurse to ask them to discuss and complete your personal plan with you. You can also download an asthma action plan for your child at [www.asthma.org.uk/childactionplan](http://www.asthma.org.uk/childactionplan).

**Key advice:** You should have an appointment with your GP within 48 hours after you leave hospital if you have been admitted or had to visit accident and emergency because of your asthma.

**Key evidence:** Forty-seven per cent (90/190) of people who died had been admitted to hospital at some point because of their asthma.

**Key evidence:** At least 21% (40/195) of people who died had attended accident and emergency with asthma in the year before the asthma attack that caused their death.

**Key evidence:** Ten per cent of people who died had been treated in hospital within the 28 days immediately before having the asthma attack that caused their death.

We know that being admitted to hospital for asthma, as well as having to go to accident and emergency because of an asthma attack, may be a sign that you are more likely to have another asthma attack in the future that may cause death. It is a good idea to see your GP within 48 hours of being sent home from hospital or after you are allowed to leave accident and emergency. You can have your medicines reviewed, your asthma action plan updated and your inhaler technique checked at this follow-up appointment. Going to accident and emergency or ending up in hospital is a warning sign that you could be in danger of having a more serious asthma attack in the future. It is very important to see your GP as soon as possible to make sure that you are doing all you can to avoid another asthma attack.

**Key advice:** Make sure you take your medicines as advised by your GP or asthma nurse.

**Key evidence:** Among patients who were prescribed short-acting relievers, 39% (65/165) were prescribed more inhalers in the year before death than they should be using.

It is really important to take your medicines as advised by your GP or asthma nurse. If you do not understand what your medicines do or if you have any worries about the types of medicine that you take, or how to use your inhalers, then talk this over with your GP or asthma nurse. Your GP and asthma nurse are there to help you get the best out of your medicines. Some people may be wary of potential side effects, but for most people the side effects of their asthma medicines are small, if they have any at all. Steroids (in inhalers called preventer inhalers) are often prescribed to prevent asthma getting out of control. These drugs are excellent at helping you to keep on top of your asthma, so it is worth following your GP's advice about what medicines to take, and when to take them. If you are not sure how to use your inhaler properly, ask your GP, asthma nurse or pharmacist to show you. You can also take a look at the videos at [www.asthma.org.uk/inhalerdemos](http://www.asthma.org.uk/inhalerdemos) to check whether you are taking your inhalers in the best way to keep you well.

It is also worth keeping an eye on how many times you are using your reliever inhaler (usually blue). If you are using your reliever inhaler three or more times per week, this may be a sign that your asthma is not as well controlled as it could be. If you are using your blue inhaler this often, you should make an appointment to have your asthma reviewed with your GP or asthma nurse.

**Key advice:** Avoiding your asthma triggers is vital.

**Key evidence:** At least 49% of people who died never had their triggers recorded in their medical notes and so may never have been told how to avoid them.

Asthma 'triggers' are the things that set off your asthma symptoms. They can be anything from pets to pollen. Talking about how you could avoid your triggers can be done when you see your GP or asthma nurse for your next asthma review. It is worth having a think about what triggers make your asthma worse, and whether you could take steps to avoid them. If you have an allergy, it is also worth talking about allergy management. Having an allergy can make your asthma symptoms worse quickly, so staying on top of your allergies could help you to avoid an asthma attack.

We know from the report that some people who died also lived with psychological conditions, such as depression and anxiety. Living with these types of condition can be stressful, and stress can be a trigger for many people with asthma. Living with depression and anxiety may also make it more difficult to be motivated to keep taking your asthma medicines. Your GP or asthma nurse can help you talk over any of these issues.

**Key advice:** Smoking and being overweight can have a very serious impact on your asthma.

**Key evidence:** Fifty-six per cent of people who died were overweight. Thirty-one per cent of people who died were obese or very obese. Twenty-eight per cent of people who died were smokers or were exposed to second-hand smoke from other people.

While many people know that smoking and being overweight can lead to many serious health problems, some people may not be aware how smoking and being overweight can affect their asthma. Smoke irritates your lungs and can bring on your asthma symptoms. Smoke can also stop your asthma medicines working properly. Stopping smoking can be difficult, but it could be one of the most important things that you do to improve your asthma. Talking to your GP about ways to stop smoking could be the first step to a better life with asthma.

Having a higher BMI (body mass index – a measure to show whether you are overweight) could also make it more difficult to manage your asthma. Talking to your GP about your diet and the best way to lose weight could form part of your annual review and could have a great impact on your asthma.

For more advice about how you can reduce your risk of an asthma attack and stay on top of your asthma, take a look at the information on [www.asthma.org.uk](http://www.asthma.org.uk) or you can call the Asthma UK Helpline to speak to an asthma nurse specialist on 0800 121 62 44.

## Key findings and recommendations for primary care by PCRS-UK

These key findings and recommendations were developed by the Primary Care Respiratory Society UK for inclusion in the report.

Key findings	Recommendations
<p>1 For 43 % of patients, there was no evidence that the patient had had an asthma review in general practice in the last year before death. Twenty-two per cent had missed a routine GP asthma appointment in the previous 12 months.</p>	<p>Practices should have proactive methods of identifying and contacting patients who fail to attend for routine asthma appointments. A range of methods of engagement should be explored (eg telephone consultations – by clinicians not support staff, telephone follow-up if patients do not attend, personalised letters explaining possible risks of not attending, alerts on prescription screen limiting inhaler issue in future, opportunistic review of patients attending for other conditions, major alert on screen for all to see lack of asthma review).</p>
<p>2 Avoidable factors relating to the adequacy of asthma reviews were identified in 42 % of cases – in areas such as the provision of written self-management plans, and checking medication adherence and inhaler technique.</p>	<p>Reviews should be conducted by clinicians trained in asthma care and aware of the factors that place patients at higher risk of exacerbation and death. Practices should devise/acquire a standard template to raise the quality of the regular review, until a standard national template is available. QOF guidance states that an asthma review should include:</p> <ul style="list-style-type: none"> <li>• assessment of symptoms using RCP three questions</li> <li>• measurement of peak flow</li> <li>• assessment of inhaler technique</li> <li>• a PAAP.</li> </ul>
<p>3 Only 44 (23 %) of the 195 who died had been provided with a PAAP in primary or secondary care.</p>	<p>The BTS/SIGN asthma guideline has recommended personal asthma action plans for all patients for many years. The evidence for the benefits of such plans is grade A, and all patients with asthma should have a written plan and know how to respond in the event of deteriorating control.</p>
<p>4 Forty-five per cent of patients died without seeking medical assistance or before emergency medical care could be provided. Of cases where the final attack was treated in primary care, 16 % had a delay in accessing appropriate care in the final attack. The panels concluded that delay/failure in seeking medical help was a potentially avoidable factor in the deaths of 36 (18 %) of those who died.</p>	<p>Clinicians should take responsibility for supporting patients in self-management so that they can identify when their asthma is worsening and when they need to seek medical help, and capture this in a PAAP.</p> <p>Practices should ensure that their systems encourage and allow swift access to advice and assessment in the event of an asthma exacerbation.</p>

Key findings	Recommendations
<p>5 The quality of routine care was assessed as inadequate in 62 % of cases, and the panels concluded that there may have been a lack of specific asthma expertise in 17 % . Potentially avoidable factors identified by panels: in 59 % of deaths, clinicians in primary care failed to adhere to the BTS/SIGN asthma guideline (including 42 % not performing adequate review and 46 % not giving a PAAP (key finding 3)).</p>	<p>The training needs of clinicians responsible for managing people with asthma need to be assessed and monitored to ensure that the clinicians are competent for the task. Each primary care practice should have a named health professional responsible for the maintenance and improvement of standards of asthma care in the practice and these professionals should engage in additional training and updating in respect of this role.</p>
<p>6 Avoidable factors relating to assessment and recognition of risk by primary care professionals were identified by the panels in 51 % of cases.</p>	<p>Practices need to adopt a system of establishing the risk profile of a patient and put a treatment plan in place that is appropriate to their risk profile.</p>
<p>7 Avoidable factors were identified by the panels in the management of the final attack by primary care professionals in 32 % of those who accessed medical treatment during their final attack. This included delays in initiating appropriate treatment, and failure to give appropriate treatment. Fifty per cent (77/153) of the deaths took place between 8am and 6pm.</p>	<p>Practice staff and clinicians in primary care need to have systems in place and the appropriate expertise to recognise serious asthma attacks, and initiate immediate treatment. As half of deaths are taking place during surgery hours, it is even more important that practices have such systems in place. Reception staff need to be trained to recognise when an individual with asthma needs to be seen urgently.</p>
<p>8 Avoidable factors relating to prescribing were identified by the panels in 47 % of the cases managed in primary care. Among patients that were on short-acting relievers at the time of death, 39 % had been prescribed more than 12 salbutamol inhalers in the previous year and six individuals had had more than 50. Overuse of short-acting bronchodilators is a key indicator of poor asthma control and of higher risk of exacerbation and death. At least five patients had been on LABAs with no concomitant inhaled steroids, which the Medicines and Healthcare Products Regulatory Agency (MHRA) has explicitly warned against on grounds of safety. Many patients on ICS alone or in combination were undertreated owing to an inadequate number of prescriptions issued in the last year. Eighty per cent were issued fewer than 12 prescriptions a year and 38 % (of 128) had fewer than four prescriptions.</p>	<p>Practice systems should be put in place – in every consultation with a person with asthma – to identify patients using one SABA inhaler a month or more and to offer advice proactively on how to improve asthma control. Practices should receive and record notification from pharmacies of SABA inhalers supplied without a prescription under patient group directions. Continuing use of single-agent LABA inhalers should be avoided so as to avoid the risk of non-use of inhaled corticosteroids in patients with persistent or severe symptoms. Concordance with inhaled steroids and combination ICS/LABAs needs to be monitored closely to ensure that adequate medication is being taken.</p>
<p>9 Poor treatment adherence, psychosocial/learning disability problems and a BMI of 25 or more were identified in 48 % (94/195), 44 % (84/190) and 56 % (68/121), respectively, of those who died. For 26 % of patients, psychosocial factors were considered a risk factor.</p>	<p>This reinforces the need for better patient education, and the importance of assessing risk in the course of routine asthma care.</p>

Key findings	Recommendations
<p>10 Ten per cent of the deaths occurred in patients who had received hospital treatment within the previous 28 days. At least 21 % had been seen for asthma in accident and emergency departments in the previous 12 months.</p>	<p>Practices should press for prompt communication from hospitals and other urgent care providers about patients seen with asthma exacerbations, and should ensure primary care follow-up within two working days of receiving such notification, so as to allow optimisation of treatment and to identify those patients whose asthma remains out of control despite their hospital attendance.</p>
<p>11 Of the 900 cases selected for data collection for the study, 272 were not included because clinicians involved in their care provided either no or inadequate information to enable the panels to make a decision about the quality of their care.</p>	<p>Doctors should regard it as a professional obligation to cooperate with confidential enquiries of this kind, and to supply the information requested.</p>
<p>12 Reports based on critical event analysis were submitted for only 12 % of the people who died from asthma – 43 % of the children and teenagers, 10 % of those aged 20–74 years, and none aged over 75 years. Only 38 % of these were deemed by the panels to be of sufficient quality for reflective learning.</p>	<p>There is a strong case for any death thought to be primarily due to asthma to be the subject of a local confidential enquiry process or critical event analysis to ensure that lessons are learned to reduce the likelihood of future asthma deaths. Practices should ensure that any asthma death is systematically investigated locally.</p>
<p>13 The study has revealed significant issues in the accuracy of death certification and in the practices of the Office for National Statistics (ONS) for England and Wales, the Northern Ireland Statistics and Research Agency (NISRA) or the National Records of Scotland (NRS) in assigning asthma as an underlying cause of death.</p>	<p>Doctors may need better training in death certification, and standards of diagnosis, in particular between asthma and COPD, are in need of improvement.</p>





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## Glossary and abbreviations

Term	Definition
ACT	Asthma Control Test
Allergen	Something external to the person that causes an allergic reaction, such as asthma, eczema, hay fever or anaphylaxis
<i>Alternaria</i>	A fungal genus in the phylum Ascomycota. <i>Alternaria</i> species are major plant pathogens and are also common allergens in humans. They are commonly found in outdoor air, and occasionally indoors. They can cause hay fever or hypersensitivity reactions that sometimes lead to asthma
Anaphylaxis	A serious allergic reaction that is rapid in onset and may cause death
Ascospore	A spore produced by sexual reproduction, characteristic to fungi in the phylum Ascomycota
<i>Aspergillus, Penicillium</i>	Two closely related fungal genera which produce asexual spores that are morphologically similar. There are more than 150 species within each genus, found in various climates worldwide. These are well-known human allergens and some species are opportunistic pathogens
Auscultation (of the chest)	The process of listening, usually with a stethoscope, to sounds produced by movement of gas or liquid within the body, as an aid to diagnosis
Autopsy	A highly specialised surgical procedure that consists of a thorough examination of a corpse to determine the cause and manner of death and to evaluate any disease or injury that may be present
Binary data	Data whose unit can take on only two possible states, traditionally termed 0 and +1 in accordance with the binary numeral system and Boolean algebra
BLF	British Lung Foundation <a href="http://www.blf.org.uk/Home">www.blf.org.uk/Home</a>
BMI	Body mass index
BMJ	British Medical Journal <a href="http://www.bmj.com/">www.bmj.com/</a>
BNF	British National Formulary
<i>Botrytis</i>	A fungal genus in the phylum Ascomycota. <i>Botrytis</i> is a plant pathogen that affects many plant species, although most notably wine grapes. <i>Botrytis</i> spores are known human allergens
BP measurement	Blood pressure measurement

Term	Definition
<b>Brittle asthma</b>	A type of asthma distinguishable from other forms by recurrent, severe attacks that are often difficult to predict and manage
<b>BTS</b>	British Thoracic Society <a href="http://www.brit-thoracic.org.uk/">www.brit-thoracic.org.uk/</a>
<b>BTS/SIGN guideline</b>	National asthma guideline produced to aid the management and treatment of asthma. Joint development by the British Thoracic Society and the Scottish Intercollegiate Guidelines Network
<b>Case-control study</b>	A type of observational study in which two existing groups differing in outcome are identified and compared on the basis of some supposed causal attribute
<b>Categorical data</b>	Data which can be represented by numbers that can be grouped together to represent similar findings
<b>Cause for concern</b>	A case for which the panel assessors have concerns that the pattern of practice fell below a standard, which indicates that the practitioner or team is likely to put future patients at risk, if not addressed
<b>CEA</b>	Critical event analysis
<b><i>Cladosporium</i></b>	A fungal genus in the phylum Ascomycota. <i>Cladosporium</i> is a well-known plant pathogen. It is commonly found indoors and outdoors and is a well-known human allergen
<b>Clinician</b>	Any healthcare professional who holds a recordable professional registration with a healthcare professional regulatory body and has undertaken a period of study post-18 years to achieve that qualification, usually within a university setting
<b>Cohen's kappa statistic</b>	A statistical measure of inter-rater agreement or inter-annotator agreement for qualitative (categorical) items
<b>Coloured basidiospore</b>	A spore produced by sexual reproduction, characteristic to fungi in the phylum Basidiomycota. A collective name for sexual spores from the Basidiomycota that appear coloured under the microscope, and which are not identified to genus level
<b>Confidential enquiry</b>	Details of each death or incident within a specified area, eg asthma, are critically reviewed by a team of experts to establish whether clinical standards were met (similar to the audit process) and also that the right clinical decisions were made in the circumstances. The purpose of a confidential enquiry is to detect areas of deficiency in clinical practice and devise recommendations to resolve them
<b>COPD</b>	Chronic obstructive pulmonary disease
<b>Coronial expertise</b>	Expertise in the appropriate legal justice system as a coroner
<b>DELPHI</b>	A research method that involves a panel of experts who answer questionnaires in two or more rounds, after which the facilitator provides an anonymous summary of the experts' forecasts from the previous round, as well as the reasons for their judgements. The rounds continue until the group moves towards the 'correct' answer and the process is finished after a predefined stop criterion is met, eg the production of 10 clear recommendations or statements
<b>DH</b>	Department of Health
<b>DHSSPS</b>	The Department of Health, Social Services and Public Safety, Northern Ireland
<b><i>Didymella</i></b>	A fungal genus in the phylum Ascomycota. <i>Didymella</i> is a plant pathogen and suspected to be a human allergen

Term	Definition
<b>Eosinophilia</b>	A condition in which the eosinophil count in the peripheral blood exceeds $0.45 \times 10^9/l$ ( $450/\mu l$ )
<b><i>Epicoccum</i></b>	A fungal genus in the phylum Ascomycota. The genus <i>Epicoccum</i> contains a single species, <i>Epicoccum nigrum</i> . It is a mould widely distributed and commonly isolated from air, soil and foodstuff. It is a known human allergen
<b>Epidemiological study</b>	A study of how often diseases occur in different groups of people and why. Epidemiological information is used to plan and evaluate strategies to prevent illness and as a guide to the management of patients in whom disease has already developed
<b>Episodic</b>	Containing or consisting of a series of separate parts or events within asthma; times when asthma symptoms are more problematic or resolved, so an episode of asthma exacerbation is when asthma becomes worse, and an episode of nocturnal symptoms is a time when symptoms at night are troublesome
<b><i>Ganoderma</i></b>	A genus of polypore mushrooms that grow on wood; includes about 80 species, many from tropical regions
<b>Genera</b>	Plural of 'genus', which is a taxonomic rank used in the biological classification of living and fossil organisms
<b>GI problem</b>	Gastrointestinal problem (which can involve the oesophagus, stomach, small and large intestines, colon)
<b>GINA</b>	Global Initiative for Asthma
<b>GMC</b>	General Medical Council <a href="http://www.gmc-uk.org/">www.gmc-uk.org/</a>
<b>GMP</b>	Good medical practice
<b>Heterogeneity</b>	Concept relating to the uniformity in a substance
<b>HQIP</b>	Healthcare Quality Improvement Partnership <a href="http://www.hqip.org.uk/">www.hqip.org.uk/</a>
<b>HPC (HCPC)</b>	Health and Care Professions Council <a href="http://www.hpc-uk.org/">www.hpc-uk.org/</a>
<b>Hyaline basidiospore</b>	A spore produced by sexual reproduction, characteristic to fungi in the phylum Basidiomycota. A collective name for sexual spores from the Basidiomycota that are colourless under the microscope, and are not identified to genus level. Airborne levels increase during wet weather
<b>Hyper-responsiveness</b>	A state characterised by easily triggered bronchospasm (contraction of the bronchioles or small airways)
<b>ICD</b>	International Classification of Diseases
<b>ICD-10</b>	A medical classification list created by the WHO that codes for diseases, signs and symptoms, abnormal findings, complaints, social circumstances, and external causes of injury or diseases. It is used to code cause of death
<b>ICD-10U</b>	ONS/NRS use information from both Parts I and II of the death certificate to assign the underlying cause of death code (ICD-10U). The condition thought to be the most likely cause of death is assigned the ICD-10U code
<b>ICS</b>	Inhaled corticosteroids

Term	Definition
<b>Interquartile range (IQR)</b>	A measure of statistical dispersion, being equal to the difference between the upper and lower quartiles; <sup>1,2</sup> $IQR=Q_3-Q_1$
<b>Inter-rater reliability (IRR)</b>	The degree of agreement among raters. It gives a score of how much homogeneity, or consensus, there is in the ratings given by judges
<b>ITU</b>	Intensive therapy unit
<b>LABA</b>	Long-acting beta agonist
<b>Late-onset asthma</b>	Asthma that is diagnosed after the age of 15 years. This is the standard definition, but often people think that this is asthma diagnosed after 40 years of age
<b><i>Leptosphaeria</i></b>	A fungal genus in the phylum Ascomycota. <i>Leptosphaeria</i> is a plant pathogen that is the causal agent of blackleg disease on <i>Brassica</i> spp. <i>Leptosphaeria</i> spores are suspected to be human allergens
<b>Lung function test</b>	A test to measure how well your lungs work
<b>Mann–Whitney test</b>	Used when it is believed that it is important to compare two or more things, but the populations identified are not necessarily similar
<b>MCCD</b>	Medical Certificate of Cause of Death (death certificate)
<b>MHRA</b>	Medicines and Healthcare Products Regulatory Agency
<b>Monotherapy</b>	Any therapy taken alone
<b>NCEPOD</b>	National Confidential Enquiry into Patient Outcome and Death
<b>NHS</b>	National Health Service
<b>NICE</b>	National Institute for Health and Care Excellence
<b>NIGB</b>	National Information Governance Board
<b>NISRA</b>	Northern Ireland Statistics and Research Agency
<b>Normal distribution</b>	Data that have, within their range, 95 % (sometimes 97.1 %) of the data within two standard deviations of the mean; the distribution is symmetrical around the mean
<b>NRES</b>	National Research Ethics Service committee <a href="http://www.nres.nhs.uk/">www.nres.nhs.uk/</a>
<b>NRS</b>	National Records Scotland <a href="http://www.nrscotland.gov.uk/">www.nrscotland.gov.uk/</a>
<b>ONS</b>	Office for National Statistics <a href="http://www.ons.gov.uk/ons/index.html">www.ons.gov.uk/ons/index.html</a>
<b>Oxygen saturation</b>	A relative measure of the amount of oxygen that is dissolved or carried in a given medium
<b>PAAP</b>	Personal asthma action plan
<b>PaCO<sub>2</sub></b>	Partial pressure of carbon dioxide in the blood. Critical in regulating breathing levels and maintaining body pH
<b>PaO<sub>2</sub></b>	Partial pressure of oxygen in the blood
<b>Parametric data</b>	Data that are either missing key information, skewed, or we suspect that the findings are not distributed around a normal distribution; data that are not symmetrical about the mean and where we suspect that there are significant outliers (values far away from the median and mean)



Term	Definition
PCRS-UK	Primary Care Respiratory Society – UK
PEF	Peak expiratory flow, also called peak expiratory flow rate (PEFR); a person's maximum speed of expiration, as measured with a peak flow meter
pH	A measure of the acidity or basicity of an aqueous solution. Actually a measure of the number of free hydrogen ions in the medium as a log scale
Physiological test	A test measuring fitness strengths and weaknesses
PM10	Particulate matter up to 10 µm in size
pMDI	Pressurised metered-dose inhaler
Post-mortem	A post-mortem, also known as an autopsy, is the examination of a body after death to determine cause of death
Primary care	Typically, this provider acts as the principal point of consultation within the healthcare system and coordinates other specialists that the patient may need. Examples of these professionals are GP, family physician, nurse practitioner, pharmacist and registered nurse
Pulse oximetry	A non-invasive method for monitoring a patient's peripheral oxygen saturation levels
QOF	Quality and Outcomes Framework
QS25	NICE Quality Standard 25 for asthma
Qualitative research	Studies in natural settings and attempts to make sense of and interpret phenomena in terms of the meanings that people bring to them
Quantitative research	This is mainly focused upon quantities, usually numbers, which will be the main type of data that these methods collect. The results will be analysed using mathematical and statistical methods
R&D	Research and development
RCGP	Royal College of General Practitioners <a href="http://www.rcgp.org.uk/">www.rcgp.org.uk/</a>
RCP	Royal College of Physicians <a href="http://www.rcplondon.ac.uk/">www.rcplondon.ac.uk/</a>
RCP three questions	Royal College of Physicians three questions relating to the control of asthma. 1 Have you had difficulty sleeping in the last week because of your asthma (including cough)? 2 Have you had your usual asthma symptoms during the day (cough, wheeze, chest tightness or breathlessness)? 3 Has your asthma interfered with your usual activities (housework/school etc) in the last week?
RCPCH	Royal College of Paediatrics and Child Health <a href="http://www.rcpch.ac.uk/">www.rcpch.ac.uk/</a>
Read code	A coded thesaurus of clinical terms that are applied in a patient's notes to help to identify the range of their current clinical conditions and aid in the management of these
Respiratory rate	The number of breaths (inhalation–exhalation cycles) taken within a set amount of time (typically 60 seconds)

Term	Definition
<b>Reversible airflow obstruction</b>	Airflow through the lungs is reduced (obstructed), but this can be improved when inhaled medication (usually a short-acting bronchodilator) is given, often to such an extent that there appears to be no evidence of the previous reduction. The reduction in airflow is often measured using spirometry or peak expiratory flow rate
<b>SABA</b>	Short-acting beta agonists
<b>SEA</b>	Significant event analysis
<b>Secondary care</b>	Healthcare services provided by medical specialists and other health professionals who generally do not have first contact with patients
<b>Section 251 (NHS Act (2006))</b>	The approval process that organisations must complete if they wish to collect patient information
<b>Serum potassium</b>	The concentration of potassium measured within one part of the blood called serum. There is a set range of normal values of this for adults and children
<b>SIGN</b>	Scottish Intercollegiate Guidelines Network
<b>Spirometry</b>	A measure of lung function, specifically the amount (volume) and/or speed (flow) of air that can be inhaled and exhaled
<b>SpO<sub>2</sub></b>	Peripheral oxygen saturation, measured indirectly (often by pulse oximetry). This is a term referring to the amount of oxygen as a percentage combined with haemoglobin within the blood
<b><i>Sporobolomyces</i></b>	A fungal genus in the phylum Basidiomycota. <i>Sporobolomyces</i> is a yeast-type fungus, commonly isolated from environmental sources such as tree leaves that can also be found indoors. <i>Sporobolomyces</i> is a suspected human allergen
<b>Standard deviation</b>	A measure of how far away from the mean the population is dispersed. A small standard deviation means that the population is closely placed around the mean; large standard deviations mean that the data population is widely dispersed around the mean
<b>System-level security policy</b>	A policy put in place by the organisation collecting patient information to ensure its security and protection
<b>Thematic analysis</b>	A qualitative analytical method generally described as a method for identifying, analysing and reporting patterns (themes) within data. It organises and describes in rich detail and interprets various aspects of the research topic
<b><i>Tilletiopsis</i></b>	A fungal genus in the phylum Basidiomycota. It is a yeast-type fungus that is a plant pathogen causing particular problems in orchards. <i>Tilletiopsis</i> is a suspected human allergen
<b><i>Ustilago</i></b>	A fungal genus in the phylum Basidiomycota. These plant pathogens are referred to as smut fungi. Smuts are cereal and crop pathogens that most notably affect members of the grass family. <i>Ustilago</i> spores are known human allergens
<b>Variable airflow obstruction</b>	Airflow through the lungs is reduced at times, but this can be improved when inhaled medication (usually a short-acting bronchodilator) is given, often to such an extent that there appears to be no evidence of the previous reduction, but the variability needs addressing and this often requires additional medication to be used
<b>WHO</b>	World Health Organization <a href="http://www.who.int/en/">www.who.int/en/</a>

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