

Why asthma still kills

The National Review of Asthma Deaths (NRAD)

Confidential Enquiry report
May 2014

Commissioned by:

Supported by:



Eastern Region Confidential Enquiry of Asthma Deaths



Why asthma still kills
The National Review of Asthma Deaths (NRAD)
Confidential Enquiry report (May 2014)

Report prepared by:

Dr Mark L Levy	NRAD clinical lead, Royal College of Physicians (RCP)
Rachael Andrews	NRAD programme coordinator, Royal College of Physicians (RCP)
Rhona Buckingham	Operations director, Clinical Effectiveness and Evaluation Unit (CEEU), Royal College of Physicians (RCP)
Hannah Evans	Medical statistician, Royal College of Physicians (RCP)
Caia Francis	Senior lecturer in adult nursing, University of the West of England, and former chair, respiratory forum, Royal College of Nursing (RCN)
Rosie Houston	NRAD programme manager, Royal College of Physicians (RCP) (until February 2013)
Derek Lowe	Medical statistician, Royal College of Physicians (RCP)
Dr Shuaib Nasser	Consultant allergist and respiratory physician; British Society for Allergy and Clinical Immunology (BSACI); Eastern Region Confidential Enquiry of Asthma Deaths
Dr James Y Paton	Reader in paediatric respiratory medicine, Royal College of Paediatrics and Child Health (RCPCH)
Navin Puri	Programme manager for respiratory medicine (asthma and lung cancer), Royal College of Physicians (RCP)
Dr Kevin Stewart	Clinical director, Clinical Effectiveness and Evaluation Unit (CEEU), Royal College of Physicians (RCP)
Professor Mike Thomas	Professor of primary care research, University of Southampton; Primary Care Respiratory Society UK (PCRS-UK)

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.

The Royal College of Physicians (RCP)

The Royal College of Physicians (RCP) plays a leading role in the delivery of high-quality patient care by setting standards of medical practice and promoting clinical excellence. It provides physicians in over 30 medical specialties with education, training and support throughout their careers. As an independent charity representing more than 29,000 fellows and members worldwide, it advises and works with government, patients, allied healthcare professionals and the public to improve health and healthcare.

Citation for this report: Royal College of Physicians. *Why asthma still kills: the National Review of Asthma Deaths (NRAD) Confidential Enquiry report*. London: RCP, 2014.

Copyright

All rights reserved. No part of this publication may be reproduced in any form (including photocopying or storing it in any medium by electronic means and whether or not transiently or incidentally to some other use of this publication) without the written permission of the copyright owner. Applications for the copyright owner's written permission to reproduce any part of this publication should be addressed to the publisher.

Copyright © Healthcare Quality Improvement Partnership 2014

Published May 2014

ISBN 978-1-86016-531-3
eISBN 978-1-86016-532-0

Royal College of Physicians
11 St Andrews Place
Regent's Park
London NW1 4LE

www.rcplondon.ac.uk
Registered Charity No 210508

Typeset by Cambrian Typesetters, Camberley, Surrey
Printed by The Marstan Press Limited, Bexleyheath, Kent

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

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.

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.¹
- 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
Organisation of NHS services								
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 ¹			✓	✓			✓	

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	✓		✓			✓	✓	

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	✓							✓
A national ongoing audit of asthma should be established, which would help clinicians, commissioners and patient organisations to work together to improve asthma care			✓					
There is a need for improved guidance for doctors completing Medical Certificates of Cause of Death (MCCDs)	✓		✓	✓				
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	✓			✓	✓	✓	✓	✓

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
Medical and professional care								
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
Prescribing and medicines use								
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		✓	✓	✓				

[illegible]

Recommendation	NHS service managers	Pharmacists	Primary healthcare settings: GP practices, 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
Patient factors and perception of risk								
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	✓		✓	✓	✓			✓

[illegible]



ISBN 978-1-86016-531-3
eISBN 978-1-86016-532-0

Royal College of Physicians
11 St Andrews Place, Regent's Park
London NW1 4LE

Clinical Effectiveness and Evaluation Unit

Tel: +44 (0)20 3075 1551
Fax: +44 (0)20 7487 3988
Email: nrad@rcplondon.ac.uk

www.rcplondon.ac.uk/nrad



**Royal College
of Physicians**