

Written evidence submitted to the APPG on Respiratory Health inquiry into Respiratory Deaths

The formal call for evidence was open between October 2013 and January 2014. Please note that blank pages have been removed from written evidence submissions, but a full copy of the submissions form is included for information.

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9. Royal College of Pathologists
10. Royal College of Physicians
11. Royal Pharmaceutical Society
12. UK Centre for Tobacco and Alcohol Studies

Pharmaceutical companies:

13. Boehringer Ingelheim Ltd

Individuals submitting written evidence:

14. Ian Culligan, Lead Physiotherapist (respiratory team), Victoria Central Hospital Wallasey
15. Dr Gwyneth Davies, Clinical Senior Lecturer and Respiratory Physician, ABMU Health Board
16. Prof Graham Devereux, Professor of Respiratory Medicine, University of Aberdeen
17. Dr Iolo Doull, Consultant in Paediatric Respiratory Medicine, Children's Hospital for Wales
18. Dr Patrick Flood-Page, Consultant Chest Physician, Aneurin Bevan Health Board
19. Prof Stephen Holgate, Clinical Professor of Immunopharmacology and Honorary Consultant Physician, University of Southampton
20. Prof Richard Hubbard, Professor of Respiratory Epidemiology, University of Nottingham
21. Dr Richard Iles, Consultant Respiratory Paediatrician, Addenbrooke's Hospital
22. Prof Warren Lenney, Professor of Respiratory Child Health, Keele University

23. Prof William MacNee, Honorary Consultant Physician, Lothian Health Edinburgh
24. Dr Nigel Masters, Medical Advisor, Chiltern CCG
25. Dr Colin Michie, Consultant Paediatrician, Ealing Hospital NHS Trust
26. Dr Gary Ruiz, Consultant Respiratory Paediatrician, Kings College Hospital
27. Dr Nicholas Sargant, Consultant in Paediatric Emergency Medicine, Bristol Royal Hospital for Children
28. Dr Dominick Shaw, Associate Clinical Professor and Honorary Consultant, University of Nottingham
29. Susan Spence, Community COPD Specialist Nurse, South Tees NHS Trust
30. Prof Mike Thomas, Professor of Primary Care Research, University of Southampton
31. Prof John Warner, Professor of Paediatrics, Imperial College London
32. Dr Robert Wilson, Consultant Physician and Head of Lung Division, Royal Brompton
33. Stephanie Wolfe, Respiratory Nurse Specialist

Patients, carers, family of loved ones and patient support groups:

34. Anonymous
35. Michaela Barnard
36. Molly Bennett (Breathe Easy Hedge End)
37. Lucy Falconer
38. Malcolm Ginever (Breathe Easy Nottingham)
39. Doug Hardy
40. Tessa Jelen (Breathe Easy Paddington)
41. Rowena Jeremy
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ORIGINAL EVIDENCE SUBMISSION FORM

All Party Parliamentary Group on Respiratory Health: Invitation to submit written evidence to the inquiry into respiratory deaths

(Deadline for evidence is 5pm Friday 10 January 2014)

Introduction

Asthma UK and the British Lung Foundation (BLF) are working together to support the All Party Parliamentary Group on Respiratory Health (formerly the APPG on Asthma). As its first activity, the APPG is conducting an inquiry into why so many people are still dying from respiratory disease.

The Group is keen to engage with relevant stakeholders to understand the circumstances surrounding respiratory deaths and to identify:

- where the system is failing;
- what the barriers to good practice are; and
- what policy changes are needed to reduce respiratory deaths.

About respiratory disease

Respiratory disease affects one in five people in the UK.ⁱ The UK's mortality rates for respiratory conditions are among the highest in Europe.ⁱⁱ

Respiratory diseases such as asthma and COPD also create a huge drain on NHS resources, costing the NHS over £4 billion in 2010/11.ⁱⁱⁱ Deaths from COPD could be reduced by nearly a third if the NHS delivered services in line with the best,^{iv} and up to 90% of asthma deaths have avoidable factors.^v

Specific areas of the Inquiry

- The inquiry will look in depth at two specific conditions: 'asthma, which affects 5.4 million people in the UK'^{vi} and COPD, which affects an estimated 3 million people in England (over 2 million of whom are undiagnosed)^{vii}.
- The inquiry will only focus on changes to health policy and clinical practice and will not include recommendations about other Government policy areas.
- This inquiry may refer to but not make recommendations on other respiratory conditions. However, we are keen to hear evidence on respiratory disease in general.
- The findings of the inquiry will be published in a short report and recommendations will be made to the Secretary of State for Health and NHS England, for their consideration and response.
- While the recommendations will be for England only, we are also seeking examples of best practice across the UK to usefully inform the inquiry.

Guidance on responding to call for evidence

The call for evidence is broken down into three sections: Asthma, COPD and Respiratory Disease. **Feel free to only answer the questions relevant to your area of expertise.**

All written evidence submitted must be:

- the respondent's original work, not previously published elsewhere, though previously published work can be referred to in a submission and submitted as supplementary material;
- no more than 300 words per question;
- provided in the single document attachment to the email below.

Written evidence may be referenced in the final report. If you wish your evidence to be anonymous please specify in the form below.

The deadline for receiving evidence is **Friday 10 January 2014**. Submissions should be emailed to appg.respiratoryhealth@asthma.org.uk

Further information

If you have any queries about the inquiry or require further information, please contact us on the email address above or call **Derry Begho, Campaigns Assistant at Asthma UK, on 020 7786 4938** or **Tamara Sandoul, Policy Officer at the BLF, on 020 7688 5588**.

The APPG on Respiratory Health would be grateful for your input into the inquiry and asks you to consider and respond to the written call for evidence questions outlined below. Please feel free to also circulate this call for evidence in its entirety amongst your networks and colleagues.

ⁱ The Burden of Lung Disease: Report 2, British Thoracic Society, 2006.

ⁱⁱ UK mortality from respiratory disease is 5th worst in the EU, after Denmark, Ireland, Belgium and Hungary. ERS White Book - the Burden of Lung Disease, Figure 1. Last accessed on October 2013. <http://www.erswhitebook.org/chapters/the-burden-of-lung-disease/>

ⁱⁱⁱ Department of Health, *England level data by programme budget*. Downloaded from: <https://www.gov.uk/government/publications/2003-04-to-2010-11-programme-budgeting-data>. Accessed on 01/10/2013

^{iv} 7,500 lives could be saved in England when total deaths were 23,000 per year from COPD. Outcomes Strategy for Asthma and COPD: NHS Companion Document, Department of Health, May 2012.

^v Partridge M, Self care plans for people with asthma. *The Practitioner* 1991, p 715-21

^{vi} Health Survey for England 2001. The Scottish Health Survey 2003. Welsh Health Survey 2005/2006. Northern Ireland Health and Wellbeing Survey 2005/2006. Population estimates from Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics & Research Agency

^{vii} Outcomes Strategy for Asthma and COPD: NHS Companion Document, Department of Health, May 2012.

APPG on Respiratory Health - Questions

Personal Information:

Name:	Rebecca Sherrington
Job Title:	Chair
Organisation:	Association of Respiratory Nurse Specialists and Royal College of Nursing
Region/location:	UK
Capacity in which you are replying to the inquiry	Chair of ARNS, with feedback from ARNS Committee and Membership and from the Royal College of Nursing
List of any supplementary information attached (if any)	<p>www.arns.co.uk</p>  <p>ARNS Association of Respiratory Nurse Specialists</p>  <p>Royal College of Nursing</p>

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

- There is an atlas of variation.
- ERS White books <http://www.erswhitebook.org/>
- There is no National Service Framework (NSF) for respiratory disease.
- There are major TV campaigns for other diseases, but not for respiratory disease.
- Major TV campaigns for other diseases often show no link to lung cancer and COPD, for example.
- There is no respiratory network for respiratory disease.
- There is poor public health awareness about respiratory disease - it does not feature in health checks, for example.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

- Smoking - we should continue to push for legislation on standardised packaging for tobacco products.
- Target 16-25 year olds with anti-smoking campaigns. Include smoking illicit drugs and recreational drugs such as cannabis in these.
- There should be greater emphasis on including common respiratory

conditions in the healthcare professional undergraduate curriculum.

- TV companies should be lobbied to prevent promotion of smoking by characters.
- There should be increased public awareness of lung disease in public places such as on television and in the press.
- Smoking cessation should be taught in schools as part of the national curriculum.
- Increasing awareness of public health in all nursing roles should be written into nurse job descriptions.
- There should be designated champions and leaders for respiratory disease to include politicians, celebrities and clinicians.
- There should be increased funding and opportunities for nurses that work in general practice, acute and community in non-respiratory disease to be trained in respiratory conditions.
- There should be promotion of the positive aspects of nursing in respiratory care.
- There should be education for general practice, which is linked to better outcomes than what the Quality and Outcomes Framework has to offer.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

- There are insufficient resources invested in respiratory care.
- Respiratory care has a low profile.
- Patient apathy.
- Respiratory nurses are often considered a luxury item - there are examples of respiratory nurses being downgraded or their roles morphed into generalist areas.
- Many nurses do not see smoking cessation as part of their role.
- Many nurses do not have the time to be able to undertake a full history when looking at 'new' patients to diagnose.
- Funding for respiratory care is very limited in some areas.
- There is no national set of standards and 'must do's' for respiratory care.
- There is policy but no guidelines - policy is open to variation and misinterpretation.

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

- Teenagers, young and older adults due to the prevalence of smoking and the use of illicit / recreational drugs among these groups.
- Lower socio-economic populations - due to: high smoking prevalence; poor diet; poor fitness; external locus of control - these all contribute to higher incidence of respiratory disease. These populations are often targeted by tobacco agencies - e-cigarette shops are common in lower socio-economic areas, for example.
- Those with mental health problems who access or who do not access mental health services and joined up services.
- The homeless and travelling community.

- Vulnerable adults who live alone, sometimes with disengaged services such as GPs.

5. What can the Government and the NHS in England do to reduce respiratory deaths?

- Legislate against smoking in as many ways as possible - standardised packaging of tobacco products and regulation of e-cigarettes, for example.
- Promote public health messages including spirometry as part of the health check.
- Increase investment in health promotion in respiratory disease.
- Support and protect respiratory nursing posts and invest in patient care both in hospital and in the community.
- Support and protect general nurses who are managing long term conditions to be given additional time to undertake diagnostic tests such as spirometry.
- Ensure that CCG's see respiratory disease as a priority area and develop a strategic clinical network for respiratory disease.

Asthma Questions:

1. What are the most important factors contributing to asthma deaths?

- Lack of awareness of the severity and potential consequences of acute exacerbation and under-estimation of symptoms.
- Lack of education and self management.
- Scarcity of services including specialist nurses for management of severe asthma.
- The importance of understanding respiratory assessment in terms of differential diagnosis.
- Taking appropriate action using the appropriate algorithm.

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

Psychosocial co-morbidities. (1). Prim Care Respir J. 2005 Dec;14(6):303-13. Epub 2005 Oct 11. An ongoing Confidential Enquiry into asthma deaths in the Eastern Region of the UK, 2001-2003 Harrison B, Stephenson P, Mohan G, Nasser S.

- Low wage earners who are not eligible for prescription costs to be waivered and cannot afford inhalers, especially corticosteroid inhalers.

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

- Respiratory care is not seen as a high priority.
- GP and Practice Nurse Services are not always quality managed - in some places provision of adequate and appropriate education and training is poor, for example.

- Lack of time allocated within GP consultations.

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

Isle of Wight Project -

<http://www.nice.org.uk/usingguidance/sharedlearningimplementingniceguidance/examplesofimplementation/eximresults.jsp?o=461>

5. What can the Government in England do to reduce asthma deaths?

- Scrap prescription charges for asthma.
- Invest in health promotion.
- Support and invest in specialist asthma services
- Ensure asthma care is seen as a priority and not an add-on.
- Fund more education and support around transitional care from child to adult.
- Ensure a national policy is agreed and implemented.

6. What can the NHS in England do to reduce asthma deaths?

- Prioritise asthma - CCGs commissioning & CQUINs.
- More than just QoF incentives.
- Ensure that every CCG has an Asthma Lead Nurse with the appropriate time and resources to support each CCG around asthma care.

7. Do you have any other comments relevant to this inquiry?

The role of nurses in chronic respiratory disease is critical. Many nurses make a significant contribution from diagnosis through to end of life care. We believe that nurse specialists are critical to any change. However, for this there must be investment and appropriate resources. These include the introduction of a nurse lead for asthma/COPD in every CCG, to champion, educate and inform patients and staff about Asthma in order to raise standards and quality of care for our patients and future patients.

Chronic Obstructive Pulmonary Disease (COPD) Questions:

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

- Late diagnosis.
- Poor and mis-diagnosis - often related to GP and nurses' lack of knowledge & understanding.
- Prevalence of smoking.
- Injudicious use of oxygen therapy.
- Sub-optimal treatment of exacerbations.
- Poor communication from hospital, GP and or community providers.
- Socio- economic factors.

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

- Difficulty accessing funding for appropriate education and training - this needs to be a priority for commissioners.
- Respiratory care has a low priority in undergraduate pre-registration nursing.
- Patient apathy.
- Patients continuing to smoke.
- A lack of time and resources to improve the accurate diagnosis of COPD.
- Concordance to treatments in patients with COPD.
- Poor uptake and completion of Pulmonary Rehabilitation.
- A lack of appropriate national patient feedback on service provision, which makes it difficult to benchmark quality care.

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?

- Invest in pulmonary rehabilitation services.
- Invest in psychology services supporting the nurse and the MDT approach to co-ordinated care.
- Provide education to all healthcare professionals.
- Provide education to the general public through campaigning.
- Invest in and promote further smoking cessation.
- Improve access to smoking cessation services.
- Provide smoking cessation products free of charge.
- Raise standards of accurate diagnosis of COPD through better training and increasing resources.
- Include spirometry screen as part of Health Screening.
- Ensure that all hospices are able to support people with advanced disease to think and plan for the future.

4. What could the Government in England do to reduce premature mortality from COPD?

- Legislate further on smoking.
- Run a national publicity campaign around smoking cessation and COPD to educate people to recognise the signs of possible COPD.
- Run a national targeted screening programme for early diagnosis of COPD.
- Improve access to services nationally.
- Make COPD a priority, investing in it to save money.
- Ensure that each CCG has a COPD champion and network locally.

8. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

Nursing Standard's 'Nurse of the Year 2013', Matthew Hodson, a Clinical Nurse Specialist at Homerton University Hospital in East London, set up a clinic with colleagues for people with advanced COPD. Recognising that there was little support for patients with COPD, Matthew launched the Breathing Space clinic in 2011. The clinic is a multi-disciplinary, inter-organisational hospice based pilot to support the holistic needs of COPD patients. The clinic helps patients better manage their illness, control symptoms, improve their outlook and plan for their future. A multi-professional and integrated approach is used for all patients with care from a palliative care consultant, a COPD nurse consultant and a palliative care physiotherapist to manage the symptoms of COPD and improve quality of life.

5. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

- By placing less emphasis on spirometry and ensuring all healthcare professionals involved in diagnosis and management of COPD are appropriately trained and educated.
- By introducing a National Programme to raise the quality of care.
- By ensuring that practice staff have time to diagnose people with quality assured spirometry and have the equipment for this.

6. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

Nationally Pulmonary Rehabilitation programmes have been cut or are not funded

In Hackney, London they have invested in supporting a hospice based planning for the future clinic which supports people with very severe disease to think about the future.

9. Do you have any other comments relevant to this inquiry?

The role of nurses in chronic respiratory disease is critical. Many nurses make a significant contribution from diagnosis to end of life care. We believe that

nurse specialists are critical to any change. However, for this there must be investment and appropriate resources. These include the introduction of a nurse lead for asthma/COPD in every CCG, to champion, educate and inform patients and staff about COPD in order to raise standards and quality of care for our patients and for future patients.

ARNS are aware that there is no central national database on the service provision of COPD care in the community, provided by nurses. Anecdotal evidence suggests that there is a huge variation in COPD service provision provided by specialist nurses, to patients across the country. There are a number of well-established specialist COPD integrated services, but in some parts there is limited specialist community support, giving postcode lottery specialist community care.

APPG on Respiratory Health - Questions

Personal Information:

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Capacity in which you are replying to the inquiry	Chair of Executive Committee of BTS
List of any supplementary information attached (if any)	Appendix 1

Respiratory Disease Questions: Please provide as much or as little information as you wish, up to a maximum of 300 words per question.

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

As far as treatments are concerned, Respiratory Medicine deals with a more diverse group of conditions than most other specialties. This includes 3 which are common causes of death - COPD, Lung Cancer and Pneumoniaⁱ - but also several others which constitute major health problems in the UK such as Asthma, Sleep Apnoea, Tuberculosis, Pulmonary Fibrosis (Interstitial Lung Disease or ILD), Cystic Fibrosis and Bronchiectasis. There is therefore no simple comparison of treatments with those in other disease areas, but broadly speaking there are effective forms of therapy for most of these diseases, many of which improve mortality.

However, there is variation around the country in death rates from Respiratory Disease, and huge improvements in mortality would result if all could be brought in line with the current best 10%. Some of the variation is difficult to address by medical means since it stems from differences in age, social deprivation etc, but we believe that significant improvements could be produced by relatively simple changes to organisation of care in the poorer performing districts. We know that changes such as introducing care bundles, composed from simple, evidence-based interventions, leads to better outcomes. Initiatives based on these take place already, but in a piecemeal fashion because Respiratory Medicine does not have the funded, formalised clinical networks that exist for other specialties. As a speciality we were disappointed not to be one of the priority areas identified by the last Government, but accepted that not everything can be a priority. However, 10+ years on, it seems astonishing to us that

the same disease-areas have been gifted Strategic Clinical Networks whilst others like Respiratory Medicine are neglected. So, the answer to the question about care and services is that Respiratory Medicine is supported significantly less well than heart disease, stroke etc.

ⁱIt is worth noting that although these are common causes of death throughout Europe, the UK does badly in comparison to other countries. The recent European Respiratory Society White Book showed that our age-standardised mortality rate for respiratory disease is 111.7, well above the average. This analysis includes some relatively poor countries and it is particularly worrying that our figures are far worse than neighbouring countries with which we would like to stand comparison (Netherlands 97.4, Germany 76.7, France 66.3).

2. What changes can be made to improve outcomes for all or most respiratory conditions?

As in Section 1, we believe that setting up a Strategic Clinical Network in Respiratory Medicine would be valuable across the range of respiratory disease. Rather than repeating this argument here, we will indicate some of the disease-specific changes which would improve outcomes. We will not refer to asthma or COPD since there are designated sections for those below.

300 words limit is inadequate here. These are brief notes - we attach an appendix with a little more detail (and would gladly expand further if required). Briefly:

Lung Cancer: Still >30,000 deaths per annum in the UK, and although falling in men this rate is increasing in women.

- Greater support for anti-smoking measures
- Awareness campaign to encourage earlier presentation
- Screening pilot study results awaited

Pneumonia: Causes >26,000 deaths per annum. Pneumonia care is amenable to improvement:

- Measures to improve vaccination uptake
- Improve adherence to existing guidelines
- Wider dissemination of BTS care bundles

Pulmonary Fibrosis: Now >3,000 deaths per year, and this is increasing remorselessly.

- Increase access to pulmonary rehabilitation programmes
- Support expert multi-disciplinary teams to assess & treat
- Need for research investment; current therapy is disappointing

Bronchiectasis: An underpublicized disease, but causes 1,000 deaths per annum and considerable disability

- Improve adherence to guidelines
- Better access to specialist assessment to identify those in need of more intensive treatment.

Cystic Fibrosis: Deaths fewer than in the diseases above, but a cause of mortality at a young age

- Measures to increase donation of organs for transplant programmes

Sleep Apnoea: Affects approx 1% of the adult population and is linked to mortality from heart disease, hypertension and stroke

- CPAP is an effective treatment, recommended by NICE TA

Tuberculosis: Increasing prevalence

- Issues about drug resistance with incorrect treatment.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

- **Disease recognition.** This encompasses prompt diagnosis but also accurate assessment of the disease severity and its trajectory. This is critical to targeting interventions at those who need it and thereby reducing mortality. There are some general practitioners who can make an accurate assessment in some of the conditions referred to above, but most of the appropriate expertise is in secondary care and it is vital that appropriate referral is encouraged.
- **Pulmonary rehabilitation facilities are under-provided.** It is normal post myocardial infarction and following episodes of heart failure for patients to undergo cardiac rehabilitation. Regrettably provision of pulmonary rehabilitation, an equally cost-effective intervention, is frequently unavailable for patients. This is despite an evidence base highlighting a reduction in readmission rate following the early use of pulmonary rehabilitation; and we know that frequent readmissions are associated with increased mortality.
- **Pneumonia** is common and usually responds well to treatment, and its potential seriousness can be overlooked by the unwary. There are well-established severity scores; these are not always applied, and even when they are the management does not follow the appropriate severity-related treatment recommendations in approximately a third of cases. Adherence to guidelines is better if these patients are treated by respiratory physicians. This illustrates a general point - patients with respiratory illness should be looked after by those with respiratory expertise.

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

Each disease listed in section 1 has specific known risk factors. Those common to several conditions are:

- **Premature birth.** The lung continues to mature throughout foetal development and undergoes an immense physiological change at delivery (greater than any other organ). With premature birth the lungs are not fully developed and this is associated with poorer lung function which tracks throughout life. Similar, less marked, decrements in lung function are associated with small-for-dates babies.
- **Exposure to cigarette smoke (passive or active).** This is well recognised in

COPD and Lung Cancer, but smoking is also associated with increased incidence and poorer outcomes in most other lung diseases including asthma, pneumonia, and ILD. Tobacco smoke is a rich source of agents toxic to the lung.

- Many respiratory diseases are more common in urban environments, and particularly those with a tradition of manufacturing industries. This is highly likely to reflect **vehicle air pollution, contamination of air** with industrial products, or both. In some specific cases there is a clear link between an inhaled agent and a disease (e.g. asbestosis, occupational asthma) but in most the association is less straightforward
- **Social deprivation** is associated with worse outcomes from most lung disease. The correlation is likely to be multi-factorial.

5. What can the Government and the NHS in England do to reduce respiratory deaths?

- Any measure which reduces population exposure to tobacco smoke, including passive exposure, will help to reduce prevalence of respiratory disease and the mortality rates. Pregnant women and families with young children are particularly important in this regard.
- Measures to reduce air pollution
- Government action on both access to recreational facilities and the promotion of safe, active means of transport (walking, cycling) will impact on respiratory mortality
- Meaningful outcome standards should be established and relevant data collected routinely. We do not think current QOF indicators are ambitious enough, and fear that the CCGOIS will also set too low a bar. Mandatory data collection on selected key outcomes would provide crucial performance information, and would also help the public by allowing comparison of providers which is both transparent and meaningful.
- Once standards are established, efforts to meet these should be based on interventions which are evidence based, or properly monitored pilot projects. Unfortunately investment sometimes take place where the evidence base is very limited e.g. tele-health, but does not occur where there is a very strong evidence base e.g. non-invasive ventilation in acute exacerbations of COPD
- We strongly suspect (and there is some evidence to support this) that greater integration of primary and secondary care skills is needed. Hospital at home schemes for exacerbations of COPD are of proven benefit and it is likely that other issues could be addressed using specialist expertise within the traditional primary care setting. In keeping with our previous point, there should be mechanisms for rapid assessment of proposals for pilot schemes along these lines, funding to support these, and an efficient means of disseminating results to the rest of the NHS
- Funding of research into respiratory disease is inadequate. In many disease

areas the agenda has been set by the pharmaceutical industry, and many simple research questions remain unanswered. We recognise the improvements which have followed the establishment of the NIHR, but here too, respiratory medicine has not been prioritised for funding

ASTHMA : Please provide as much or as little information as you wish, up to a maximum of 300 words per question.

Background

Over 4 million people in England are affected by asthma⁸ and, on average, three people die every day from their asthma. We know three quarters of these deaths are amongst people aged 65 or over, and evidence suggests 90% of all asthma deaths are preventable if managed properly.⁹ In 2010 the UK death rate from asthma was one of the highest in Europe.¹⁰

In February 2012, the National Review of Asthma Deaths (NRAD), led by the Department of Health, began a review into all deaths from asthma across the UK for one year. The review aims to reduce the number of asthma deaths and the findings will be published in April 2014.

Questions

1. What are the most important factors contributing to asthma deaths?

The NRAD report should provide the most up to date answer to this question.

Previous studies of asthma deaths and near-fatal asthma have suggested that the following are relevant:

- A. Disease-related factors. Most deaths are in those with the most severe, chronic asthma. It is less common for there to be a sudden, severe attack in those with milder asthma (although there are issues around severity being under-estimated which can arise if control is not systematically assessed).
- B. Management factors. Studies have highlighted the following (which may reflect behaviour by patients as well as medical staff):
 - i. Inadequate objective monitoring of chronic asthma
 - ii. Inadequate use of appropriate doses of inhaled steroids, and of oral steroids during acute attacks
 - iii. Delayed or inadequate assessment of patients during attacks
 - iv. Excess use of short-acting β-agonist inhalers
 - v. Prescription of long-acting β-agonists without inhaled steroid
- C. Adverse psychosocial and behavioural factors. A number of such features have been identified, and are listed in the next section

Most of these are potentially avoidable. There are a relatively small number of patients with extremely severe disease, probably with different patho-physiology than the majority of asthma. In all other cases death is extremely unlikely if people with asthma take inhaled cortico-steroids regularly in the dose appropriate to the severity of their asthma, know what to do and who to contact if their symptoms worsen, and have swift access to medical help when required.

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

The groups requiring particular attention are those with severe asthma and those with adverse behavioural or psychosocial features.

The factors contributing to severe asthma are not fully characterised, but some patients do not have the typical asthmatic pattern of inflammatory cells in their bronchi, and therefore do not respond as well to conventional medication which targets this common inflammatory cell profile. This patient group can be recognised as those with

- Previous severe attacks of asthma
- Requirement for 3 or more classes of asthma medication

The main requirement for these people is a more detailed assessment of their asthma, which may require tests not available in either primary care or in many secondary care facilities.

Numerous psychosocial factors have been identified as associated with increased risk of asthma death;

- Failure to attend GP or hospital appointments
- Frequent A&E attendance
- Self-discharge from hospital
- Alcohol or drug abuse
- Learning difficulties
- Employment or income problems
- Severe domestic stress

It is likely that the common factor here is poor adherence to asthma medication.

It is also worth noting that smokers and the obese have greater problems with asthma. The adverse affects of smoking on lung health are well recognised. The role of obesity in asthma is less well understood and the subject of current research efforts.

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

There is a disconnection between guidance and implementation in some very simple areas. For example, the British Asthma Guideline has long advocated the use of Asthma Action Plans, and this was also one of the measures advocated in the recent NICE Quality Standard publication. However, it is not included in the QOF indicators. Similarly, we understand that most or all of the NICE Quality Standards will not be reflected in the CCG Outcome Indicator Set. It is hard to understand why National Guidance developed using strict evidence-based methodology does not get supported in national systems designed to offer incentives to best practice.

One of the major weaknesses in asthma care is in the initial process of diagnosis. There is evidence of errors in both directions i.e. false positive and false negative. This is partly because of genuine difficulty in cases with atypical presentation, but also because practitioners do not seem willing to fully utilize the available aids to diagnosis. There is a diagnostic algorithm in the British Asthma Guideline which is under-used. NICE are currently working on a guideline which will cover this area of care, but even a NICE guideline does not guarantee change to practice.

At local level there is often inadequate communication of detail between primary and secondary care, and in particular Accident and Emergency departments (as per Section 2 above, frequent A&E attendance is a marker of poor asthma care). Enhancements to electronic information exchange would make a big difference in alerting all involved Health-care professionals when a person's asthma control is showing signs of deterioration; would eliminate the potential for confusing information being delivered to patients; and would significantly reduce the risk of misinformation regarding changes to drug prescriptions.

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

The National Asthma Programme in Finland between 1994 and 2004 was associated with a reduction in asthma mortality. In the last year with data available there were only 6 deaths in patients under the age of 65 in Finland (population 5.3 million). There was an increase in drug prescription costs with the programme, but there was also a reduction in hospital bed days from asthma. Overall the estimated cost of treating a person with asthma was shown to fall by 36%. (Thorax 2006; 61:663-670)

This is the most convincing example of a change in mortality rates. Other countries have instituted Asthma Programmes and seen a fall in mortality (e.g. France) but it is possible that some of the reductions seen are due to changes in coding.

5. What can the Government in England do to reduce asthma deaths?

BTS would suggest:

1. Asthma should be added to the list of chronic medical conditions which qualify for free prescriptions. Some of the situations listed in section 2 above clearly reflect an economic motive for not taking treatment regularly, and anecdotally most healthcare professionals know of patients, often young adults, who stop medication because of the cost
2. Any measure which reduces exposure of those with asthma to cigarette smoke, including passive exposure, will help to improve levels of asthma control.
3. Those government agencies which have a role in air pollution control should increase their efforts to understand and reduce the impact of environmental pollution on asthma.
4. Funding of research into respiratory disease is inadequate. In relation to asthma deaths it is important to address questions on:
 - Effective prevention strategies including signs of imminent worsening of asthma control
 - How to promote adherence to treatment

6. What can the NHS in England do to reduce asthma deaths?

1. There are variations in asthma prevalence, drug prescription and outcomes across England. Efforts should be made to understand this variation, to assess how much is due to the normal variance which occurs in any natural system and how much can be explained by differences in health care which would be amenable to change via organisational or educational means.
2. Good guidance exists on asthma management, but this needs to be given some teeth. Simple measures which would improve asthma care have not been well implemented and stronger incentives need to be introduced (see section 3). The best starting point for this would be to look at the recently published NICE Quality Standards and to consider how these could be implemented more vigorously.
3. Meaningful targets should be set. A reduction in hospitalisation is desirable, but if pushed as a target on its own could lead to admission being inappropriately denied or delayed. A better approach would be to promote the collection of data on asthma control (several well validated symptom based tools are available, and consideration might also be given to measurement of a simple biomarker, FeNO) and set targets for improving levels of control. As above, deaths usually occur in those with more severe and/or poorly controlled asthma.
4. We are concerned about access to Difficult Asthma services. In the new commissioning arrangements we understand that not every Local Area will have a designated Difficult Asthma Centre. This contrasts with the arrangements for most conditions funded via specialised commissioning where each of the 10 Local Areas can, if appropriate, name at least one Centre for that disease. As stated repeatedly, those who are likely to die are those with the worst asthma, and there is a danger that their ability to access the detailed assessment and new treatments will be impeded.

5. Further suggestions are likely to emerge from the imminent NRAD report.

7. Do you have any other comments relevant to this inquiry?

CHRONIC OBSTRUCTIVE PILMONARY DISEASE (COPD) Questions: Please provide as much or as little information as you wish, up to a maximum of 300 words per question.

Background

COPD kills about 25,000 people a year in England and Wales. Recent figures showed that COPD accounted for 4.8% of all deaths in England between 2007 and 2009. It is the fifth biggest killer disease in the UK after cancer, heart, stroke, and liver disease. Premature mortality from COPD in the UK was almost twice as high as the European (EU-15) average in 2008 and 1 in 8 people over 35 has COPD that has not been properly identified or diagnosed.¹¹

Questions

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

- The bulk of COPD is caused by tobacco smoke so targeting this is vital. 570 children aged 11-15 start to smoke every day in the UK and measures to prevent this must be prioritised since this will prevent the development of COPD in the vast majority of cases. Once a diagnosis is established, disease progression is slowed if cigarette smoking ceases, therefore smoking cessation help remains important at all stages of the disease.
- Adverse early life environment will increase the risk of COPD by impacting on lung development so that age related and tobacco related decline in lung function starts from a lower base. This includes exposure to smoke through maternal smoking while in utero and passive exposure during childhood. Poor nutrition through poverty will also impact on lung development.
- Delay in diagnosis is likely to be extremely important since this leads to delays in effective intervention. Diagnostic delays result partly from failure to present, because symptoms of cough and breathlessness are dismissed or down-played, and partly because of inadequacies in the use of spirometry, which is the main readily-available diagnostic tool. There have been improvements in this regard over the last 10 years, but there is evidence that spirometry is still under-used, and that the quality of spirometry measurement in Primary Care is inconsistent
- There are effective therapies which are unevenly accessed around the country. The prime example of this is Pulmonary rehabilitation.
- In secondary care, management of acute exacerbations of COPD is not always optimal. Oxygen therapy can be mismanaged, there being a false perception that more is always better which continues despite some progress being made as a result of the publication of the British Thoracic Society's Guideline on the use of Emergency Oxygen. Use of antibiotic and steroid therapy is not always consistent with current guideline recommendations.

	<ul style="list-style-type: none"> • There is evidence that access to Intensive Care facilities is sometimes denied because of the COPD label, with inappropriate assumptions about likelihood of survival (although we recognise the general pressure on over-stretched ITU services).
2.	<p>What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?</p> <ul style="list-style-type: none"> • Smoking cessation services are not well integrated. There is a focus on primary care services, and we fully support provision here, but patients are often more susceptible to advice on quitting at the time of a worsening of their symptoms, and delay in accessing advice when in hospitals represents a missed opportunity. • A different approach to breathlessness in middle life is needed, emphasising it as a symptom requiring investigation rather than a normal feature of aging. • There is a difficult balance to be struck in relation to spirometry, which is essential to the diagnosis of COPD. For many years spirometry was not performed in Primary care, yet this is the obvious place to be picking up cases of COPD before it becomes severe. Opportunistic performance of spirometry should therefore be encouraged, and is obtained more frequently than 10-15 years ago (although it is likely, based on diagnostic rates, that some practices have adopted this more vigorously than others). However, spirometry can be misleading if not performed properly, and there is a need for a system which balances quick, ready access to spirometry in all Practices with a more stringently performed spirometric measurement for confirmation of the diagnosis. • Access to Pulmonary Rehabilitation is inadequate. There is a strong evidence base for this intervention but inadequate provision of facilities and staff leads to unacceptable waits for a place on a programme. • Adherence to guidelines for the use of oxygen, is better on designated respiratory wards. • Patients with acute exacerbations of COPD should be managed by respiratory specialists. We know that adherence to guidelines is better when this happens. It would be unthinkable for a patient with an acute myocardial infarction not to be managed by cardiology; acidotic exacerbations of COPD have a mortality approaching 50% but these patients are not guaranteed to see a respiratory consultant. Most larger hospitals have a specialist respiratory ward, although they can become full very easily particularly in winter months. In smaller hospitals access to a respiratory opinion may not be available

throughout the week.

- Apart from smoking cessation, the strongest evidence for reduction of mortality in COPD is with appropriate prescription of long-term oxygen therapy. Assessment of cases for suitability must be facilitated.
- For patients with severe disease access to intensive care can be an issue. An appropriate ceiling of care needs to be agreed with patients. However, outcomes in COPD patients who are admitted to ITU with COPD are similar to those for other medical conditions and therapeutic nihilism means that this care may be being denied inappropriately.

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?

- Despite each country in the UK having national directives to reduce the population of smokers by 2020, there is still no integrated policy joining Public Health with Primary and Secondary Care, so cessation services end up being patchy and of variable standard. Services in secondary care are particularly in need of strengthening.
- Spirometry screening should be rewarded, targeting people with a smoking history and at risk occupations – those exposed to dust, fumes and chemicals. Systems should be put in place to ensure that screening spirometry is available in primary care, and that diagnostic-quality spirometry can be obtained readily.
- Pulmonary rehabilitation is one of the most effective and best value interventions for patients with COPD, improving exercise performance, quality of life and reducing hospital admission. Following hospital admission with an acute exacerbation of COPD only 4 people need to be treated to prevent one readmission. The impact is much greater than that for inhaled medications but provision of pulmonary rehabilitation, despite an A grade evidence base in UK and international guidelines, is poor and many patients are unable to access a program. There needs to be a parity of esteem between this kind of intervention and (in many cases less effective) pharmacological therapies that are promoted by pharmaceutical companies
- Improving the systematic delivery of care to all COPD patients through strategies such as care bundles is important to ensure that all receive vaccination, smoking cessation as a treatment for COPD, pulmonary rehabilitation and appropriate pharmacotherapy. This requires training, systematic data collection and empowering/informing patients as to what they should expect. The BTS COPD audit is a key part of this to identify unwarranted variation.
- Specialist care is also important. Techniques such as lung volume reduction surgery have been shown to improve survival in selected subgroup of COPD patients with the appropriate pattern of emphysema. This requires the

development of networks (similar to cancer networks) where a multidisciplinary team can assess patients with advanced disease.

- Most people with COPD, a disease of aging associated with smoke exposure, have other long term medical conditions such as cardiac disease, diabetes and osteoporosis. A more systematic approach to ensuring that cardiovascular disease is sought and addressed in people with COPD (and COPD identified in patients with cardiovascular disease) is needed. For example, there is evidence that COPD patients are missing out on preventative cardiac interventions such as beta blockers, and this may well contribute to overall COPD mortality

4. What could the Government in England do to reduce premature mortality from COPD?

- Barriers to young people taking up cigarette smoking, and help for those of all ages who want to quit, are the major priorities. There are numerous ways in which these might be achieved, but we would particularly mention legislation on smoking in cars; standardised packaging; regulation of additives that make smoking more palatable such as menthol; and better access to smoking cessation services.
- Measures to incentivise women not to smoke during pregnancy, and parents not to expose children to cigarette smoke
- Low levels of physical activity have been consistently associated with a more rapid decline in lung function. Government action on both access to recreational facilities and the promotion of safe, active means of transport (walking, cycling) will impact on respiratory mortality for the individual performing the exercise. The latter also reduces particulate emissions improving air quality for all,
- A great deal of pharmaceutical effort and resource has gone into developing inhaled medications that are slight variations on existing treatments and therefore have little benefit for patients. The system needs to remove incentives for this sort of activity and rather promote the development of novel rather than “me too” drugs.
- Cold makes increases exacerbations of COPD and thereby risk of death – fuel poverty is therefore a preventable contributor to respiratory mortality. Withdrawal of community facilities increases social isolation which is also associated with increased mortality in older people. This is especially an issue in people with respiratory disease who face social isolation because of breathlessness and have a higher chance of having lost a spouse because of shared smoking habit.

5 Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

6 How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

We agree that this is a major part of the problem. There is evidence that too many patients with COPD obtain the diagnosis when the disease is already well established. Patients are more likely to die when they have severe disease, and there are interventions which will slow the rate of disease progression and which will therefore have a bigger effect on mortality (and morbidity) if they can be applied at an earlier stage. We have already referred to some of the issues in previous sections:

- Patients often present late because they believe their slowly worsening breathlessness to be part of the normal aging process rather than a treatable disease. A careful education campaign is needed
- Patients also believe incorrectly that “it’s too late to stop smoking”.
- Improvements to spirometry services in primary care are required. This includes immediate access to spirometry, which may exclude the diagnosis of COPD; and making diagnostic standard spirometry available to all in whom initial assessment suggests the possibility of COPD
- Although most of this is achievable in primary care, it is a false economy to discourage referral for an expert diagnostic assessment in cases of doubt. Current initiatives to reduce referrals to secondary care may lead to missed cases of COPD or, conversely, to other patients being treated unnecessarily with COPD medication. Appropriate referrals must not be penalised. The BTS has produced clear guidelines indicating which patients should be referred to hospital. There is some evidence that these guidelines are not widely known about nor adopted by CCG's. It is likely that such widespread use of these guidelines would have minimal financial impact as it would reduce inappropriate attendances at secondary care clinics whilst promoting those that do need to be seen in secondary care for either a diagnosis or management to be seen appropriately

7 Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

8 Do you have any other comments relevant to this inquiry?

¹ The Burden of Lung Disease: Report 2, British Thoracic Society, 2006.

² UK mortality from respiratory disease is 5th worst in the EU, after Denmark, Ireland, Belgium and Hungary. ERS White Book - the Burden of Lung Disease, Figure 1. Last accessed on October 2013. <http://www.erswhitebook.org/chapters/the-burden-of-lung-disease/>

³ Department of Health, *England level data by programme budget*. Downloaded from: <https://www.gov.uk/government/publications/2003-04-to-2010-11-programme-budgeting-data>. Accessed on 01/10/2013

⁴ 7,500 lives could be saved in England when total deaths were 23,000 per year from COPD. Outcomes Strategy for Asthma and COPD: NHS Companion Document, Department of Health, May 2012.

⁵ Partridge M, Self care plans for people with asthma. *The Practitioner* 1991, p 715-21

⁶ Health Survey for England 2001. The Scottish Health Survey 2003. Welsh Health Survey 2005/2006. Northern Ireland Health and Wellbeing Survey 2005/2006. Population estimates from Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics & Research Agency

⁷ Outcomes Strategy for Asthma and COPD: NHS Companion Document, Department of Health, May 2012.

⁸ Health Survey for England 2001. Population estimates from Office for National Statistics

⁹ Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics & Research Agency

¹⁰ OECD, Deaths - *International comparisons, all ages*. Downloaded from

<http://stats.oecd.org/> Accessed on 02/10/2013

¹¹ All references in this paragraph: An Outcomes Strategy for COPD and Asthma, Department of Health, July 2011.

/CONTINUED (Appendix)

APPENDIX TO BTS RESPONSE TO APPG CONSULTATION JANUARY 2014

Lung Cancer: There are >30,000 deaths from Lung Cancer each year in the UK, more than from any other form of cancer. Historically rates were much higher in men, but this ratio is narrowing and is now approximately 1.5:1. Moreover, while deaths are falling in men they are increasing in women, and it is now the commonest cause of cancer-related death in both sexes. Overall, in recent years the mortality data has shown some improvement and our comparative standing against other European countries is not as bad as for some other respiratory diseases, although still not as good as we would wish (the age-standardised mortality in the UK is 39.4 per 100,000 population, compared to 45.4 in the Netherlands and 44.5 in Belgium, but not as good as in Germany at 33.2 or France at 35.8). It is highly likely that the improvements are related to the establishment of well supported Lung Cancer networks; this is the only respiratory disease which has this provision.

- The incidence of lung cancer is highly dependent on smoking rates, and further anti-smoking measures should be introduced, for example: legislation on smoking in cars; standardised packaging; regulation of additives that make smoking more palatable such as menthol; and better access to smoking cessation services
- Lung cancer is also strongly associated with social deprivation, more so than with other cancers. This is partly, but not entirely, due to smoking rates.
- Patients in the UK appear to present to specialist services with more advanced disease than in other countries, which inevitably impacts on survival. Research aimed at understanding and tackling this problem should be supported. At least some of the delay is related to acceptance of symptoms, and evidence is emerging that careful awareness campaigns may be beneficial
- There are ongoing studies of screening to detect early stage lung cancer

Pneumonia: Pneumonia causes >26,000 deaths per year (more than acute myocardial infarction) in the UK. Moreover, changes to the assignation of cause of death when the current ICD coding was introduced mean that this probably underestimates the mortality. Pneumonia care is amenable to improvement:

- Improved uptake of influenza and pneumococcal vaccination would help. In addition, the pneumococcal vaccine is imperfect and further research should increase its effectiveness
- Adherence to guidelines is poor, and better management of oxygen, antibiotic prescription and acute ventilatory support should impact on mortality (as well as improving downstream effects on antibiotic resistance).
- The BTS care bundle for pneumonia improves outcomes. Wider dissemination and support would be hugely beneficial

Pulmonary Fibrosis: There are issues around terminology in this disease area also commonly known as Interstitial Lung Disease (ILD) - several other labels are also applied. What is clear is that this is becoming a major health problem for the UK. The incidence is increasing, up by 35% between 2000 and 2008 (Navaratnam et al. Thorax 2011; 66:462-467) which equates to >5,000 new cases per year. The importance of this on mortality cannot be underestimated since the disease carries a very poor prognosis. Overall life expectancy from the time of

diagnosis is around 3 years, with a mean 5 year survival of between 30 and 50% This is worse than many cancers. The major problem is that ILD in most people responds very poorly to currently available medicines.

- There are proven benefits from Pulmonary Rehabilitation programmes. Access to these should be improved.
- There are already moves to focus care in specialist departments with Multi-disciplinary inputs. The benefit of this is unproven as yet but similar models have worked in virtually every sphere in which they have been introduced and should be effective in ILD.
- There is an urgent need for investment in research into new pharmacological therapy for ILD.

Bronchiectasis: This is an underpublicised disease which has a big effect on morbidity, but less on mortality. Nonetheless approx 1,000 patients per year die of the disease, and importantly this appears to be increasing steadily. The disease is very variable and the key is appropriate treatment for those displaying adverse features, particularly related to their bacterial colonisation profile

- There are good Guidelines for management of bronchiectasis. Patients should have access to specialist assessment to identify those in need of more intensive treatment

Sleep apnoea: This common condition which affects approximately 1% of the adult population, with an increasing prevalence associated with obesity. It has close links to morbidity and mortality from ischaemic heart disease, hypertension, stroke and diabetes.

- Sleep apnoea is a significant contributor to road traffic accidents.
- Strong links to morbidity and mortality in ischaemic heart disease, heart failure, hypertension and stroke.
- Associated with road traffic accidents and consequent high mortality.
- CPAP is an effective NICE TAG recommended treatment.
- Sleep apnoea remains under diagnosed and therefore under treated.
- Untreated patients with sleep apnoea have increased healthcare utilisation.
- Identification of patients via simple tools embedded in QoF and/or health checks and/or screening programmes should be considered.

Tuberculosis: This is not a common cause of death in the UK, with <400 people dying annually over recent years. However, it is crucial that cases are treated promptly and with appropriate therapy to avoid spread of resistant organisms. These represent a potential health catastrophe if they become prevalent in any region or country

- Rigorous contact tracing when new cases are detected, with immunisation or treatment of contacts as appropriate, must be maintained
- Treatment must be administered by those with experience of the disease, and of the relevant medication.

Name:	Monica Fletcher
Job Title:	Chief Executive
Organisation:	Education for Health
Region/location:	Warwickshire (National organisation)
Capacity in which you are replying to the inquiry	On behalf of the Charity and its team of respiratory clinical leads

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

- There is a perception / reality that there is greater investment and profile in the other non-communicable diseases and in particular cancer and heart disease as these are seen as diseases which kill.
- There is not the same perception that one dies from respiratory disease. The general public perceive the heart to be of more importance as without your heart you cannot live but little knowledge about the function or importance of the lungs. These perceptions are furthered by media campaigns around cancer and heart disease but not respiratory
- Lung disease is often perceived as being self-inflicted but the same is not true of heart disease: despite: Increasing issues of obesity, lack of exercise, poor diet etc.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

- Education and attitudes of the staff providing the care so that diagnosis is not made late in the process and that diagnostic tests such as spirometry are seen as important and only to be undertaken by those with the skills and knowledge to do it and more importantly interpret it alongside an appropriate clinical history.
- Having used QOF to raise the profile of asthma and COPD in primary care – improving rates of diagnosis -there now needs to be a move to less tick box and more holistic care: we would be

supportive of seeing QOF radically reviewed to enable this to happen.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

- There is something about guidelines and templates impeding the use of critical thinking skills and clinical decision making. QoF being a prime example – as long as the box is ticked!
- Communication between all providers of care but mainly between primary and secondary care. There also needs to be a greater awareness of the co morbidities and the impact of these on premature mortality
- Communication with patients is still poor and needs to be more patient centred

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

- Those without a diagnosis and education and support to self-manage
- Vulnerable patients including mental health issues, learning disability and those who do not have English as a first language and who often have different health beliefs
- Homeless and those with poor literacy skills and those with chaotic lifestyles
- Young children where HCP's do not have the knowledge and skills to recognise and treat probable asthma
- The elderly are often overlooked – in particular those with asthma can be misdiagnosed – frequently as COPD and when diagnosed undertreated! The elderly die of asthma and yet the news headlines are always about children dying.

5. What can the Government and the NHS in England do to reduce respiratory deaths?

- Raise awareness of the number of deaths and stop blaming those who smoke so that they come forward to seek help without fear of reprisal.
- Open access to earlier quality assured diagnosis for asthma and COPD and other lung conditions via spirometry in the first instance
- Put patients in control, engage them and improve self-management support

Asthma Questions:

1. What are the most important factors contributing to asthma deaths?

- We would do well to await the NRAD findings for asthma to see why people died from asthma. However much is already known:
- Most definitely an underuse of inhaled and oral steroids and an overuse of bronchodilators
- Limited awareness among people themselves & their families, teachers, HCPs that people can and do die from asthma.
- Individuals presenting too late
- When people present to health care services – they are not treated as an emergency
- Patients and HCPs not using inhalers correctly – both adherence and technique!!
- Access to correct treatment and adequately trained HCP's
- HCPs not treating properly or patients not coming for review. Do we make it easy enough for people to attend? Do we tick our boxes rather than theirs? Potential failures are with: early and accurate diagnosis, appropriate treatment for stable disease and exacerbations of disease and ensuring there is good quality education for both HCPs and patients
- Patients not empowered to self-manage ref: Shared decision making or paternalism in nursing consultations? A qualitative study of primary care asthma nurses_ views on sharing decisions with patients regarding inhaler device selection Jane Upton, Monica Fletcher, Hazel Madoc-Sutton Aziz Sheikh, Ann-Louise Caress and Samantha Walker doi: 10.1111/j.1369-7625.2010.00653.x

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

- Association with other factors increasing vulnerability, mental health, social circumstances. (Chaotic lifestyles, lack of access to health care, treatments, overlooked by HCPs, not seen as important etc.)
- Particular care needed with children and young people in vulnerable circumstances. HCP's need greater understanding of the impact of family dynamics on child health.
- Elderly (Misdiagnosis and under treatment)
- Very young (Difficult to diagnose and to treat) -Need to raise awareness of link to eczema/ atopy and asthma in children as there is a greater risk of death from associated anaphylaxis.

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

- Poor communication all round: HCPs between each other, to patients and patients to HCPs
- Access to timely care and treatment in general practice: - long waiting times for appointments – cannot get timely appointments when needed

- Time a huge factor, even if poor asthma control is identified HCP's often lack the time and critical thinking skills to ascertain why, far easier and quicker to just step up treatment rather than identifying the root cause of the exacerbation and try to avoid happening again in future. Length of time for appointments to make a proper impact on control and education – Many practices have stopped running specified asthma / respiratory clinics, partly in responses to patients DNA's to accommodate patients at other times appropriate. This has diluted care – i.e. Patients not necessarily seeing the most experienced and trained HCP professional in the practice.
- There does not appear to be an identified respiratory lead GP in every practice and much of the care is now devolved to nurses. When they were appropriately trained in the past this was more acceptable, but as investment in training has been reduced, it is leading to a dangerous situation.
- Poorly educated HCPs and patients; is the problem more to do with unconsciously incompetent HCPs or with patients who don't do what they need to do? Probably a mixture of both.
- Too many inhalers on the market causing confusion amongst prescribers and users!
- People aren't always given enough time and consultations are not patient focused and too much emphasis on QOF. HCPs need more training in patient focussed decision making and PPI.

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

I suspect everyone will refer to the Finnish programme, however this has to be set in the context of the health care system.

I am very keen to see us concentrate on a targeted component part this project such as a 'national inhaler education programme' – see attachment but introduction included below:

Background

- In 2011 45 million prescriptions¹ for inhaler medications were dispensed in England
- Total cost of these medications: £900m¹
- Poor inhaler technique is commonly demonstrated among both patients² and health care professionals (HCPs)³
- This results in:
 - Suboptimal control
 - Avoidable morbidity – including hospital admissions
 - Drug wastage (patients believing they do not work)
 - Escalation of treatments to potentially more costly and higher risk medicines
 - NHS avoidable costs
 - Time taken by increased consultations

Proposal

With the increasing number of inhalers available, the issues regarding inhaler technique may potentially worsen. We would like to see the introduction of a standardised education package for patients who are using an inhaler in to achieve optimal inhaler technique. This should include education as to the function and whereabouts of the lungs and the importance of inhaled drug delivery. The education needs to be standardised - across the health care system, and also be offered in schools, nursing homes etc. and made available via non-medical channels, social media, YouTube etc. The inhaler technique patient education package will be developed to address all users of inhalers, such as, different minority groups.

References

1. The Health and Social Care Information Centre (2011) Prescriptions dispensed in the community: England, Statistics for 2001 to 2011. <http://tinyurl.com/mk5qo9q>
2. Newell K, Hume S (2006) Choosing the right inhaler for patients with asthma. *Nursing Standard* 21 (5):46-8
3. Anon (2012) Improving inhaler technique – who needs teaching? Drugs and Therapeutics Bulletin 50 (10): 109. DOI:10.1136/dtb.2012.10.0131

5. What can the Government in England do to reduce asthma deaths?

A strong and sustained public health campaign would be good - something that is right in the public eye rather than just being for a select audience. When have we ever seen a programme on TV about asthma/COPD/inhaler devices for example? Yet so many people know someone who has respiratory disease.

6. What can the NHS in England do to reduce asthma deaths?

Implement the findings from NRAD!
Support the inhaler campaign (see attachment)
Commission a national patient education programme – similar to that in diabetes – DAFNE (stands for Dose Adjustment For Normal Eating)
Prioritise supported self-management for patients and training for HCP's

7. Do you have any other comments relevant to this inquiry?

Please make reference to the importance of training

National Survey on the roles and training of primary care respiratory nurses in the UK in 2006: are we making a difference? **Upton J, Madoc-Sutton H, Sheikh A, Frank TL, Walker SM & Fletcher MF**

This research describes nurse-led UK general practice asthma and chronic obstructive pulmonary disease (COPD) care, and the training undertaken to support it, and finds many nurses with an advanced role did not have accredited training and are under-supervised, particularly those working with COPD patients. Link to paper:

Diploma and degree level asthma training is essential to develop the critical thinking skills of HCP's to enable them to support patients with asthma to manage their condition in a holistic manner particularly in relation to their lifestyle and comorbid health conditions.

Chronic Obstructive Pulmonary Disease (COPD) Questions:

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

Lack of diagnosis and misdiagnosis by most HCPs managing this group of patients.

Patients with moderate – advanced disease not being given sufficient help to give up smoking or easy and timely access to pulmonary rehab

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

- Need to educate HCP's to look for and treat effectively people with COPD. It is not appropriate to devolve care to untrained nurses or HCAs
- Nurses and GPs need a minimum of 20 minute appointments to review patients with LTC recognising that tick box care cannot work for this group of patients

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?

- Diagnose earlier and ensure that the guidance in Quality Assured Spirometry is implemented across primary care in England.
- Recommend to HEE that all staff involved in diagnosing and managing COPD are appropriately educated to do so
- Educate patients about the disease rather than blame about the smoking!
- Help patients who find it difficult to give up smoking
- Encourage smoking cessation services to be provided in a range of locations including in the workplace
- Create incentives for routine smoking cessation advice/NRT for those in hospital
- Stigma: still believed to be a condition of the elderly and men: prioritise the younger working age population and women
- Very few patients know where their lungs are let alone knows what they do!

4. What could the Government in England do to reduce premature mortality from COPD?

- Ensure spirometry is available in a multitude of places – including the workplace
- Diagnose early and invest in nurse care in primary care. We need to be training nurses to give high quality care to patients with COPD. They need a lot of support and education and patient centred care is important. They frequently have extensive comorbidities so the nurses need to be highly educated and to have the support of their GPs,

8. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

no

5. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

Allow investment in practice nurses' training in order to optimise diagnosis, treatment and ongoing management and allocate adequate time to appointments so they can see the patients and treat effectively.

6. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

There appears to be limited investment.

9. Do you have any other comments relevant to this inquiry?

COPD is not just a disease of the elderly!

Name:	Siân Williams
Job Title:	
Organisation:	NHS England Clinical Leadership Group - respiratory
Region/location:	London
Capacity in which you are replying to the inquiry	On behalf of the Clinical Leadership Group - Respiratory
List of any supplementary information attached (if any)	Our flu factsheet, London Respiratory Team Final Report July 2013, inhaled steroid safety card, stop smoking CQUIN and COPD care bundle CQUIN. If you require further information about any of these material please contact Siân Williams 07980 541664.

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

According to ONS data for 2009-2011, respiratory disease was the underlying cause of 14% of all deaths in England, rising to 20% if lung cancer is included. A respiratory disease (including lung cancer) is mentioned on 39% of death certificates – either as the underlying cause of death or a contributory factor. Yet respiratory disease does not have the sustained attention in terms of national programmes, investment or leadership that this warrants.

Respiratory disease accounts for 20% of deaths in England yet less than 5% of total NHS expenditure.

There is insufficient investment in stop smoking as treatment for respiratory disease, particularly for those who are most tobacco-dependent eg those with mental health problems, those in prisons and those living at home alone with little outside contact. Historical inequalities remain because most commissioning of health services is still based on previous years' activity: for example the National Service Framework for heart disease led to investments in stop smoking services that mainly remain today but are not necessarily "owned by" or used to the maximum by the respiratory community. For some treatments, investment is relatively high but does not necessarily create the best value for the public purse. We would argue for keeping the same level of investment but rebalancing how it is spent to achieve better value. There is substantial investment in pharmacological interventions. Five respiratory inhalers account for all top 5 drug costs by total expenditure to the NHS costing between them £556 million per year¹ and we would argue that some of that investment generates poor value: prescribing at too high doses that could cause patients harm; waste created by use of medicines for a mis-diagnosed condition or dispensed but not used by patients who have not received adequate self-management support. There is also overuse of oxygen that can also cause harm and should not be prescribed without a proper expert assessment. There is insufficient access to specialist end of life expertise for people with terminal respiratory conditions. Although many patients wish to die at home rather than in hospital, more people with COPD/ILD die in hospital compared with patients dying of other diseases, such as cancer. The national end of life report found that 69% of people with respiratory conditions other than lung cancer die in hospital - compared to an average of 58% of all deaths. That figure is higher than for any other condition and these patients are also the least likely to die at home (13%). Some of that is warranted, but some is not. Lower levels of engagement in advance care planning also deprive

people with terminal respiratory disease of opportunities for active symptom management and support for their anxiety: breathlessness is a frightening and distressing condition.

[*Deaths from Respiratory Diseases: Implications for End of Life Care in England* June 2011. http://www.endoflifecare-intelligence.org.uk/resources/publications/deaths_from_respiratory_diseases]

There is under-diagnosis of COPD, heart failure and anxiety so breathless patients may suffer triply.

Whilst lung cancer rates have decreased because the prevalence of smoking has decreased over the last 50 years, lung cancer remains the most common cause of death from cancer for men and the second most common cause of death for women after breast cancer. The annual incidence of lung cancer in South East England is 54.5 per 100,000 men and 27.8 per 100,000 women. Mortality rates are almost as high: 47.9 per 100,000 men and 23.4 per 100,000 women. Survival is poor, with less than 10% of people surviving more than 5 years.

Smoking is the single biggest factor in the development of cancer, and is responsible for over 85% of cases. There have been no randomised controlled trials, however we know from a systematic review of observational studies that continued smoking is associated with a significantly increased risk of dying in early stage non-small cell lung cancer and limited stage small cell lung cancer. This equates in modelling to a 70% 5-year survival in 65 year old patients with early stage non small cell lung cancer who stop smoking compared to a 33% 5-year survival for those who continue to smoke and 63% 5-year survival in limited small cell lung cancer who stop smoking compared to a 29% 5-year survival for those who continue to smoke.²

Some pneumonia deaths can be avoided through intensive and timely acute interventions such as those included in the evidence-based pneumonia admission bundle, which has been successfully incentivised through CQUINs in the North of England.³

2. What changes can be made to improve outcomes for all or most respiratory conditions?

Flu vaccination rates of people at risk and staff need to be increased (see supplementary new flu factsheet).

People who smoke and have asthma and COPD have an increased risk of hospitalisation⁴ and poorer and shorter lives. Smoking cessation reduces the risk of developing bronchitis and pneumonia compared to continued smoking; introduction before the initiation of radiation therapy in lung cancer is associated with an increased rate of complete response to treatment compared to those who continue to smoke through treatment. Therefore outcomes could be improved by supporting people who smoke to stop smoking.

The first step is to increase awareness of smoking prevalence and the success of all stop smoking interventions by capturing the data. It is not routinely analysed in primary care by disease and therefore key questions such as "How many people with asthma in your practice are current smokers and how does that compare to last year?" cannot routinely be answered. It is not routinely analysed in secondary care – a stop smoking CQUIN can incentivise change (see attached). It is not routinely recorded in death certification, but that can be changed by working with hospital mortuaries and local authority certification registrars. Smoking is not currently in the lung cancer audit and therefore its planned addition should be applauded, supported and closely monitored. This will be helped by implementation of NICE PH guidance 48 that states "Secondary care providers have a duty of care to protect the health of, and promote healthy behaviour among, people who use, or work in, their services." One way of formalizing clinical leadership in quit smoking is to require a British Thoracic Society Stop Smoking Champion in every NHS Trust (see <http://www.brit-thoracic.org.uk/Stop-Smoking>).

Champions.aspx)

Earlier diagnosis of people at risk from COPD and lung cancer can be achieved through case-finding amongst the smoking population; then the first intervention should be quit smoking.

Apart from stopping smoking, the other interventions that will improve outcomes for people with COPD and other lung diseases, such as pulmonary fibrosis, are access to programmed pulmonary rehabilitation that meets the standards of the specification described by the DH Commissioning Toolkit and by the London Respiratory Team's minimum standards. It is not enough to provide it, GPs and others caring for people with COPD need support and practice in referring. The IMPRESS guide offers useful guidance.

Investment in behaviour change training for clinicians and an agreed local approach to increasing levels of physical activity, weight management and medicines adherence is essential.

Responsible respiratory prescribing [<http://www.networks.nhs.uk/nhs-networks/london-respiratory-network/key-documents/responsible-respiratory-prescribing>], following the London Respiratory Team's 7 messages (see end).

All of these services need to be made available to all those who would benefit and that means that some people such as certain ethnic groups and populations with high smoking prevalence like Bangladeshi men and other highly dependent smokers in prison and mental health units, including those people with enduring mental illnesses living in residential care, need additional support through education and encouragement to ensure they have equal access.^{5 6}

There are stop smoking CQUINs in London mental health trusts to reduce smoking rates. Maidstone Jail has trialled PR for prisoners. Tower Hamlets has also tested and reported on a number of interventions to improve uptake of stop smoking and PR interventions in its local community that can be shared.

Recognition that the driver for patient use of emergency care is breathlessness (usually frightening), but that those who would benefit from acute admission are those who have new or worsening respiratory failure. Pulse oximetry should therefore be included as a mandatory component of assessment in the community by any clinician of breathless patients to identify those who have respiratory failure and need hospital admission, compared to those who do not, and could be managed at home.

Incentivisation of the pneumonia admission bundle using CURB 65, or one aspect such as reporting of chest X-rays within 4 hours would make a difference.

Outcomes for people with ILD are improved if they attend tertiary centres because whilst there are currently no treatment options for most people with severe ILD, general survival rates are better at tertiary centres and people can also be entered into clinical trials. Therefore earlier diagnosis would enable appropriate referral.

The way forward in respiratory care is to practise both individual and population medicine and for clinicians to have time, support, education and information to think about and respond to the question "who am I not seeing that would benefit from our care?", so that we reduce the number of people who first receive a diagnosis during an emergency admission to hospital. It also requires a shift in aspiration and understanding about the "day job" which is increasingly about supporting people with multiple long term conditions who require complex and coordinated interventions over years. This needs reflection in training curricula and posts and different appraisal systems for "long term condition clinicians".⁷

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

Late diagnosis of COPD, lung cancer and other respiratory diseases, such as ILD, which means that the first time some people hear of their diagnosis is on admission to hospital and therefore the interventions to slow the progression of the disease are not offered in a timely way.

The best chance of a cure from lung cancer is with early diagnosis and surgery, but as more than 80% of deaths are attributable to smoking, clinicians need to take every opportunity to help someone quit, particularly those on the 2-week wait pathway. Lung MDT structures provide a mechanism to address this systematically. In the same way that any clinician seeing a patient with lung cancer has to have done communication skills training, it would be possible to mandate that every member of the MDT has done quit smoking training and is confident to prescribe quit smoking medication including varenicline.

Currently the majority of inpatients who smoke do not receive interventions to support them to stop smoking during their hospital stay. In trusts seeing at least 20 patients there is also variation in the percentage of patients with stages I and II non-small cell lung cancer treated surgically from 21%-62% (depending on the Trust of *diagnosis*). There is similar variation for small cell lung cancer: percentages of patients receiving chemotherapy range from 50%-76%. There is now a London Cancer Network agreed treatment guideline and we would hope that this will increase the rates of people treated to those of the best-performing trusts. In addition to stop smoking, key recommendations from the clinical London Cancer Network to increase early diagnosis of lung cancer and other lung diseases include:

- Improvements in the availability of reports by radiologists of chest X-rays of patients attending emergency departments that will be challenging to achieve
- CT scanning for patients referred through the 2-week wait pathway prior to the first clinic appointment (note, this needs audit to ensure there are the right overall radiological priorities to support all respiratory patients at risk of premature mortality)
- Use of the Royal College of Pathologists minimum dataset for specimens
- Essential multi-disciplinary team to decide on diagnosis, stage and treatment that meets peer review standards including a thoracic surgeon
- Data collection to measure outcomes, supported by a data manager
- Key standards for supporting patients and giving the diagnosis
- Revised treatment guidance
- Palliative treatment to improve quality of life

The barriers to better respiratory care also include lack of consultation time. An annual primary care review that lasts 30-40 minutes using a structure like SIMPLES (<http://vimeo.com/66828323>) could pick up on poor medicines adherence, smoking and self-care. It is not possible to conduct this in a 10 minute primary care consultation or a 20 minute outpatient appointment.

As in all analyses, data are important, and there would be great value in increasing the involvement of consultants in death certification and ensuring smoking is included where it is a cause of death.^{8 9}

National and hospital audit data¹⁰ and primary care studies^{11 12} all show that respiratory guidelines are not followed consistently, yet once the right priorities have been agreed with commissioners, based on what yields most value, the other challenge is to do things right, and guidelines exist to help this process. We strongly suggest use of local multi-disciplinary meetings including all clinician groups who provide care to patients with respiratory diseases (including out of hours, emergency medicine and acute medicine) to review the literature and local data and to agree on what Right Care should be, and how to achieve it locally.^{13 14}

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

COPD is a disease caused by smoking, poverty and early life effects. Tobacco dependence in England is now typically a problem of lower socio-economic groups and therefore there are known at-risk groups for developing the disease and for premature mortality. Those at risk of COPD include men and women who are, or have been, in "routine and manual" jobs, certain ethnic groups with high smoking prevalence such as Bangladeshi men, men from the new EU countries¹⁵ those in prison and those with mental health problems. Those at risk of premature mortality are those with a substantial pack-year history at a relatively young age and this is particularly true for people with severe mental illness: men with schizophrenia living in the community have a 20.5 year reduced life expectancy and most of this excess mortality is due to increased levels of smoking.¹⁶ The 2007 Adult Psychiatric Morbidity Survey that found that 42% of all cigarettes smoked by the English general population are smoked by people with a mental disorder.¹⁷ There is a persistent and increasing gap in mortality from circulatory and respiratory diseases, for which smoking is a major risk factor, between people with serious mental illness and the general population.¹⁸

5. What can the Government and the NHS in England do to reduce respiratory deaths?

The UK should follow South Africa's example as the only country to ask during routine death notification about smoking history. We strongly recommend that smoking status about 5 years before death should be noted when registering causes of death. There is no reason not to.^{8 9 19}

Require the use of a value framework for clinicians and value-based commissioning in respiratory care. The London Respiratory Team Value Pyramid and the IMPRESS relative value work with LSE provide a basis for this in COPD.^{20 13 14}

Introduction of smoking bans and support to quit smoking for staff and patients in institutions such as hospitals, mental health units and prisons. Hospitalisation offers an opportune time to encourage patients to stop smoking for four reasons.

1. This time is often a "teachable moment" where patients are more receptive to intervention and are more motivated to quit.
2. The hospital smokefree environment creates an external force to support abstinence.
3. Patients are ideally placed to be given information about treatment options, support through withdrawal and signposted to specialist services.
4. Abstaining from smoking at this time can lead to significant health benefits and more rapid discharge.

Improved assessment of breathlessness by supporting the planned Breathlessness Awareness campaign with information to clinicians, patients and commissioners. It requires a joined-up service that addresses multi-morbidity in both assessment and treatment. There are resources available that need promotion by NHS England:
http://www.impressresp.com/index.php?option=com_content&view=article&id=172:impressions-31-breathlessness&catid=11:impressions&Itemid=3

People with COPD are at risk of exacerbations if they are cold due to fuel poverty or other causes. The features of the "Warm Homes Healthy People" scheme should be available to people with COPD in the future as part of the Public Health England Cold Weather Plan and should address areas of low referrals despite the prevalence of COPD. Encouraging closer working between hospitals and the relevant local authority department, including Public Health, by joint action nationally would be helpful.

People in damp homes may have worsening respiratory symptoms due to mould so need housing support.

It is inequitable to offer certain at risk groups eg people with cancer special housing support and yet offer nothing to people for whom there is a system review evidence base that warmth and energy efficiency improvements to housing improves outcomes for people with respiratory disease.^{21 22 23}

National data collection informed by epidemiologists and clinicians, and informed by coders, to identify avoidable deaths accurately and also to quantify the effects of implementation of changes.

There is a need to monitor standards for some common conditions such as pneumonia more closely. As an example, the BTS audit 2012/13 showed that 1 in 5 patients admitted with pneumonia are not getting a chest-X-ray within four hours of admission. The actual target is received and reported within 4 hours and therefore we can assume that the proportion reported within four hours is worse). The trend is also in the wrong direction: this is a decrease from previous audit periods.²⁴

Asthma Questions:

1. What are the most important factors contributing to asthma deaths?

The interim NRAD report found that in a third of cases information is missing, and therefore it would be good to wait until the final NRAD report's conclusions. However the interim report found that

- Over 50% asthma death certificates are > 75 yrs
- Death certification data unreliable
- Coroners post mortem conclusions on asthma death are unreliable
- ONS/GRO Scotland seem to overestimate asthma as an underlying cause of death

Therefore we need to support clinicians to make accurate diagnoses, and review patients' asthma control. We also need to check and improve coding by involving senior clinicians.

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

We still do not know what causes asthma. Therefore there are no particular known groups at risk of asthma although there are individuals at greater risk of asthma death. However, what we do know is the strong relationship between smoking and asthma admission: a 1% increase in general practice smoking prevalence equates to a 1% increase in asthma admissions.⁴ and there is a faster decline in lung function in patients with asthma who smoke.²⁵ We also know that after adjusting for season, variation in population size and long-term trends in admissions, the introduction of smoke-free legislation in 2007 was associated with a 4.9% (95% CI 0.6% to 9.0%) drop in emergency admissions for asthma.²⁶

Other at risk groups include people who are misdiagnosed and therefore not treated correctly; people who have difficult to manage asthma either because their asthma is severe and so needs very careful management and "stratified prescribing", or because they find it difficult to manage. They may smoke, or need psychological support to help them accept their diagnosis and cope with their concerns about the treatment or treatment side-effects, or they need adherence support because they have cognitive difficulties. It should be remembered that asthma is not just a disease of young people, but older people too: either who have always had asthma, or who develop it later in life, perhaps because of uncontrolled allergic rhinitis or occupation or inability due to cognitive impairment or arthritis to use inhalers effectively. It is also important to confirm coding and data in older people in case there are additional or alternative explanations for their breathlessness.

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

Most asthma is managed in primary care. Therefore the challenges are about supporting practices to reach the standards of the best performing practices. Part of that is achieving a better relationship between professionals and patients so that patients are supported to self-manage. This requires longer consultations and training in co-creating health-type consultations so that patients feel confident in managing their asthma and understand the consequences of behaviours such as smoking, incorrect inhaler technique, lack of exercise, not managing their hay fever. It also requires a practice system for call and recall, and accurate coding, as well as connection to a responsible respiratory prescribing network including pharmacists who can organise medicines use reviews. Better sharing of information on issues and dispensations between GPs and community pharmacists using established electronic prescribing systems could allow more accurate assessment of adherence to treatment.

Flu vaccination rates of people at risk and staff need to be increased (see new flu factsheet). We commend review of the 75% staff vaccination target linked to winter pressures money.

We have lacked audit data on some key metrics such as smoking data but now we have them we should act on them. Smoking was only added to the BTS asthma audit in 2011. In the 2012/13 audit report, of those admitted, 33.1% of patients were current smokers (higher than the national average), and a further 17.3% were ex-smokers. In addition, 8.2% of patients did not have a smoking history documented, which is a significant omission.

There is also a gap between guidelines and reality. We need better recognition and acceptance at a clinical level and patient level of the value of using peak flow readings to guide care because people with asthma who are sick and need admission often haven't been measuring their peak flow, particularly when they are unwell, so they start steroids later than they should. ED clinicians and ambulance staff often don't take peak flow measurements either because they don't have a peak flow meter available or because the patient says they are too sick to use one, and so clinicians do not have a baseline measure of how sick the patient was on admission. The consequence is that patients then they get discharged too early, and the clinician offering long term care doesn't have the narrative to explain to how sick they were and why they need to change.

Another important example is the concept of "stepping down" not just "stepping up". The London analysis of prescribing data shows that there is wasteful and potentially harmful prescribing of high dose inhaled corticosteroids. Disinvestment in these and reinvestment in other services would improve value.

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

Finland, and more usefully for London and the UK, the Irish Government has now adapted the Finnish programme and developed an evidence-based guideline that incorporates "how to" guidance for GPs.

5. What can the Government in England do to reduce asthma deaths?

Take them seriously as many are avoidable deaths. Tobacco control measures.²⁶

6. What can the NHS in England do to reduce asthma deaths?

Prioritise improvements in respiratory diagnosis and review in primary care, and negotiate the right incentives for general practice.

7. Do you have any other comments relevant to this inquiry?

Chronic Obstructive Pulmonary Disease (COPD) Questions:

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

1. About 40% of people with COPD are current smokers.
2. Many people with COPD are not diagnosed or diagnosed late so that they miss out on cost-effective/high value treatments including stop smoking, pulmonary rehabilitation, safe oxygen therapy and non-invasive ventilation (NIV), which are the four interventions with evidence to support their impact on mortality.

a. See above for more information on stop smoking support.

b. As described above, the provision of pulmonary rehabilitation is still extremely limited and variable.^{27 28} In addition, there is a research need to develop and evaluate structured education and activity programmes that precede and follow pulmonary rehabilitation in the same way that DESMOND that exists for people with Type II diabetes and their educators and DAFNE for people with Type 1.

c. According to 2012 data, 14% of patients in hospital at any one time are on oxygen, yet nearly half of patients (48%) did not have an oxygen prescription. Of those who had an oxygen prescription less than half (46%) had a prescription that used, as recommended in national guidelines, a target saturation range.²⁴ We know that patients come to harm on inappropriate oxygen. In the national 2008 COPD audit high flow oxygen was associated with not only an increased risk of needing ventilatory support (22% vs 9%, P<0.001) but also patients who received high flow oxygen had a higher in-hospital mortality (11.1% vs 7.2%, P<0.001).²⁹ Despite this shocking finding, in the 2012 BTS national oxygen audit, oxygen toxicity was still found to contribute to the need for NIV in 17% of patients; and where data were available, hospital care was implicated in inappropriate oxygen delivery in 60%, and pre-hospital care in 40%.

Perhaps there should be a NICE oxygen guideline, as there is for intravenous fluids? A requirement for British Thoracic Society Oxygen Champions in every NHS acute hospital would significantly leadership and coordination of safe oxygen prescribing (<http://www.brit-thoracic.org.uk/Guidelines/Emergency-Oxygen-use-in-Adult-Patients/Oxygen-Champions-2012.aspx>)

d. Non-invasive ventilation (NIV) is a well-established evidence-based treatment used in the management of COPD exacerbations and one of the key interventions that significantly reduces acute mortality from respiratory failure alongside reducing ICU admissions, length of hospital stay and costs.³⁰ Recommendation 20 of the Outcomes Strategy³¹ states all patients with acute respiratory failure should be identified and investigated promptly and offered treatment with NIV with access to mechanical ventilation if required. However clinical practice clearly falls short in implementing this recommendation: 5% of all acidotic patients and 3.2% of all NIV patients went on to receive invasive ventilation.¹⁰ Reasons for this are likely to be complex and include resource availability (beds and staff) and beliefs of ITU teams eg previous studies have shown that gate-keepers of UK ICUs may under-estimate survival.^{32 33}

Despite an excellent level of randomised controlled trial (RCT) evidence for ward NIV, the outcomes are not replicated in day-to-day management of these patients as evidenced from consecutive national COPD audits.¹⁰ The reasons are multi-factorial and require a multi-disciplinary and multi-pronged approach to improve the value of NIV care. This will need shared ownership and leadership from all clinician groups who provide care to sick patients with respiratory failure ie working closely with emergency medicine, acute medicine and critical care so that patients who meet the evidence-based criteria for ward NIV receive it in a timely manner in the right place by skilled staff and that those who are too sick for ward NIV are offered timely access to intensive care unless a shared (by patient and senior clinician) escalation plan with a ward-based ceiling of treatment is already in place.³⁴ It is clear from national audits that most patients receiving ward NIV have severe acidosis and a high mortality and therefore

meet the criteria for intensive care, in particular, pathways need to ensure that NIV is not used as a treatment for metabolic acidosis, which was the case for 10% of patients started on ward NIV in the 2008 COPD audit.²⁹

There is an opportunity to improve outcomes and patient experience by the systematic delivery of skilled and appropriately informed advance care planning.³²⁻³⁵ This should include escalation plans for all patients whose disease is severe enough to result in hospital admission in particular for anyone with COPD who has a raised serum venous bicarbonate and is therefore at high risk of acute type II respiratory failure. According to the latest audits, although one third (34%) of people with NIV died during admission, a quarter of patients being started on NIV did not have a treatment escalation plan.

Given reported prognostic pessimism,³⁶ outcome prediction models, with much better calibration than that of participating clinicians, may be one way to improve the appropriateness and consistency of decision-making.³⁶

3. Some people would benefit from lung volume reduction surgery (LVRS) which has been shown in trials to increase survival in selected patients with poor baseline exercise capacity and upper lobe predominant emphysema. Yet in the UK and other countries LVRS is substantially underused. A paper in press suggests that in the UK there may be up to 16,000 people eligible, but only 90 procedures are carried out per year.³⁷

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

Speed with which national audit findings are addressed in clinical practice which needs better collaboration between commissioners, managers and clinicians to ensure the right things are measured, incentivised and prioritised. Silo-working between cardiologists and respiratory physicians in many hospitals and communities and yet only 18% of people with COPD only have COPD and many people have heart disease and COPD – they may have COPD but die from heart disease. There is also a lack of implementation of prescribing guidelines eg the low use of beta-blockers that are effective in people with COPD and heart failure.

Co-morbidities have a significant impact on the health status, healthcare utilization, all-cause hospital admissions and mortality of people with COPD. COPD patients are more likely to die from a comorbid disease such as cardiovascular disease than COPD itself.

An evolving understanding of COPD as a multimorbid disease that affects an aging population, rather than just a lung-specific disease, should lead to an integrated, personalised and value-based approach to care.

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?

Flu vaccination rates of people at risk and staff need to be increased (see new flu factsheet). We commend review of the 75% staff vaccination target linked to winter pressures money.

People who smoke and have COPD have an increased risk of hospitalisation⁴ and poorer and shorter lives. Therefore outcomes could be improved by supporting them to stop smoking. The first step is to increase awareness of smoking prevalence and stop smoking success by capturing the data. It is not routinely analysed in primary care by disease and therefore key questions such as “How many people with COPD in your practice are current smokers and how does that compare to last year?” cannot routinely be answered. It is not routinely analysed in secondary care – a stop smoking CQUIN can incentivise change. It is not routinely recorded in death certification, but that can be changed by working with hospital mortuaries and death certification registrars.

Apart from stopping smoking, the other interventions that will improve COPD outcomes

are access to programmed pulmonary rehabilitation that meets the standards of the specification described by the DH Commissioning Toolkit and by the London Respiratory Team's minimum standards. There is evidence that post-admission pulmonary rehabilitation reduces mortality in COPD.

In the 2009 (updated 2011) Cochrane Review of Pulmonary Rehabilitation (PR) following exacerbations of COPD, PR reduced mortality and admissions: one life was saved for every 6 treated, and one admission was avoided for every 4 treated. In all trials, pulmonary rehabilitation improved patients' capacity to exercise. No adverse events were reported.

Therefore effective discharge processes should include support for patients to attend PR in a timely manner once they have gone home.

It is not enough to commission PR, GPs and others caring for people with COPD need support and practice in referring. The IMPRESS guide offers useful guidance. See http://www.impressresp.com/index.php?option=com_docman&task=doc_download&gid=41&Itemid=82

Use positive messages such as the London Respiratory Team's "Breathe better, feel good, do more"

The use of the COPD discharge bundle is a practical way to achieve implementation of these interventions.³⁸ (see attachment including a CQUIN to incentive its implementation).

Inclusion of oxygen toxicity as a never event from 2014/15.

4. What could the Government in England do to reduce premature mortality from COPD?

Address poverty and factors that worsen social isolation.

People with COPD are at risk of exacerbations if they are cold. The features of the "Warm Homes Healthy People" scheme should be available to people with COPD in the future as part of the Public Health England Cold Weather Plan and should address areas of low referrals despite the prevalence of COPD. Encouraging closer working between hospitals and the relevant local authority department, including Public Health, by joint action nationally would be helpful.

Tobacco control measures.

8. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

There is a lack of systematic evaluation of projects at a community level however there is strong clinical trial evidence to support the contention that systematic application of the following will reduce the number of people dying from COPD - smoking cessation, flu vaccination, appropriate treatment of cardiovascular comorbidities, pulmonary rehabilitation. Also, in selected patients long term oxygen therapy, NIV and lung volume reduction surgery.

5. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

Local Enhanced Services can make a difference, providing locally appropriate incentives. The Kensington and Chelsea LES introduced in 2008 increased the rate of diagnosis. By 2011 the prevalence was 1.17% compared with a predicted value of 0.91% based on the pre-LES trend.³⁹ The Islington LES, partnered by an integrated care consultant, has made 1377 new diagnoses of COPD in the three years 1.4.10 to 31.5.13 and the analysis from the subsequent year's LES shows that the rate of new COPD diagnoses per annum is being maintained.⁴⁰ This is an illustration of joined up planning, and building good relationships between general practice, the CCG, public health and the hospital, so that trust, honesty and respect grow.

6. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

In London we have promoted pulmonary rehabilitation strongly and some CCGs where there was none have now commissioned some, which is excellent. However, commissioning a new service is not the same as supporting its growth. It is not easy to persuade a breathless person to go to an exercise class. It takes knowledge and skill, and a good relationship with the patient. Please make sure that PR services are not withdrawn because they lack patients. Give them time and support local clinicians to learn what happens in PR, and how best to refer. We also need new ways of measuring value and a better understanding of the dynamics of workforce and costs if you move services closer to patients. For example, using real figures from London, an effective community-based PR programme that is accessible to patients might cost £1000 per patient because venues have to be booked, transport provided, scheduling done carefully to allow travel time to and from the hospital and extra hours provided because respiratory physiotherapists can't nip between the ward and PR. This is more than the recommended tariff. However, when you consider the number of patient contact hours with an expert team: 25 hours per programme, this is an order of magnitude greater than any other self-management support offered to patients and costs £40 per hour with an evidence base showing its impact on admissions and mortality.

9. Do you have any other comments relevant to this inquiry?

We strongly support Coordinate My Care which is the London response to advance care planning and to good practice recorded in *Deaths from Respiratory Diseases: Implications for End of Life Care in England* June and the IMPRESS guide to end of life care.

We strongly support a priority to implementation of NICE PH Guidance 48 (see supplementary paper). This requires commissioners to demand that hospitals provide this. There is also a return on investment for hospitals if their staff absence rates decrease, and if they take an external role, and support their local community to quit, it increases the pool of local recruits who are non-smokers.

The “wellbeing” agenda could mean that more options are generated amongst social care as well as health professionals to

- a) Make services more accessible through using ordinary community bases or leisure facilities for PR and with the potential for engaging the broader community/voluntary sector to work alongside patients;
- b) Integrate care “around the person”. For example, there could be new opportunities to use the Better Care Fund (previously Integration Transformation fund) to develop schemes/projects which address the needs of people with multiple long term conditions, including COPD in fresh ways, building on existing evidence from re-ablement projects.
- c) Use Personal Health Budgets (PHBs) or Personal Budgets (PBs) to enable individuals to commission their own PR/ exercise or transport assistance to meet need, and to give them more sense of autonomy in self-care and how they manage their condition so that the benefits of the interventions can be as sustainable as possible.

We need better integrated research into the costs and benefits of local authority interventions so that value-based commissioning is based on the best health and local authority evidence.

There are also opportunities for local service development contained in the Care Bill. The duties about effective information and advice services, along with support planning, allied with a drive towards prevention and the commissioning of services which support prevention offer opportunities to local authority and health commissioners.

Evidence suggests that telehealth approaches are poor value in COPD with a cost per quality adjusted life year exceeding £90,000. Resources allocated to telehealth, at the expense of the high value interventions which do improve survival in COPD outlined here, are likely to have an “opportunity cost” of increasing mortality for COPD patients.

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Supplementary Evidence:

1. Respiratory medications are expensive

Doing the Right Things:

2. When prescribing any new respiratory inhaler, ensure that the patient has undergone NICE-recommended support to stop smoking
3. Pulmonary rehabilitation is a cost effective alternative to stepping up to triple therapy and should be the preferred option if available and the patient is suitable.

Doing the Right Things Right:

4. When prescribing any inhaled medication, ensure that the patient has undergone patient centred education about the disease and inhaler technique training by a competent trainer
5. When prescribing an MDI (except salbutamol), ensure that a spacer is also prescribed and will be used
6. When prescribing high dose inhaled corticosteroids (>1000ug BDP equivalent?), ensure that the patient is issued with an inhaled steroid safety card (**see attachment**)
7. No Prednisolone EC prescribing without good clinical reason

NICE PH Guidance 48 recommends

- All hospitals have an on-site stop smoking service.
- Identifying people who smoke, offering advice and support to stop.
- Providing intensive behavioural support and pharmacotherapy as an integral component of secondary care.
- Integrating stop smoking support in secondary care with support provided by community-based services.
- Ensuring staff are trained to support people to stop smoking while using secondary care services.
- Supporting staff to stop smoking or to abstain while at work.
- Ensuring there are no designated smoking areas or staff-facilitated smoking breaks for anyone using secondary care services.

From:

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Inhaled Corticosteroids in Adults: Prescribing Guidance for Healthcare Professionals

1. Inhaled corticosteroids (ICS) are generally considered safe when used in low doses. However, when higher doses are used over long periods, there is a risk of systemic side effects. All clinical guidelines stress the importance of ensuring that the lowest effective dose of inhaled corticosteroids is used.
2. The systemic side effects of corticosteroids are well known. High doses of inhaled corticosteroids are associated with clinically detectable adrenal suppression (*Arch Intern Med* 1999;159:941-55), increased risk of non fatal pneumonia in patients with COPD (*Arch Intern Med* 2009;169:219-29), increased risk of type II diabetes (*Am J Med* 2010;123:1001-6), and may increase the risk of fractures (*Thorax* 2011;66:699-708). It is strongly recommended that all patients on higher doses of ICS (>1000 micrograms Beclometasone dipropionate (BDP) equivalent per day, or Step 4 or above of BTS/SIGN Asthma guidelines) should be made aware of the potential risks and given an inhaled corticosteroid safety warning card about adrenal suppression.
3. Patients taking nasal corticosteroids in addition to inhaled corticosteroids should be assessed for their potential total daily dose of corticosteroid. For those patients on doses of inhaled corticosteroids between 800-1000 micrograms of BDP equivalent per day, a corticosteroid safety card is recommended, especially if additional corticosteroids are taken.
4. Clinical trials of combination therapy in COPD show that both **Symbicort 400 1 inhalation twice a day** (*Eur Respir J* 2003;22:912-19, *Eur Respir J* 2003;21:74-81) and **Seretide 500 Accuhaler 1 inhalation twice a day** (*N Engl J Med* 2007;356:775-89, *Am J Respir Crit Care Med* 2008;177:19-26) (Seretide 250 evohaler is not licensed for use in COPD) are equally effective in reducing the frequency of exacerbations and statistical improvements in quality of life in those with severe or very severe COPD and who have 2 or more exacerbations a year. However, the recommended BDP equivalent dose of Seretide is more than twice that of Symbicort. This may have an effect on the long term risk of corticosteroid side effects. The choice of which to use should be discussed with your patient.
5. At equipotent doses, there is no difference in the safety profile of different inhaled corticosteroids. Budesonide and ciclesonide are roughly equipotent to BDP. Fluticasone, mometasone and the newer ultrafine particle BDP HFA inhalers (QVAR and Fostair) are roughly twice as potent as standard BDP inhalers – see the BDP dose equivalence chart.

Before increasing the dose of inhaled corticosteroid:

6. Check inhaler technique. Poor inhaler technique, especially with aerosol inhalers is very common, and will contribute to treatment failure. Improving delivery of ICS to the lungs may be more effective than increasing the dose. Thus it is imperative that inhaler technique is checked at all times and appropriate changes made. All ICS MDIs (other than the newer ultrafine Beclometasone-HFA) should be used, and use taught, with a spacer (Volumatic or Aerochamber). The use of a large volume spacer may double drug delivery to the lungs (*Br J Clin Pharmacol* 1998;46:45-8, *Clin Pharmacokinet* 2004;43:349-60). It is important to prescribe a spacer that is compatible with the MDI device.
7. Although it is recommended in clinical asthma guidelines, there is limited evidence that increasing the dose of inhaled corticosteroid over 800 micrograms BDP equivalent/day is effective in improving asthma control. Even in acute exacerbations, there is little evidence that doubling the dose of inhaled corticosteroid is effective as self management (*Cochrane Review CD007524*). In asthma, add on therapy with long acting beta agonists should be tried before increasing the dose of inhaled corticosteroid above 800 micrograms BDP equivalent/day (step 3 of BTS/SIGN Asthma Guidelines).
8. MHRA guidance on the prescribing of fluticasone states that because of the risk of systemic side effects, doses between 250-500 micrograms twice daily should only be prescribed for moderate to severe asthma. Doses above this level should only be prescribed by a specialist in asthma (consultant or GP) where additional benefit is expected or demonstrated, or by the ability to reduce oral corticosteroid use.
9. Where there is dose equivalence, consider prescribing the lowest cost inhaler that the patient can use effectively and if prescribing an MDI, prescribe with a spacer if appropriate. Overleaf is a list comparing the costs of each inhaler per month at commonly used dosages.
10. Once a patient has achieved good asthma control on higher doses of inhaled corticosteroid for a period of time (e.g 3 months), consider stepping down the dose of inhaled corticosteroid by 25%.

When should you give an inhaled corticosteroid card?

Inhaled corticosteroids < 800 micrograms (BDP Equivalent)/day

Steroid	Proprietary	Dose/inhalation	Daily dose used	Cost/month
Beclometasone (BDP)	Asmabec, Clenil	50	2 twice a day	£ £
Beclometasone (BDP)	Asmabec, Pulvinal EasyHaler-BDP, Becodisk, Clenil	100	2 twice a day	£ £ £ £ (refill) £
Beclometasone HFA	Qvar	50	2 twice a day	£
Budesonide	Pulmicort 100, Easyhaler-BD	100	2 twice a day	£ £
Fluticasone	Flixotide 50 Accuhaler, Flixotide 50 Evohaler	50	1-2 twice a day 1-2 twice a day	£-££ £
Fluticasone	Flixotide 100 Accuhaler	100	1 twice a day	£
Fluticasone	Flixotide 125 Evohaler	125	1 twice a day	££
Ciclesonide	Alvesco	80	1-4 a day	£-£££
Mometasone	Asmanex	200	1 once a day	££
Beclometasone HFA/Formoterol	Fostair	100/6	1 twice a day	££
Budesonide/Formoterol	Symbicort 100	100/6	2 twice a day	£££
Budesonide/Formoterol	Symbicort 200	200/6	1 twice a day*	££
Fluticasone/Salmeterol	Seretide 50 Evohaler	50/25	2 twice a day	££
Fluticasone/Salmeterol	Seretide 100 Accuhaler	100/50	1-2 twice a day	££

CORTICOSTEROID SAFETY CARD NOT REQUIRED

Inhaled corticosteroids 800-1000 micrograms (BDP equivalent)/day

Steroid	Proprietary	Dose/inhalation	Daily dose used	Cost/month
Beclometasone (BDP)	Clenil	200	2 twice a day	£
Beclometasone (BDP)	Pulvinal, EasyHaler-BDP, Becodisk	200	1 twice a day	££ ££ £££ (refill)
Beclometasone HFA	Qvar	100	2 twice a day	££
Budesonide	Pulmicort 200, Easyhaler-BD, Budelin	200	2 twice a day	££ ££ ££ (refill)
Budesonide	Pulmicort 400, EasyHaler-BD	400	1 twice a day	££ ££
Fluticasone	Flixotide 100 Accuhaler	100	2 twice a day	££
Fluticasone	Flixotide 125 Evohaler	125	2 twice daily	£££
Fluticasone	Flixotide 250 Accuhaler Flixotide 250 Evohaler	250	1 twice daily	£££
Ciclesonide	Alvesco	160	2-3 once a day	££-£££
Mometasone	Asmanex	200	2 once a day	£££
Mometasone	Asmanex	400	1 once a day	££-£££
Beclometasone HFA/Formoterol	Fostair	100/6	2 twice a day	£££
Budesonide/Formoterol	Symbicort 200	200/6	2 twice a day*	£££
Budesonide/Formoterol	Symbicort 400	400/12	1 twice a day**	££££
Fluticasone/Salmeterol	Seretide 125 Evohaler	125/25	2 twice a day	££££
Fluticasone/Salmeterol	Seretide 250 Accuhaler	250/50	1 twice a day	££££

CORTICOSTEROID SAFETY CARD RECOMMENDED
(Especially if additional corticosteroids taken)

Inhaled corticosteroids >1000 micrograms (BDP equivalent)/day

Steroid	Proprietary	Dose/inhalation	Daily dose used	Cost/month
Beclometasone	Asmabec, Clenil	250	2-4 twice a day	££-£££ £-££
Beclometasone	Pulvinal, EasyHaler-BDP, Becodisk	400	2 twice a day	£££ £££ ££££ (refill)
Beclometasone HFA	Qvar	100	3-4 twice a day	££
Budesonide	Pulmicort 200, Easyhaler-BD, Budelin	200	3-4 twice a day	£££ ££ ££-£££ (refill)
Budesonide	Pulmicort 400, EasyHaler-BD	400	2 twice a day	££££ £££
Fluticasone	Flixotide 250 Evohaler	250	2 twice a day	££££
Fluticasone	Flixotide 500 Accuhaler	500	1 twice a day	££££
Ciclesonide	Alvesco	160	2 twice a day	££££
Mometasone	Asmanex	200	2 twice a day	££££
Mometasone	Asmanex	400	1 twice a day	££££
Budesonide/Formoterol	Symbicort 200***	200/6	3-4 twice a day*	£££££
Budesonide/Formoterol	Symbicort 400***	400/12	2 twice a day**	£££££
Fluticasone/Salmeterol	Seretide 250 Evohaler	250/25	2 twice a day	£££££
Fluticasone/Salmeterol	Seretide 500 Accuhaler***	500/50	1 twice a day	££££

CORTICOSTEROID SAFETY CARD REQUIRED

Approximate costs (April 2012): £ = <£10 ££ = £10-20 £££ = £20-30 ££££ = £30-40 £££££ = £40+

* Symbicort 200 is licensed for use as maintenance and relief therapy (SMART), and as adjustable maintenance dosing. The daily dose may vary between 1 inhalation twice a day, up to a maximum of 8 a day, but in studies, the average daily dose was 3 inhalations a day.

** Maximum recommended dose of Symbicort 400 2 twice a day is for asthma only, for COPD, dose is 1 twice a day.

*** Only Symbicort 200/400 and Seretide 500 Accuhaler are licensed for use in COPD. Any other combination inhaler does not currently have licence for COPD.

Inhaled Corticosteroid Safety Information for Adults

Inhaled corticosteroid agents are very important in the treatment of respiratory conditions such as asthma and sometimes, chronic obstructive pulmonary disease (COPD). They act by reducing inflammation and preventing symptoms from developing. Corticosteroid sprays are also used for nasal conditions such as sinusitis and hayfever. Generally, they are very safe and free from serious side effects when used in standard doses.

Inhaled corticosteroids can cause local side effects such as sore throat, hoarse voice or oral thrush (sore white patches in the mouth). The risk of these side effects may be reduced by using a spacer device with aerosol inhalers (MDI's) that contain corticosteroids, and rinsing your mouth out with water (and spitting out) after using any corticosteroid inhaler. Prolonged use of inhaled corticosteroids may lead to easy bruising or thinning of the skin, especially in older people. Very rarely, higher doses of inhaled corticosteroids may temporarily reduce your body's ability to produce its own corticosteroids when under stress, such as in severe illness or undergoing surgery, or to fight off some infections (e.g. chickenpox).

You have been given this information and the attached safety card because you have been prescribed a higher dose of inhaled corticosteroid.

It is important that you do NOT stop using your inhaled corticosteroid medications suddenly if you have been taking this medication for more than 3 weeks.

Be sure to get your repeat prescription of your inhaler before it runs out.

If you become ill for any reason, be sure to alert the medical staff looking after you that you are using higher doses of inhaled corticosteroid as you may need additional corticosteroids. Ideally, carry the safety card attached to this information sheet with you at all times and show this to your medical team. Recorded on the safety card opposite are any inhaled and nasal corticosteroids that you should currently be taking.

If you start to experience any of these symptoms: worsening fatigue, muscle weakness, loss of appetite, unintentional weight loss, dizziness, unexplained nausea, vomiting and diarrhoea), go and see your general practitioner (GP), because they might be related to the inhaled corticosteroid you are taking. Do not stop taking your inhaled corticosteroid suddenly. If you have never had chickenpox, you should avoid close contact with people who have chickenpox or shingles. If you do come into contact with someone with these conditions, see your doctor urgently.

To be completed by medical practitioner

High Dose Inhaled Corticosteroid Safety Card

Name: DOB:

I am currently taking: 1. Since:
2. Since:

My normal dose is: 1. puffs times a day
2. puffs times a day

If MDI – using Spacer? Yes No

I may be at risk of corticosteroid insufficiency when I am ill and supplementation should be considered.

Consultant/GP: Contact No:

Please peel off card

Flu vaccination protects you, your family and your patients – still time to make a difference

Introduction

Receiving a flu vaccination protects you, your family and your patients - there's still time to make a difference if you've not had a flu jab this winter. This paper aims to explain the benefits for you and your patients and asks you to commit now to getting a flu jab.

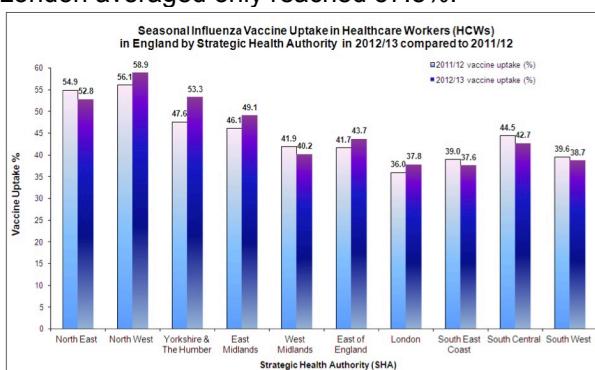
What are the facts: death, admission and vaccination rates?

In 2010-11 in the UK, 602 people died from flu and in the same year nearly 9000 patients were admitted to hospital in England with flu. 2200 required admission to intensive care. There were fewer deaths and admissions in the 2012-13 season, but flu remains unpredictable and it is hard to forecast the severity or timing.

Young children, older people and those with long term medical conditions have a higher risk of death or serious illness if they catch flu and these groups are targeted by national vaccination programmes. Despite this by 12 December 2013 national vaccination rates of patients were only:

- 38.2% in all 2 year olds
- 35.2% in all 3 year olds
- 47.3% in under 65 years in a clinical risk group
- 36.8% in all pregnant women
- 70.0% in 65+ year olds

By 31 October 2013 vaccination rates of frontline workers were 21.7% across London trusts compared to the best performing region of 42.2% in the North of England Region. Last year vaccination rates for NHS frontline workers in London averaged only reached 37.8%.



Organisation 2012-13 London data	PCT CCGs	Acute Trusts	Mental Health Trusts	London Ambulance Service
Vaccination rates %	8-67.5%	20.1-59.4%	12.3-37.2%	26.8%

Why does it matter?

- Flu vaccination of staff has been shown to reduce mortality in patients in residential care.ⁱⁱ
- Immunisation of patients with COPD reduces hospital admission.ⁱⁱⁱ
- It protects people from acute MI.^{iv}

For a vaccination program to work there needs to be sufficient coverage to produce herd immunity so that transmission rates are low enough to protect those who are vulnerable but who have not been vaccinated.

What should you do?

- You can support your patients to get vaccinated - and should be a role model for this.
- You can protect those who aren't vaccinated by not passing flu on to them. Up to 1 in 4 healthcare workers may become infected with flu during a mild flu season, a much higher incidence than expected in the general population.^{v vi} Half of these will not be ill with it and therefore will continue to work with patients. Therefore healthcare workers are an important vector of transmission; particularly healthcare workers supporting people with heightened risk from flu such as those with chronic respiratory problems.
- You can protect your family - vaccination reduces the risk of taking flu contracted at work home to your family.

Despite little evidence of disbenefits and substantial evidence for benefits, the average vaccination rate for NHS frontline staff in London was only 37.8% last year. Although an improvement on previous years it is still less than half and falls well short of the 80% of the healthy population needed to achieve to "herd immunity".^{vii}

This average also hides considerable variation between trusts and between professions. Typically AHPs are the most concordant; doctors next and nurses the least.^{viii} Yet the staff with potentially the most contact time with patients at risk from flu are nurses.

Seasonal Influenza Vaccine Uptake amongst Frontline Healthcare Workers (HCWs) in London SHA Winter season 2012/13: doses given (%)			
All Drs inc GPs	All Qualified Nurses (including GP Practice Nurses)	All other qualified clinical staff	Support staff
35.9	32.3	37.7	47.8

For example, figures from last year's flu surveillance by the London School of Hygiene and Tropical Medicine show that in the general population these groups were more likely to report flu-like symptoms:^{ix}

- Women were 18% more likely than men
- Smokers were 12% more likely than non-smokers
- People who have sustained contact with children were 17% more likely

This fits most closely to the profile of nurses and care workers. And these are the staff groups who have a lot of contact with at risk patients.

Flu vaccination protects you, your family and your patients – still time to make a difference

The fact that some professions can reach a high level suggests that whilst it is partly due to access to vaccination it is also about beliefs and behaviours. A recent Twitter campaign #WeNurses achieved 1,500 tweets from 160 accounts, making 2.7 million impressions and concluded the three barriers to uptake amongst hospital nurses were:

- Misconceptions and common myths
- Unavailability of flu jabs during work hours
- Having access to the vaccine in the ward or department

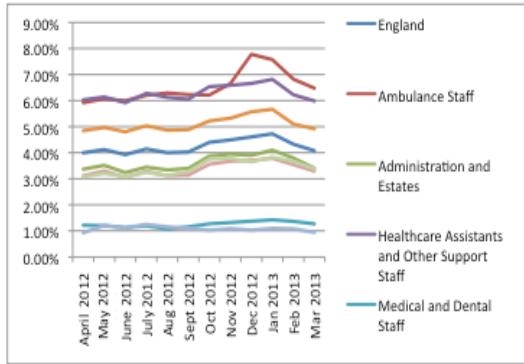
The good news is that they have identified successful strategies to combat these problems:

- Peer to peer vaccination
- Using clinical evidence and myth-busters such as flu facts, vaccination information and flu FAQs
- Drop-in and roaming clinics throughout the trust

Indirect benefits to patients

As well as protecting patients directly, we also know that this year patients might be harmed indirectly by performance pay for trusts: unless 75% of staff are vaccinated “winter pressures” money may not be released.

Staff absence will also be affected. London has the lowest rates of staff absence in the country but the rates increase in December and January (3.78% and 3.9% respectively compared to 3.31% in March 2013) and the groups with the lowest flu vaccination rates are those more likely to be off sick: ambulance workers, healthcare assistants and nurses.^x



What should you do?

If you are a respiratory clinician, get a flu jab, help your patients and tell them that you have had a flu jab, collect real time data to share using Flu Fighters or another tool and encourage your colleagues too.

Flu fighting is a team game with a result that matters. For more help:

Practical support from Flu Fighters
[@NHSFlufighter #flufighter](http://www.NHSFlufighter.com)
<http://www.nhsemployers.org/HealthyWorkplaces/StaffFluVaccination/Pages/seasonal-flu-campaign.aspx>

Letter from Sally Davies and Bruce Keogh to doctors summarising the evidence and referring to Good Medical Practice:

<http://www.nhsemployers.org/SiteCollectionDocuments/Staff%20flu%20letter%20for%20Doctors.pdf>

Letter from Jane Cummings to nurses and midwives:

<http://www.nhsemployers.org/SiteCollectionDocuments/Flu%20vaccination%20letter%20for%20nurses%20and%20midwives.pdf>

Letter from Karen Middleton to AHPs:

<http://www.nhsemployers.org/SiteCollectionDocuments/Flu%20vaccination%20letter%20for%20AHPs.pdf>

Nick S Hopkinson, NIHR Biomedical Research Unit at Royal Brompton and Harefield NHS Foundation Trust and Imperial College London, Siân Williams

for the London Respiratory Clinical Leadership Group

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All Party Parliamentary Group on Respiratory Health: inquiry into respiratory deaths

Written submission from Medical Directorate, NHS England

Context

Asthma UK and the British Lung Foundation (BLF) are working together to support the All Party Parliamentary Group on Respiratory Health (formerly the APPG on Asthma). As its first activity, the APPG is conducting an inquiry into why so many people are still dying from respiratory disease.

The Group is keen to engage with relevant stakeholders to understand the circumstances surrounding respiratory deaths and to identify:

- where the system is failing;
- what the barriers to good practice are; and
- what policy changes are needed to reduce respiratory deaths.

The inquiry is focussing on chronic obstructive pulmonary disease (COPD) and asthma.

NHS England's roles and responsibilities

NHS England's goal is high quality care for all, now and for future generations, and we have a dual role in helping to ensure this goal is achieved.

We are a direct commissioner of healthcare services including primary care, specialised services, secondary care dental services, some public health services, offender health and armed forces health. We are here also to provide leadership and support to CCGs as commissioners of secondary and community healthcare services. Improving outcomes for people with or at risk of respiratory diseases like COPD and asthma will be achieved through actions in each of these roles.

In our role as a direct commissioner of services, we will:

- Drive the prevention and earlier diagnosis of respiratory diseases
- Support better management of respiratory disease in primary care

We will also provide leadership and support to CCGs as commissioners of secondary and community services to deliver high-quality care, as defined by the National Institute for Health and Care Excellence (NICE)¹, to people with and at risk of respiratory disease.

¹ Relevant in this particular instance are the Quality Standards for COPD and for asthma, and the associated clinical guidelines.

What is NHS England doing to reduce premature mortality from COPD and asthma?

The strategic direction for NHS England is set in the [Mandate](#) from the Government. The Mandate gives NHS England a clear objective to demonstrate progress against the indicators in the NHS Outcomes Framework. In Domain 1, reducing premature mortality, the Mandate sets the objective for NHS England, working with CCGs, to develop their contribution to the new system-wide ambition of avoiding an additional 30,000 premature deaths per year by 2020. ‘Under 75 mortality rate from respiratory disease’ is one of the key indicators in Domain 1 of the NHS Outcomes Framework against which NHS England is required to demonstrate progress.

Through our role as a direct commissioner of primary care, we will drive prevention, earlier diagnosis and appropriate management, to fulfil the Mandate objective to reduce the under 75 mortality rate from respiratory disease

Over the next few years, we will continue to develop the GP contract and incentives to help identify those at risk, earlier diagnosis and incentivising active management of risk factors identified.

NHS Improving Quality and its partners are working in collaboration with commissioners and providers of primary care services in England to develop and spread the use of innovative case-finding and audit tools in general practice to support earlier diagnosis and better management of a range of conditions including COPD.

We are, since April 2013, the sole commissioner of primary care services in England. We have produced single operating models for all directly commissioned services,ⁱ including primary care,ⁱⁱ to ensure there is consistency across the whole of England, with the ambition to reduce inequalities and provide better outcomes for patients. There will be a clinically-driven focus on improving outcomes for people with long-term conditions, including COPD and asthma. Commissioning of primary care will support responsive access to general practice, and systems to enable timely specialist advice where needed.

We are developing a strategic framework for commissioning primary care, including general practice, community pharmacy, primary care dentistry and optometry services. The strategic framework for commissioning of general practice services will be published in 2014 and will set out the action we are taking at national level to support commissioners in developing joint strategies for primary care as part of their five year strategic plans. In the development of all the frameworks, we are considering how best to enable primary care contractors (general practice, community pharmacy, primary care dentistry and optometry services) to provide high quality services for patients, in particular those with long-term conditions including COPD and asthma.

We will continue to encourage the best care and management for people with COPD and/or asthma through the Quality and Outcomes Framework (QOF) payment mechanism to GP practices. In 2014/15, there will be 4 asthma indicators, 6 COPD

indicators and 4 smoking indicators (including an indicators on recording status and offering support and treatment to smokers with COPD and/or asthma).

We published the Risk Profiling and Care Management Enhanced Service specification for GPs at the beginning of 2013.ⁱⁱⁱ The Service encourages GP practices to identify their patient cohort who are most at risk of admission to hospital, using a multi-disciplined approach to work with health and social care professionals to deliver an enhanced care package for these patients. The multi-disciplinary teams identify how these patients are best supported and who is best placed to deliver support, and also help patients to improve self-management of their condition/s to reduce hospital admission. People with respiratory diseases who have an increased risk of hospital admission will be supported by this programme.

We are committed to making available to the public the information that the health care system uses to understand how well it is performing or that patients need to make decisions. In December 2013, NHS England published an additional 40 general practice level indicators on the NHS Choices website in a new accountability area designed to provide information to people who want to get involved in conversations about their local health services.^{iv} NHS Choices and NHS England will work with HealthWatch and other stakeholders to further develop the content and presentation of this information to ensure it is as relevant and usable as possible. The new items are presented alongside those that were already published and available on NHS Choices. Of the 40 new indicators, the following are relevant to respiratory disease:

- COPD diagnosis: percentage of people with COPD with diagnosis confirmed through spirometry
- Asthma diagnosis: percentage of people with asthma aged 8 and over diagnosed with measures of variability or reversibility
- Flu vaccination for older people: percentage of people aged over 65 who have had a seasonal flu vaccination
- Flu vaccination for at risk groups: percentage of people aged between 6 months and 65 years in clinical risk groups that receive the seasonal flu vaccination
- Smoking status: percentage of patients who smoking status has been recorded in the last 27 months
- Smoking cessation advice: percentage of patients in at-risk groups who have been offered smoking cessation advice

NHS England also provides the primary care web tool to assist GP practices and CCGs in comparing practices for the purpose of performance improvement.^v This information is practice-specific and every practice, CCG and Area Team in England has sight of their own and everyone else's data.

We will also work with and support CCGs, as commissioners of secondary and community care, to fulfil the Mandate objective to reducing the under 75 mortality rate from respiratory disease

To support delivery of the objective in the Mandate to demonstrate progress against the indicators in the NHS Outcomes Framework, NHS England has asked, through the [planning guidance](#), for CCGs to set individual levels of ambition across the five

domains of the Framework. The areas where they will be setting levels of ambition are:

- Securing additional years of life for the people of England with treatable mental and physical health conditions (Domain 1)
- Improving the health related quality of life of the 15 million+ people with one or more long-term condition, including mental health conditions (Domain 2)
- Reducing the amount of time people spend avoidably in hospital through better and more integrated care in the community, outside of hospital (Domain 3)
- Increasing the proportion of older people living independently at home following discharge from hospital (Domain 3)
- Increasing the number of people having a positive experience of hospital care (Domain 4)
- Increasing the number of people with mental and physical health conditions having a positive experience of care outside hospital, in general practice and in the community (Domain 4)
- Making significant progress towards eliminating avoidable deaths in our hospitals caused by problems in care (Domain 5)

To help CCGs in setting and delivering their level of ambition on securing additional years of life for people with treatable mental and physical health conditions, we have published a [resource](#) on the high-impact interventions that they could commission to do so. This resource currently has sections on the treatment of community-acquired pneumonia in hospital and the treatment and management of COPD. We will be continuing to update the resource over the next few months, with the National Clinical Director, and would welcome input from the findings of the APPG's inquiry in developing the respiratory section.

The Outcomes Strategy for COPD and Asthma remains a live document and the Companion Document to that Strategy clearly sets out the actions that are needed to support improved outcomes in both COPD and asthma, including reducing premature mortality. The Strategy and Companion Document are referenced and linked to in the reducing premature mortality resource for CCGs.

We will also work with partners to improve prevention

We are working with the Department of Health and Public Health England on the development of a pilot public awareness campaign on breathlessness, which aims to help drive up the early identification of respiratory and cardiac conditions. The pilot will be in Oldham and Rochester, launching 24 February and running to 23 March. If successful the campaign will be rolled out across a TV region 2014/15, and we will make an assessment after that about whether a national campaign in 2015/16 is appropriate.

We welcome the Department of Health looking again at the evidence on tobacco packaging, and await the decision from Government in March. Smoking is the main cause of respiratory disease, and we would support any initiatives that would contribute to a reduction in the number of smokers, and of young people taking up smoking in the first place.

How is quality of care and outcomes assured in new NHS?

CCGs and NHS England are under a statutory duty to continuously improve quality across the comprehensive service. CCGs and NHS England in their respective commissioning roles are accountable for meeting this duty.

NHS England is held to account for improving outcomes by the Secretary of State, supported by the NHS Outcomes Framework, which sets out the outcomes that matter to people using NHS services. In addition to securing an improvement in outcomes through our own direct commissioning, NHS England is also responsible for ensuring that CCGs meet this core statutory duty. The [CCG Assurance Framework](#) sets out the basis for this assessment.

Integral to the assurance assessment is a discussion, based on a comprehensive delivery dashboard, of CCG delivery of the improved outcomes which they have planned to deliver. Where CCGs are found to be at risk of failing to deliver these improvements, NHS England, through area teams, will support CCGs to make the required improvements, with statutory intervention powers remaining a last resort where CCGs demonstrably lack the capacity to make these improvements.

In addition to the assurance delivery dashboard, NHS England has developed [CCG Outcomes Indicator Set \(CCG OIS\)](#) which can be used by CCGs as a tool to understand trends in outcomes and to help them identify potential priorities for improvement. The CCG OIS is supportive of the NHS Outcomes Framework and is an important piece of additional insight to inform the assurance assessment.

Indicators specific to respiratory care in the CCG OIS include:

- Under 75 mortality from respiratory disease
- People with COPD & Medical Research Council Dyspnoea scale ≤3 referred to a pulmonary rehabilitation programme
- Emergency admissions for children with lower respiratory tract infections

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- i <http://www.england.nhs.uk/ourwork/d-com/>
 - ii <http://www.england.nhs.uk/wp-content/uploads/2012/06/ex-comm-pc.pdf>
 - iii <http://www.england.nhs.uk/wp-content/uploads/2013/03/ess-risk-profiling.pdf>
 - iv <http://www.nhs.uk/Service-Search/Accountability>
 - v <https://www.primarycare.nhs.uk/>



Royal College of
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17 January 2014

Introduction

1. We welcome the opportunity to contribute to this Inquiry. The Royal College of General Practitioners (RCGP) is the largest membership organisation in the United Kingdom solely for GPs. Founded in 1952, it has over 49,000 members who are committed to improving patient care, developing their own skills and promoting general practice as a discipline. We are an independent professional body with enormous expertise in patient-centred generalist clinical care.

Background

2. The extent of the problem regarding respiratory deaths is clearly laid out in two key publications from the Department Health – (i) “Consultation for a Strategy for COPD Services in England” (Feb 2010); (ii) “An outcomes Strategy for COPD and Asthma in England” (2011).
3. The key features arising are:
 - UK has the second highest death rate from respiratory disease in Europe but could reduce deaths by 2,000 per year if the UK achieves the EU average and by 8,000 if the lowest rates of death in Europe were achieved.
 - The rate of deaths from COPD in 2008 were twice that of the European average and for asthma 1.5 times the average (WHO).
 - There is evidence of disparity in death rates across the UK from repeated surveys.
 - 33% of patients admitted to hospital with an exacerbation of COPD will be readmitted and 15% will die within 3 months.
4. Key recommendations for the improvement of asthma and COPD care in England have been made in the Outcomes Strategy for COPD and Asthma in England 2011 and also in the NICE Quality Standard for COPD 2011(based on the NICE COPD Guideline 2010) and NICE Quality Standard for Asthma 2013 (based on NICE COPD Guideline 2010).

5. While evidence was called for COPD and asthma deaths, in our view the Group should consider extending this remit to include respiratory deaths such as deaths from lung cancer. Five year survival rates are low in the UK at 6.5% compared to 9.3% in Norway and 11.3% in Sweden. We would like to see a greater awareness of the presenting symptoms of lung cancer by patients, and a correspondingly greater awareness by GPs, particularly when dealing with high risk groups such as patients with COPD/IHD see "Lost Lives", British Lung Foundation 2013). The RCGP continues to provide support to GPs by the provision of learning resources to assist in their care of patients with respiratory disease (details are set out in paragraph 19 below).

Where the current system is failing: Asthma

6. The National Review of Asthma Deaths (under direction of the Royal College of Physicians) is due report early in 2014 and will give some indication where the system might be failing.
7. The Confidential Enquiry into Asthma deaths in the Eastern Region (Harrison et al PCRJ 2005) showed the following factors to be contributory:
 - Inappropriate routine drug management
 - Inappropriate acute management
 - Poor written evidence of self management plans or education.
 - Complex patient psychosocial problems including poor compliance
8. Similar factors were noted in the children's enquiry (PCRJ 2012) with the added factor of use on long-acting beta₂ agonist without inhaled corticosteroid.
9. "Compare your care" published by Asthma UK in 2013 surveyed patients with asthma, showing that only 14% patients reported receiving care in line with NICE asthma standards. There is a need for improved discharge planning by hospitals, including the provision of written action plans. Also there should be better communication between secondary and primary care around the time of discharge to allow primary care follow up of patients discharged from hospital within 2 working days, in line with the NICE asthma standard.
10. There is widespread evidence of poor concordance with inhaled corticosteroid medication.
11. For asthma therefore key factors associated with continuing asthma deaths are:
 - Failure for health professionals to follow NICE asthma standards/BTS/SIGN guidelines in particular around management of the acute attack
 - Failure to provide self management plans
 - Failure to follow up after an acute attack
12. In spite of the strong evidence that asthma self management plans and education can reduce the rate of hospital admission (Cochrane review 2002) and the lack of provision of written self-management plans has been highlighted in the asthma death enquiries above, advice to include the provision of self-management plans into QOF has been rejected by the NICE QOF Committee. This decision could be revisited.

Where the current system is failing: COPD

13. Although there has not been a formal enquiry into COPD deaths several publications have highlighted problems associated with poor COPD outcomes. These are the Consultation Document on the National COPD and Asthma Strategy (2010) and COPD and Asthma Outcomes Framework (2011) and the national COPD Audit (Royal College of Physicians 2008).
14. This shows problems to be :
 - Lack of awareness of COPD in the general population leading to late presentation
 - Continuing tobacco smoking
 - Mis-diagnosis of COPD associated with poor spirometry standards
 - Poor adherence to NICE pharmacotherapy Guidelines (e.g. Price et al in press)
 - Inadequate provision and uptake of pulmonary rehabilitation
 - Inadequate provision of self-management plans and education, including standby antibiotics and oral steroids and the use of care planning
 - In particular studies of patients surrounding their discharge from hospital after an acute attack of COPD (Gruffydd-Jones et al PCRJ 2007 and "Ready for Home" British Lung Foundation 2010) show many patients feel ill prepared for discharge, feel isolated on arrival home, with inadequate communication between secondary and primary care and poor follow up procedures. There is also a relative lack of a "whole systems approach" to COPD management. COPD is not just a disease of the lungs but has multiple medical and psychosocial co-morbidities. This multi-system approach is often neglected in secondary care which continues to operate in disease-specific silos.

Other important barriers

15. Apparent down-grading of the importance of respiratory disease at a national level.
 - The very effective DoH respiratory team has been dissolved leaving a lead respiratory physician with minimal administrative back up.
 - Key messages of the COPD and Outcomes Strategy and Framework may have become diluted by being subsumed into the greater long term condition strategy.
 - There is no dedicated respiratory clinical network.
 - Diminished prioritisation of respiratory care at a central level translates into a downgrading of respiratory care as a priority at local level (e.g. through health improvement funding).
16. Under-investment in general practice
 - At a time when the UK's population is both expanding and ageing, the share of NHS resources spent on general practice has been shrinking in recent years. In order to achieve better outcomes for patients in the area of respiratory health, we need to reverse this decline in investment and focus much greater resources on delivering high quality care in the community.
 - The [Put patients first: Back general practice](#) campaign, launched in November 2013 by the RCGP in partnership with the National Association of Patient Participation, has been highlighting the urgent need to address under-investment in primary care. The campaign has been making the following key points:

- Around the country in GP surgeries ballooning workloads, the increasing complexity of delivering care to an ageing population and diminishing resources threaten to overwhelm the system with disastrous consequences for patients and the NHS as a whole.
- At the launch of the campaign RCGP revealed new research highlighting the shrinking share of NHS resources being allocated to general practice – currently down to 8.5% in England compared to much closer to 11% in 2005/06. This seems to run counter to many of the Government's aspirations to deliver more care closer to home.
- General practice is facing a real terms funding shortfall of £405 million compared to three years ago. Figures compiled by the RCGP reveal successive underinvestment in general practice – with the amount spent in general practice per person in England dropping by 7% in real terms between 2010 and 2013, due to a combination of funding cuts and population growth.
- Patients deserve much better than this. A relatively small increase in the share of NHS funding spent in general practice in England - from 8.5% to 11% - would transform care for patients and benefit the NHS as a whole by alleviating pressure on our hospitals and providing cost effective care closer to home. It will also enable GPs to provide improved continuity of care to vulnerable elderly people, helping the NHS to better meet the needs of the growing number of patients living with multiple long term conditions.

17. Changes which could improve the system to reduce respiratory deaths

- Greater commitment to respiratory disease by government, e.g. restore the very successful DOH respiratory team.
- Continued Government support to cut down smoking e.g. increasing tobacco duty above the rate of inflation.
- The need for government to introduce plain packaging for tobacco products (an issue the RCGP, as a member of the Smokefree Action Coalition strongly supports).
- Continue health education for patients and health professionals
- Give greater incentives for health professionals and commissioners to follow NICE COPD and Asthma Quality Standards and also to follow national treatment guidelines.
- Better education of health professionals and patients about what these standards of care involve.
- Greater recognition of the importance of primary care in delivering the care of patients with multimorbidity by: (i) improved funding to care for people in the community; (ii) improved integration with social care.
- But there is also recognition that, whilst there is a need to deal with the multimorbidity nature of people's diseases, specialist support needs to be provided (and not necessarily in hospitals).

18. Specific actions to improve the situation

- Action to tackle recent under-investment in general practice, bringing the share of the NHS budget spent on general practice up to 11% by 2017.
 - Incentivise the provision of self management education including action plans in COPD and especially asthma (e.g. through QOF): care planning is central to this.
 - Prioritise research into risk stratification / management of patients with COPD and asthma.
 - Consider pilot projects where there is a whole systems approach to asthma /COPD care as in Finland (Haahtela et al "Thorax 2006").
 - Renewed Government campaign to highlight the early signs of lung cancer, including education of primary health care professionals.
19. The RCGP has produced a number of resources to assist GPs and fellow healthcare professionals to support their care of patients with respiratory disease. These include the following and can be accessed via the RCGP website:
<http://www.rcgp.org.uk/clinical-and-research/clinical-resources/respiratory-care.aspx>
- RCGP Care Planning Report of 2011:
<http://www.rcgp.org.uk/clinical-and-research/clinical-resources/~/media/Files/CIRC/Cancer/Improving%20the%20Lives%20of%20people%20with%20LTC%20-%202012%2005%2009.ashx>
 - Managing multi-morbidity in practice: this RCGP Clinical Innovation and Research Centre (CIRC) publication aims to find out how general practice has risen to the challenge of organising chronic care of patients with multi-morbidity, using Chronic Obstructive Pulmonary Disorder (COPD) and its co-morbidities as an exemplar.
 - National COPD Audit – this audit will collect data which maps the patient journey and variations in patient care, with one of the areas of focus being primary care. The audit commenced in 2013 and is being led by the Royal College of Physicians, in partnership with the British Thoracic Society, the British Lung Foundation and the Primary Care Respiratory Society. The RCGP, led by the Clinical Innovation and Research Centre (CIRC) is a key stakeholder in this audit.
 - The National Review of Asthma Deaths (NRAD) is collecting details of asthma deaths in hospital and in the community across the UK for a 12 month period, from 1 February 2012. The Royal College of Physicians is leading the NRAD which is commissioned by the Healthcare Quality Improvement Partnership (HQIP), and run in collaboration with professional and patient organisations.
 - RCGP e-Learning: Respiratory Health in Primary Care. This is a comprehensive e-learning course that provides primary care practitioners with an overview of the common respiratory problems seen in primary care. It explores the prevention, presentation, diagnosis, assessment and ongoing management of common respiratory disorders and the promotion of respiratory health.
 - Managing Acute Respiratory Tract Infections: this course enables GPs to improve the care they provide to patients presenting with acute ear pain, acute sore throats, sinusitis and acute cough. It explains why it is crucial for GPs to evaluate their everyday prescribing decisions and gives examples of methods that can be used to do this, as an individual and with a practice, and encourages GPs to identify barriers to change. It also reviews the clinical knowledge, communication skills and tools needed to assess and treat patients most effectively.

Name:	Emily Arkell
Job Title:	Head of Policy
Organisation:	Royal College of Paediatrics and Child Health
Region/location:	The College is a UK organisation which comprises over 15,000 members who live in the UK, Ireland and abroad and plays a major role in postgraduate medical education, as well as professional standards. The College's responsibilities include: <ul style="list-style-type: none"> • setting syllabuses for postgraduate training in paediatrics • overseeing postgraduate training in paediatrics • running postgraduate examinations in paediatrics • organising courses and conferences on paediatrics • issuing guidance on paediatrics • conducting research on paediatrics
Capacity in which you are replying to the inquiry	On behalf of the RCPCH. We have focused our response on respiratory disease and asthma as this is where our expertise and knowledge in relation to the care and treatment of children and young people lies.

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

There is currently a lack of data about outcomes and expenditure in children with respiratory disease both to allow comparison between regions and to enable comparisons with other disease areas.

We would welcome more data about outcomes and investment in respiratory disease treatments, care and services for children and young people compared with other big killer diseases to ascertain whether it is on an equitable footing.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

There are a broad set of changes which could improve outcomes for respiratory conditions which include:

- Public policy interventions to reduce children's and young people's exposure to tobacco smoke. In particular we recommend introduction of plain packaging for tobacco products.
- Improvements in housing stock to reduce damp and overcrowding which can contribute to poor respiratory health.
- Interventions to improve diet and quality of nutrition which would help improve respiratory health.
- Measures to improve both air and environmental pollution.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

The National Review of Asthma Deaths (NRAD) will be published later this year. It is expected that the NRAD will outline some of the causes of asthma deaths in children and young people which could lead to policy interventions to reduce premature mortality.

Some of the main barriers to better respiratory health are outlined above in response to question 2. In particular, inadequate housing, exposure to tobacco smoke, lack of access to good diet, poor air quality and environmental pollution all act as barriers to better respiratory care for children and young people.

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

Premature babies and children who have complex disabilities, specifically neurodisabilities are at higher risk of respiratory disease. This may be because of factors such as an increasing trend to initiate resuscitation and treatment at an earlier gestational age and an increasing proportion of children with long-term respiratory and/or neurological impairment.

One important long-term consequence of prematurity is BPD or chronic lung disease of prematurity (CLD). It is one of the most important complications of prematurity with a reported incidence of 23% of infants born at 28 weeks, increasing to 73% of infants born at 23 weeks. It is characterised by prolonged respiratory support, compromised lung function and recurrent respiratory infection during the first year of life. Furthermore, BPD is considered an independent risk factor and is associated with neurodevelopmental impairment.

5. What can the Government and the NHS in England do to reduce respiratory deaths?

Information about how to reduce respiratory deaths in children and young people are outlined in our response to questions 6 & 7 below.

Asthma Questions:

1. What are the most important factors contributing to asthma deaths?

Asthma is the commonest chronic disease in childhood with one in 11 children in the UK currently receiving treatment for asthma¹. Children aged 6-7 in Western Europe report a prevalence of asthma at 9.7% but the UK reports figures between 10-20% and these may be even higher in the adolescent age group².

The NRAD will provide detailed information about factors contributing to asthma deaths and will help inform the inquiry by the All Party Parliamentary Group on Respiratory Health.

Studies have shown that the UK has a higher rate of asthma deaths compared to other European countries. It is estimated that the asthma death rate is 1.5 times higher than the European average, with figures not decreasing over the last 10 years³.

Lack of prevention of asthma attacks combined with inconsistent care and absence of care plans all contribute to asthma deaths. Asthma management should be tailored to the individual's requirements and based on severity, triggers and age. Most guidelines recommend that treatments are stepped-up progressively until disease control is attained and thereafter reductions are effected very slowly. There is evidence that asthma may be either under-treated as a consequence of inappropriate diagnosis or over-treated when the disease is infrequent, episodic or if cough occurs in isolation of wheezing.

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

The NRAD will provide further information and detail about factors which could increase some children and young people's risk of dying from asthma. Previous research studies have concluded that poor recognition of severity by both patients and healthcare professionals as well as under-treatment were avoidable factors.

Examples of other avoidable factors related to asthma deaths include: long term under-treatment of asthma, under-assessment of asthma severity, problems with routine management with a failure to follow guidelines and delays in referrals to specialists, failure in follow up of people after severe asthma attacks and lack of patient education. Previous studies have also shown that allergic factors such as pet ownership in children can increase the risk of death from asthma.

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

It is essential that all professionals are fully competent in delivering the care and treatment for children and young people with asthma. Professionals also need to adequately diagnose the symptoms and severity of asthma and be competent in referring to appropriate services.

¹Asthma UK. For journalists: key facts & statistics 2011 [cited 27 February 2011]; Available from: http://www.asthma.org.uk/news_media/media_resources/for_journalists_key.html.

² Lai CK, Beasley R, Crane J, Foliaki S, Shah J, Weiland S. Global variation in the prevalence and severity of asthma symptoms: phase three of the International Study of Asthma and Allergies in Childhood (ISAAC). Thorax. 2009 Jun;64(6):476-83.

³ Department of Health. *An outcomes strategy for people with chronic obstructive pulmonary disease (COPD) and asthma in England*. London: DH;2011

A quality standard for asthma was published by NICE in February 2013. The standard states that services should be commissioned from and coordinated across all relevant agencies encompassing the whole asthma care pathway. The standard includes 11 statements in total and one of the major challenges to the NHS will be ensuring that these are properly implemented and delivered within a networked approach to care delivery.

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

We know that Sweden has a very low mortality rate for children and young people diagnosed with asthma, in comparison to the prevalence rate. We'd recommend that further research is undertaken for the reasons behind this including both health and social care provision.

A National Asthma Programme was undertaken in Finland from 1994 to 2004 to improve asthma care and prevent an increase in costs⁴. The main goal was to lessen the burden of asthma to individuals and society.

The action programme focused on implementation of new knowledge, especially for primary care. The main premise underpinning the campaign was that asthma is an inflammatory disease and requires anti-inflammatory treatment from the outset. The key for implementation was an effective network of asthma-responsible professionals and development of a post hoc evaluation strategy. In 1997 Finnish pharmacies were included in the Pharmacy Programme and in 2002 a Childhood Asthma mini-Programme was launched.

The programme showed that although the incidence of asthma was still increasing, the burden of asthma has decreased considerably. The number of hospital days fell by 54% from 110,000 in 1993 to 51,000 in 2003, 69% in relation to the number of asthmatics, with the trend still downwards. The research showed that it was possible to reduce the morbidity of asthma and its impact on individuals as well as on society and that although improvements would have taken place without the programme, but not of this magnitude.

5. What can the Government in England do to reduce asthma deaths?

We recommend that each patient has a named clinician (such as a GP) who coordinates all information regarding the care the child or young person receives or requires.

The Government also plays a role in raising the priority as a healthcare issue of asthma in children and young people because a healthier child will go on to be a healthier adult in the future.

We also recommend more funding for research into effective asthma treatments and reducing risk factors with the aim of reducing deaths in children and young people.

⁴ Haahtela, t et al (2006) Thorax 2006;61:663-670

6. What can the NHS in England do to reduce asthma deaths?

We recommend that NHS England commission the development of a patient related outcome measure (PROM) to ascertain children and young people's experience of their treatment and care in episodes which require hospital admission.

We also recommend the development of an asthma passport for children to enable a more consistent response to a child in acute episodes. This would include information about the child's medication and key information that would help health professionals provide a quick, personalised and responsive service to patients.

7. Do you have any other comments relevant to this inquiry?

Current service delivery models focus on emergency presentations of asthma but often fails to manage the chronic long term care phases including the prevention of asthma attacks which have a serious impact on the child or young person and their family, particularly their quality of life.

Asthma has far-reaching consequences for a child's general health and well-being, including school attendance and performance, normal sporting and exercise activities. With this in mind, it is essential that there is initial recognition, as this is the first step on the ideal patient care journey. Health professional recognition and management should be supported by a number of evidence-based documents, which constitute core reference material for this pathway.

The CQC have recently undertaken a new set of themed inspections. We recommend that consideration should be given to calling for a themed inspection of asthma services to identify areas of good practice which could be replicated in other areas.

Name:	Dr Michael OSBORN
Job Title:	sub speciality adviser NON FORENSIC AUTOPSY
Organisation:	Royal College Pathologists
Region/location:	NATIONAL
Capacity in which you are replying to the inquiry	On behalf of Royal College Pathologists. The College is a standards setting organisation that provides guidance on the diagnosis of disease, including through post mortem examinations.

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

- 1/ Improving the accuracy in specifying the cause of death in patients who die of a respiratory disease is important for public health purposes.
- 2/ The majority of post mortem examinations are performed under authority of a Coroner and diagnosis is made at a balance of probability, usually not involving detailed investigation.
- 3/ The coronial autopsy system need to be reviewed and reorganised. By improving the provision for high quality post mortem services throughout the UK the best information on the numbers and reasons behind all types of death including respiratory deaths will be available to help research, development of new services and treatments. Poor coronial autopsy provision currently means much invaluable information on respiratory deaths and disease as well as all other causes of death and disease is being lost. Revamping these services need not cost much and the benefits would be large.
- 2/ Bureaucracy around the use of human tissue from both the living and (even more so) the dead needs to be reduced so that useful research into respiratory illness and death can be more easily conducted. This would allow the UK to become a world leader in human tissue based research.
- 3/ Microbiology/Virology etc: These specialities need to be properly funded and supported as they are vital in undertaking the relevant research, developing the treatments and leading the responses to all respiratory disease.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?
4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?
- Smokers, those with genetic lung disorders, those exposed to environmental inhaled noxious or toxic substances, immunosuppressed, the elderly.
5. What can the Government and the NHS in England do to reduce respiratory deaths?
- Reduce smoking. Spend more money on respiratory services. Fund research. Revamp and reorganise the coronial autopsy service. Support microbiology and virology with funding and in other ways.

Asthma Questions:

1. What are the most important factors contributing to asthma deaths?
- The data related to asthma-related deaths are probably unreliable. Currently there is very poor assessment of asthma deaths at autopsy. It is a hard diagnosis to make at autopsy especially given the inadequacies of the coronial autopsy service currently. It is likely that a proportion of asthma related deaths are being missed as a result. Addressing the issues of the coronial autopsy system will alleviate this problem.
2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?
3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?
- If the contribution of asthma to deaths were more reliably ascertained this would allow for better public health planning. The current inadequacies of the coronial autopsy service to identify and fully investigate asthma and other respiratory deaths needs to be addressed.
4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?
- No

5. What can the Government in England do to reduce asthma deaths?

- 1/ In order to make an accurate assessment of the proportion of deaths caused by asthma, the coronial autopsy system need to be reviewed and reorganised. It needs to be taken under one authority - currently it is under the two ministries of Justice & Health and is poorly organised and funded. By improving the provision for high quality post mortem services throughout the UK the best information on the numbers and reasons behind all types of death including respiratory deaths will be available to help research, development of new services and treatments and the best use of scarce resources. Poor coronial autopsy provision currently means much invaluable information on respiratory deaths and disease as well as all other causes of death and disease is being lost. Revamping these services need not cost much and the benefits would be huge.
- 2/ Bureaucracy around the use of human tissue from both the living and (even more so) the dead needs to be reduced so that useful research into respiratory illness and death can be more easily conducted. This would allow the UK to become a world leader in human tissue based research.
- 3/ Microbiology/Virology etc: These specialities need to be properly funded and supported as they are vital in both undertaking the relevant research, developing the treatments and leading the responses to all respiratory disease.
- 4/ Reduce smoking.
- 5/ Spend more money on asthma services.
- 6/ Fund research.

6. What can the NHS in England do to reduce asthma deaths?

- 1/ Microbiology/Virology etc: These specialities need to be properly funded and supported as they are vital in both undertaking the relevant research, developing the treatments and leading the responses to all respiratory disease.
- 2/ Reduce smoking.
- 3/ Spend more money on asthma services.
- 4/ Fund research.

7. Do you have any other comments relevant to this inquiry?

Chronic Obstructive Pulmonary Disease (COPD) Questions:

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

Smoking

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

Currently there is very poor assessment of COPD and respiratory deaths

at autopsy. It is a difficult diagnosis to make at autopsy especially given the inadequacies of the coronial autopsy service. It is likely that numerous COPD & respiratory related deaths are missing in as a result. Addressing the issues of the coronial autopsy system will alleviate this problem.

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?
 - 1/ Microbiology/Virology etc: These specialities need to be properly funded and supported as they are vital in both undertaking the relevant research, developing the treatments and leading the responses to all respiratory disease.
 - 2/ Reduce smoking.
 - 3/ Spend more money on respiratory services.
 - 4/Fund research.
4. What could the Government in England do to reduce premature mortality from COPD?
 - 1/ The coronial autopsy system need to be completely revamped and reorganised. It needs to be taken under one authority - currently it is under the ministries of Justice & Health and is poorly organised and funded. By improving the provision for high quality post mortem services throughout the UK the best information on the numbers and reasons behind all types of death including respiratory deaths will be available to help research, development of new services and treatments and the best use of scarce resources. Poor coronial autopsy provision currently means much invaluable information on respiratory deaths and disease as well as all other causes of death and disease is being lost. Revamping these services need not cost much and the benefits would be huge.
 - 2/ Bureaucracy around the use of human tissue from b the living and (even more so) the dead needs to be reduced so that useful research into respiratory illness and death can be more easily conducted. This would allow the UK to become a world leader in human tissue based research.
 - 3/ Microbiology/Virology etc: These specialities need to be properly funded and supported as they are vital in both undertaking the relevant research, developing the treatments and leading the responses to all respiratory disease.
 - 4/ Reduce smoking.
 - 5/ Spend more money on asthma services.
 - 6/Fund research.
8. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

No

5. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

Improving the diagnosis and investigation of respiratory related deaths by improving the coroners' autopsy system would help this immeasurably. It would give accurate measures of the mortality and morbidity of COPD and other respiratory disease and feedback on treatments as well as providing unrivalled education and audit opportunities.

6. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

1/ In order to make an accurate assessment of the proportion of deaths caused by asthma, the coronial autopsy system need to be reviewed and reorganised. It needs to be taken under one authority - currently it is under the two ministries of Justice & Health and is poorly organised and funded. By improving the provision for high quality post mortem services throughout the UK the best information on the numbers and reasons behind all types of death including respiratory deaths will be available to help research, development of new services and treatments and the best use of scarce resources. Poor coronial autopsy provision currently means much invaluable information on respiratory deaths and disease as well as all other causes of death and disease is being lost. Revamping these services need not cost much and the benefits would be huge.

2/ Bureaucracy around the use of human tissue from both the living and (even more so) the dead needs to be reduced so that useful research into respiratory illness and death can be more easily conducted. This would allow the UK to become a world leader in human tissue based research.

9. Do you have any other comments relevant to this inquiry?

Name:	Andrew McCracken
Job Title:	Public Affairs Manager
Organisation:	Royal College of Physicians
Region/location:	Representing nearly 30,000 in the UK and overseas
Capacity in which you are replying to the inquiry	Professional body for physicians

NB – The Royal College of Physicians is leading the National Review of Asthma Deaths, which is due to report in April 2014. The APPG for Respiratory Health has kindly allowed the RCP to submit supplementary written evidence once the review has been published. As such, this submission does not reflect the work of the National Review of Asthma Deaths.

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

Other conditions have been made national priorities with targets, and requirements set in hospitals for outcomes driven by national audit as part of mandatory Trust reporting. We have known for some time of variation in outcomes for respiratory diseases, but with the exception of Lung Cancer there has been no national drive to improve quality of care. The Primary Care Quality Outcomes Framework (QOF) for lung diseases is a step in the right direction, but it is based upon process measures not outcomes, and risks distorting priorities by losing priority for non-reimbursed quality measures. There is a lack of alignment with other reference standards. For example, the National Institute for Health and Care Excellence (NICE) Quality Standards are not all reflected in the QOF and the standards include outcomes, whereas the QOF does not.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

Prevent smoking

Smoking causes over 80% of deaths, and over 80% of hospital admissions for COPD and lung cancer. Continued smoking increases the rate of progression of COPD and asthma. Historically high smoking rates in the UK explain our currently high but declining mortality from COPD and lung cancer. Passive smoking causes around 41,000 new cases of asthma, wheeze and lower respiratory infection in children, generating over 140,000 GP consultations and nearly 6000 hospital admissions, in the UK each year. Smoke-free legislation has substantially reduced hospital admissions for asthma in children. Smoking cessation is the only intervention known significantly to

reduce the rate of progression of COPD. Preventing smoking uptake, promoting smoking cessation, and preventing passive smoke exposure are thus the key priorities in preventing morbidity and mortality from respiratory disease in the UK.

Give respiratory patients access to specialist services at secondary care level

Community and primary care services should be better integrated with secondary care support. More specialist respiratory care should be provided to the very sick patients who are currently often managed by generalists. Incentives should be changed to focus on outcome measures and for there to be rewards to make them attractive to GPs and to Trusts.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

Local level

Most respiratory illness is managed in primary care, often without input from specialists. There is huge variation in care, with much of it below levels needed. In the community there is fragmentation of services with few standards. Patients themselves do not know what level of care to expect.

Among the medical professional

At individual level, there is a failure to learn or deliver effective smoking cessation interventions; and at organisational level there is a failure to implement cessation interventions and smoke-free policies as systematic components of medical care.

Government level

The government should fully implement policies that will reduce smoking, including tobacco tax rises and minimum pricing, tackling illicit supply, retail licensing, preventing secondary advertising and promotion, mass media health promotion campaigns, integrating cessation interventions into health and social care, extending smoke-free policies and harm reduction. Moves towards standardised packaging are a welcome step.

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

Smokers are by far the largest group of people at high risk of respiratory disease, and this group will generate most cases of lung cancer and COPD. They are at high risk because they smoke.

5. What can the Government and the NHS in England do to reduce respiratory deaths?

The government can reduce respiratory deaths by implementing the policies outlined under (3) above. The government should also support a quality improvement initiative for respiratory care.

The NHS should be implementing smoking cessation interventions, and smoke-free

policy, in line with (3) above; including full implementation of NICE guidance PH48 on smoking cessation in secondary care settings.

The QOF should be better aligned with key outcomes not process measures and patients should be provided with better data on ideal care and their own care as a measure.

Asthma Questions:

1. What are the most important factors contributing to asthma deaths?

Respiratory infections, ambient pollution (and particularly tobacco smoke pollution), smoking, poor compliance with medication, damp homes, obesity.

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

Highly allergic individuals, and those exposed as in (1) above.

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

This question will be covered in supplementary written evidence to be submitted following publication of the e National Review of Asthma Deaths, expected in April 2014.

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

The epidemics of asthma deaths in the 1960s appear to have been driven by overuse of beta agonists. This effect, which also probably applies to reliance on long-acting beta-agonists, appears to be prevented by inhaled steroid use.

Self-management and education programmes that encourage appropriate use of medication, and self-referral for help during exacerbations, improve quality of life and should reduce mortality.

5. What can the Government in England do to reduce asthma deaths?

Prevent smoking, improve housing, prevent obesity, reduce outdoor pollution.

This question will be covered in more detail in supplementary written evidence to be submitted following publication of the e National Review of Asthma Deaths, expected in April 2014.

6. What can the NHS in England do to reduce asthma deaths?

Prevent smoking, prevent obesity, promote physical fitness, and ensure delivery and monitoring of effective therapies.

This question will be covered in more detail in supplementary written evidence to be submitted following publication of the e National Review of Asthma Deaths, expected in April 2014.

7. Do you have any other comments relevant to this inquiry?

N/A

Chronic Obstructive Pulmonary Disease (COPD) Questions:

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

Smoking accounts for most cases of COPD. Industrial exposure to dust and fumes, and ambient pollution account for much of the rest. COPD risk is also determined by fetal development and birth weight, which are also heavily influenced by maternal smoking and, to a lesser extent, passive smoking, nutrition and other determinants of fetal development.

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

Failure to implement effective smoking prevention policy and variability in care. More detail in response to question (4) below.

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?

The NHS Should:

- Move away from a programme of narrow targets and initiatives aimed at part of the system, and move to a comprehensive and joined up programme of quality improvement.
- Provide patients with individualised quality score cards of the care they are receiving set against the national standards of care they should be receiving.
- Provide a mechanism for standardising processes and practices which are proven to benefit patients and which all areas of the country need to implement yet which all are re-inventing with various degrees of success.
- Set mandatory time set aside for clinical leaders (of all professions) to achieve change and quality improvement rather than including these targets within

- their existing work programme.
- Provide an IT solution that promotes a standardised patient care record that can be shared across primary/community/secondary care.
 - Provide the infrastructure support where needed to promote better care e.g. clinical system IT templates to prompt quality care, spirometry services offered by all acute or community trusts to provide testing that many GPs cannot.
 - Promote smoking cessation and smoke-free policy

4. What could the Government in England do to reduce premature mortality from COPD?

A key role for the government is to prevent smoking. The government should also:

- Commission audit as data collection followed by an integral quality improvement programme of change management.
- Promote the sharing of patient identifiable information across providers of health and social care to enable ‘joined up care’. The current information governance rules are so complex that they work against the majority of patients’ clinical interest in the name of protecting the rights of individuals not to share health data.

5. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

COPD mortality tracks smoking prevalence with an approximate 25 year lag. Declining mortality from COPD in the UK reflects the trend in smoking 25 years previously. So, reducing smoking successfully reduces deaths from COPD, and preventing smoking would prevent at least 80% of them.

6. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

Diagnosis would be improved by routine spirometry. Barriers include a lack of suitable equipment and expertise to make and interpret the measures. Quality assured spirometry should be made available to primary care and diagnosis should be incentivised using financial drivers.

7. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

Provision of home COPD support appears to be extremely effective as a means of preventing admission to hospital, and facilitating early discharge.

In Outer North East London there was an award winning programme for COPD in which the team did many of the things suggested above. Unfortunately, once the

three year intervention was completed many of the positive process and outcomes began to fall back again. The team produced a patient score card for care quality and a self-management proforma and an IT template for COPD management. The team did demonstrate cost savings and improved care evaluated externally.

8. Do you have any other comments relevant to this inquiry?

We would be delighted to share views and evidence with the inquiry team.

APPG on Respiratory Health - Questions

Personal Information:

Name:	Heidi Wright
Job Title:	Practice and Policy Lead for England
Organisation:	Royal Pharmaceutical Society
Region/location:	Great Britain
Capacity in which you are replying to the inquiry	Organisation
List of any supplementary information attached (if any)	

Respiratory Disease Questions: Please provide as much or as little information as you wish, up to a maximum of 300 words per question.

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

Respiratory disease is the third leading cause of death in England after circulatory disease and cancer. Yet despite this fact, in our opinion respiratory disease treatments are not in par with the other diseases mentioned above.

We know there is a huge variation around the country in clinical activity, delivery of services and outcomes for people with respiratory disease. This variation also differs depending on the respiratory disease in question, with respiratory disease covering a wide spectrum of diseases for example asthma, tuberculosis, interstitial lung disease. The *NHS Atlas of Variation in Healthcare for People with Respiratory Disease* published September 2012 underlines the substantial scope clinicians and commissioners have to improve outcomes for people with respiratory disease if all receive the quality of care that is delivered in the best-performing localities.

Due to the complex nature of the delivery of services to respiratory disease it is difficult to address by medical treatments alone. To achieve improvements in care it is essential that services are co-ordinated and involve the wider multidisciplinary care teams, including public health and social care. There are many evidence based interventions and evidence of best practice around the country that

can be utilised at a local level to improve care. However, this needs to be supported by a funded, formalised strategic clinical network. We know that such a network can bring together those who use, provide and commission the services for respiratory disease to make improvements in outcomes for complex patient pathways using an integrated, whole system approach. It is disappointing that unlike cancer, mental health and cardiovascular disease, respiratory disease has not been supported as one of the initial four clinical networks. Respiratory disease is not on par with the other diseases listed.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

With respiratory disease impacting widely on people in terms of high levels of mortality and morbidity and also impacting on the NHS in terms of pressure on current service provision and the associated high costs we would welcome respiratory disease to be supported as a formalised strategic clinical network.

Examples of changes that can be made to improve outcomes are listed below:

- Support for stop smoking services
- Improved diagnostic services for people with respiratory disease, in particular lung cancer, asthma, bronchiectasis and COPD
- All members of the healthcare team that are involved in the patient pathway, such as the community pharmacist, become integral members of the team - improving communication links between all members of the team
- Enhanced attention on the medicines optimisation agenda - encompassing improved education on appropriate prescribing of medicines with adherence to national guidelines, inhaler technique and patient self management of their disease
- Enhanced liaison between practices and community pharmacists to support the New Medicine Services and Medicine Use Reviews provided by community pharmacists
- Improved uptake of vaccination programmes
- Improved communication between primary and secondary care services, especially on discharge from hospital
- Wider dissemination of care bundles
- Initiatives to support adherence to medication for all respiratory disease

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

- Many people with respiratory disease, in particular COPD delay seeking medical attention for many months and in some cases

years after first noticing symptoms. Prompt diagnosis is essential to ensure that health messages and appropriate treatments are initiated early in their disease pathway. Diagnostic services are currently a barrier with as many as 27% of people on COPD registers in GP practices not having COPD. This leads to high levels of inappropriate prescribing and potential harm to people with COPD. Likewise early diagnosis of lung cancer is essential and can affect outcomes and reduce premature mortality.

- Reduced access to GP review at the onset of an exacerbation of asthma/COPD/ILD leads to delay in people receiving appropriate care for their disease
- Adherence to medication in respiratory disease is similar to any long term condition with as few as 50% of people adhering to their treatment regimens. It has been shown that people with difficult asthma and low adherence rates to inhaled corticosteroid are 1.8 times more likely to be ventilated for their asthma (Murphy, et al. Thorax 2012)

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

- Social deprivation is associated with worse outcomes from most lung disease. The correlation is likely to be multi-factorial.
- People who smoke or through their occupation are exposed to noxious particles are at risk
- Babies born prematurely
- Immigrants to the UK from areas of the world where TB is prevalent, homeless people (tuberculosis)

5. What can the Government and the NHS in England do to reduce respiratory deaths?

Any measures that:

- Improve lung health through people wellbeing - exercise, nutrition
- Enhance stop smoking services and key messages to the public
- Address occupational pollution
- Help to address air pollution
- Support wider dissemination of good practice across the country
- Support research and evaluation of services and models of care for people with respiratory disease

The development of a clinical network for respiratory disease

Asthma: Please provide as much or as little information as you wish, up to a maximum of 300 words per question.

Background

Over 4 million people in England are affected by asthma⁸ and, on average, three people die every day from their asthma. We know three quarters of these deaths are amongst people aged 65 or over, and evidence suggests 90% of all asthma deaths are preventable if managed properly.⁹ In 2010 the UK death rate from asthma was one of the highest in Europe.¹⁰

In February 2012, the National Review of Asthma Deaths (NRAD), led by the Department of Health, began a review into all deaths from asthma across the UK for one year. The review aims to reduce the number of asthma deaths and the findings will be published in April 2014.

Questions

1. What are the most important factors contributing to asthma deaths?

The NRAD will report on May 6th and will therefore answer this question comprehensively.

However, we know from previous publications that the following can influence asthma mortality:

- Poor adherence to asthma treatments, in particular inhaled corticosteroid medicines
- Over-reliance on short acting relievers treatments for asthma
- Inappropriate prescribing - using long acting beta-2 agonists with no inhaled corticosteroid combined
- Lack of personalised asthma action plans being provided to people and ensuring that they understand what to do
- Lack of inhaler technique checking by healthcare professionals who are competent and confident in teaching people with asthma
- Poor uptake of annual asthma reviews at GP practices
- People with severe disease not being assessed correctly and being referred to specialist asthma services

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

People with severe asthma are more at risk from dying from their asthma. This group of patients require careful characterisation of their disease to ensure appropriate medical care and treatments are provided. Those at high risk are those patients who have had a previous severe exacerbation of asthma, who require 3 or more classes of

medicines to treat their asthma (Step 4/5 BTS/SIGN guidelines for asthma).

Potential high risk groups include those who fail to attend GP or hospital appointments, those with low or erratic adherence to medication, frequent A&E attendances, those with social problems, smokers, and alcohol or drug abuse. Why these are more at risk of dying is multifactorial but is likely to be partly related to lack of appropriate medication usage and self management.

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

One of the most effective ways to manage asthma is via the use of appropriate medicines. It is extremely important that asthmatic patients take their medicines regularly and in the correct way as this will prevent them from having an asthma attack and being admitted to hospital as an emergency admission. A large proportion of the medicines budget in England, around 13% of the primary care prescribing budget (2012)¹, is spent on respiratory medicines and implementation of the medicines optimisation principles² could ensure that the investment made in these medicines is not wasted.

Asthma is seen as a common condition and is sometimes perceived as ‘not serious’. If patients with asthma can control their symptoms with the appropriate use of medicines they can lead a normal, healthy life. Patients attitude is often ‘it’s only asthma’ as most patients only have mild or moderate asthma. There is a real need to get asthma patients interested in their health and how they can make changes to stay as healthy as possible.

Pharmacists have a crucial role in supporting patients to get the best outcomes from their medicines. They are the healthcare professional that the patient sees on a regular basis as they pick up their regular supply of inhalers and other medicines. This provides an opportunity for pharmacists to engage with patients with asthma and provide advice on their medicines and on inhaler technique. It is important for patients understand stepping up and stepping down their medicines.

The RPS has recently published guidance for its members to help them support patients with asthma.³ Under the current Contractual Framework for Community Pharmacy, community pharmacists are commissioned to provide Medicine Use Reviews (MURs) and New Medicine Service (NMS) for asthmatic patients. However, although this is commissioned at a national level it is an enhanced service which

¹ <http://www.hscic.gov.uk/searchcatalogue?productid=11412&q=title%3a%22prescription+cost+analysis%22&sort=Relevance&size=10&page=1#top>

² <http://www.rpharms.com/what-we-re-working-on/medicines-optimisation.asp>

³ <http://www.rpharms.com/promoting-pharmacy-pdfs/mo-briefing---asthma.pdf>

means not every pharmacy provides it and limits have been set as to how many MURs a pharmacy can deliver.

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

There are a number of projects where community pharmacists have improved the asthma control and outcomes for people with asthma. No study was powered to show a reduction in asthma deaths but focused on asthma control. Due to the word limit these projects have been summarised in Appendix 1.

5. What can the Government in England do to reduce asthma deaths?

The RPS would recommended the following:

1. Support the medicine optimisation agenda
2. Improve communication and consultation skills to support adherence behaviour (see CPPE Consultation skills for pharmacy practice publication)
3. Review prescription charges for people with asthma - encourage prepayment certificates for those on more than 2 medicines or abolish charges for this group of people
4. Improve community pharmacy services and communication between other services.
5. Support any measures to encourage stop smoking
6. Promote lifestyle improvements

6. What can the NHS in England do to reduce asthma deaths?

There is evidence to support the inappropriate prescribing of medicines for people with asthma, with both over prescribing with high dose inhaled corticosteroids and under prescribing. This varies across England and the reasons for this require investigation. The consequence of this leads to high medicine acquisition costs as well as poor patient asthma outcomes and the potential for adverse side effects. The BTS/SIGN guidance for asthma management is structured and evidence based. Many healthcare professionals acknowledge that the guideline exists but still fail to follow the guidance appropriately. There needs to be better incentives to prescribe as per the guideline. Likewise, NICE have published quality standards for asthma, which support evidence based care. Adherence of local areas to these standards would help improve mortality and morbidity from this disease.

Provide support to the community pharmacist, who is likely to have contact with the person more times than any other healthcare

professional. Using the pharmacist to help people monitor their asthma control (using Asthma Control Tests, or exhaled Nitric Oxide) could help to engage patients and help them understand their disease. Introducing effective communication links between GPs and community pharmacists could support signposting from one to another.

7. Do you have any other comments relevant to this inquiry?

Information is key to reducing medicine errors, improving medicines adherence and delivering safe and more effective care to patients. We believe that all healthcare professionals involved in a patient's care should have access to the appropriate information.

We believe that all hospital and community pharmacies should have, as a first step, access to a patients' Summary Care Record (SCR). Ultimately, registered pharmacy professionals should have appropriate read and write access to the patient health record in the interest of high quality safe patient care.

A position of "access to health records in the patient's interest" must be adopted. Registered pharmacy professionals have a legitimate need to access patient health records as the more information available to them when providing care to patients, the better the outcome for patients. We are calling on NHS England and the HSCIC to make this a reality for the community pharmacy network that dispense over 1 billion prescription items a year.

Chronic Obstructive Pulmonary Disease (COPD) Questions: Please provide as much or as little information as you wish, up to a maximum of 300 words per question.

Background

COPD kills about 25,000 people a year in England and Wales. Recent figures showed that COPD accounted for 4.8% of all deaths in England between 2007 and 2009. It is the fifth biggest killer disease in the UK after cancer, heart, stroke, and liver disease. Premature mortality from COPD in the UK was almost twice as high as the European (EU-15) average in 2008 and 1 in 8 people over 35 has COPD that has not been properly identified or diagnosed.¹¹

Questions

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

Approximately 90% of COPD is caused by smoking. Targeting this group of people is essential in tackling the level of premature death from COPD. Stopping smoking has been shown to reduce disease progression and is more cost effective than other treatments. Smoking cessation

should be seen as an intervention - not a lifestyle choice.

Many people with COPD delay seeing their GP for many years after first noticing symptoms. There is often a delay in diagnosis which subsequently delays the initiation of appropriate treatments (pharmacological and non-pharmacological). Diagnosis is also not always accurate with HCPS using spirometry to diagnose, which is not always performed to the required standard and in isolation from the patient's medical history.

Treatment of COPD does not always follow recent evidence based guidelines. One example is the inter-patient variation in the appropriate use and timely use of antibiotics and oral steroids for acute exacerbations. Also, high dose inhaled corticosteroids (as combination inhalers) are over prescribed for many people with COPD, with the potential to lead to adverse effects, such as pneumonia, diabetes etc. The intervention of issuing a prescription to a patient is seen to be easier than considering non-pharmacological interventions such as pulmonary rehabilitation.

Few patients (and healthcare professionals) can effectively use an inhaler device to ensure optimum delivering of the medicine to the lung. A review of training in this area is required to ensure that consistent clear messages are given to patients to improve technique, with HCPS being accredited on a yearly basis to ensure they are competent.

Oxygen therapy is also poorly prescribed and administered to people with COPD, both in primary care and secondary care and in transit between the two.

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

The following are the main barriers:

1. Lack of competency based education and training for HCPS in spirometry, inhaler technique and treatment guidelines.
2. Poor communication between primary and secondary care especially on discharge from hospital.
3. All HCPs to be more active in promoting lung health and to be aware of the signs and symptoms of lung disease with effective signposting to GPs
4. Few opportunistic case finding services to support early diagnosis. Utilising the role of pharmacy would help to identify people who require follow up for diagnostics at their GP practice.
5. Diagnostic spirometry is a major barrier as many people are inaccurately diagnosed.
6. Prescription charges (promote pre-payment certificates)

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?
- Encourage all secondary care services to incorporate stop smoking programmes into hospital, encouraging the person to stop smoking during an acute exacerbation, increasing the successful quit rates
 - It is reported that 30% of people with COPD also have cardiovascular disease. It is important that people receive the appropriate pharmacological treatments for all co-morbidities. Prescribing beta-blockers in such sub-groups may help reduce overall mortality. Likewise, ensuring patients psychosocial needs are addressed will help to reduce anxiety and depression rates.
 - Exercise promotion and the provision of pulmonary rehabilitation services - available and accessible for all people with COPD
 - Appropriate assessment and provision of oxygen therapy as per national guidelines
4. What could the Government in England do to reduce premature mortality from COPD?
Support the recommendations in question 3 above
5. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?
The projects are outlined in **Appendix 2** due to word constraints in this section
6. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?
This is an important aspect of COPD care. Many people with COPD are diagnosed late in their disease process. Poor quality spirometry in some cases performed by HCPs not adequately trained to undertake and interpret spirometry
Improved and efficient identification of the person displaying symptoms with timely referral to GP practice for diagnostics.
7. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.
No further comments
8. Do you have any other comments relevant to this inquiry?

None

Please see Appendix 1 and 2 for examples of projects.

¹ The Burden of Lung Disease: Report 2, British Thoracic Society, 2006.

² UK mortality from respiratory disease is 5th worst in the EU, after Denmark, Ireland, Belgium and Hungary. ERS White Book - the Burden of Lung Disease, Figure 1. Last accessed on October 2013. <http://www.erswhitebook.org/chapters/the-burden-of-lung-disease/>

³ Department of Health, *England level data by programme budget*. Downloaded from: <https://www.gov.uk/government/publications/2003-04-to-2010-11-programme-budgeting-data>. Accessed on 01/10/2013

⁴ 7,500 lives could be saved in England when total deaths were 23,000 per year from COPD. Outcomes Strategy for Asthma and COPD: NHS Companion Document, Department of Health, May 2012.

⁵ Partridge M, Self care plans for people with asthma. *The Practitioner* 1991, p 715-21

⁶ Health Survey for England 2001. The Scottish Health Survey 2003. Welsh Health Survey 2005/2006. Northern Ireland Health and Wellbeing Survey 2005/2006. Population estimates from Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics & Research Agency

⁷ Outcomes Strategy for Asthma and COPD: NHS Companion Document, Department of Health, May 2012.

⁸ Health Survey for England 2001. Population estimates from Office for National Statistics

⁹ Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics & Research Agency

¹⁰ OECD, Deaths - *International comparisons, all ages*. Downloaded from <http://stats.oecd.org/> Accessed on 02/10/2013

¹¹ All references in this paragraph: An Outcomes Strategy for COPD and Asthma, Department of Health, July 2011.

APPENDIX 1

Lloyds Pharmacy project:

Many patients with asthma accept symptoms as a normal part of living with the condition and many are unaware of the steps they can take to gain better control. While primary care makes considerable effort to manage these patients, the Lloyds pharmacy Asthma Medicines Support Service (AMSS) explores the role for community pharmacists in improving patient care.

AMSS identifies patients who are experiencing difficulties with controlling their asthma. The service combines the use of a short series of questions, the Asthma Control Test (ACT), with a focused medicines use review.

The service highlighted a number of issues with patient asthma control and allowed the pharmacists to identify ways in which they could help improve patient care.

Findings show that a patient's ACT score significantly improves following a MUR. Thus MURs are a positive intervention to improve the control of asthma and are well accepted by this patient group.

This service demonstrates how the community pharmacist can make a direct and meaningful contribution to the management of patients with asthma utilising the services introduced as part of the pharmacy contract.

Of those patients reviewed:

- 96% experienced day time symptoms of asthma
- 56% were using their reliever inhaler too frequently
- 41% were forgetting to use their preventer inhaler
- 52% required further patient education
- 22% needed help with inhaler technique
- 38% were identified as having poor control due to therapeutic inefficiency
- 26% were referred to their GP practice of whom
- 42% were prescribed add-on therapy
- 14% had a change in therapy
- 14% had their inhaler type altered
- 30% received changes to their directions

Patients were followed up to reassess asthma control using the ACT.

Patients whose asthma was:

- 'Well controlled' increased from 5% to 9%
- 'Reasonably controlled' increased from 36% to 46%
- 'Not controlled' decreased from 59% to 45%

From a Lloyds pharmacy perspective, we have a dedicated service development team working collaboratively across internal departments with each department providing pivotal support in developing the service. The

development of this model of care was further supported by collaborative working with established charity partners such as Asthma UK.

This service demonstrates how pharmacy can make a direct and meaningful contribution to the management of patients with asthma, and has utilised the advanced service element of the pharmacy contract as a platform for delivery. This is also supported by the additional tools available to support the management of asthma, such as the ACT questionnaire and the Incheck dial.

Rowlands and GSK:

The average community pharmacy in the UK supports about 400 asthmatic patients in the use of their inhaled medicines. Community pharmacy has a key role to play in helping patients use and understand their medications in asthma therapy.

Rowlands Pharmacy working in collaboration with GSK developed and implemented a national community pharmacist led asthma support service for asthmatic patients. This service aimed to improve the health and optimise the use of medicines in a cohort of patients with asthma.

It was hoped that by taking measures to educate asthmatic patients regarding their medication, and by supporting the effective and appropriate use of medicines, better asthmatic control could be achieved and patient quality of life improved.

A UCL School of Pharmacy report, (<http://www.rpharms.com/support/map-of-evidence.asp>) provides an evaluation of the collaborative programme that was developed between Rowlands Pharmacy and GSK. It initially describes the details of the intervention, before presenting the study results and an analysis of the data set captured electronically by the participating pharmacists. The report then describes the findings from a series of qualitative interviews with a sample of pharmacists involved in the programme and concludes by discussing the implications of these results for future national policy.

The overall results from this evaluation show a positive effect on asthma control as a result of a pharmacist intervention and are consistent with other community pharmacy based studies in asthma management. The findings from this evaluation suggest that collaboration and partnership between the pharmaceutical industry and community pharmacy can produce an improvement in patient outcomes.

Community pharmacists are in a unique position to make a useful contribution to chronic disease management due to their accessibility, expertise on medication and their frequent contacts with patients collecting repeat medication.

Bristol project:

A two year initiative has helped the Bristol area achieve a reduction in admissions for asthma through a range of medicines optimisation initiatives:

- specialist respiratory nurses working with GP practices to target people frequently admitted to hospital, smokers and those not attending for an annual asthma review;
- community pharmacist Medicines Use Reviews for patients not attending GP practices for their regular review;
- enhanced training for patients and general practice teams;
- targeted education for minority groups;
- incentives for GPs to review patients prescribed excessive reliever inhalers and patients who need to be stepped down.

South of England project:

(file:///C:/Documents%20and%20Settings/Heidi%20Wright/My%20Documents/Downloads/120904%20CIREM_ITIP_HIEC_Evaluation.pdf)

An analysis of results from a respiratory MUR project in the south of England has demonstrated significant improvements in patient outcomes, with the interventions leading to better asthma control and COPD symptom management.

An inhaler technique improvement project in the south of England saw over 5,100 MURs delivered across 206 pharmacies, with over 800 “secondary intervention”, or follow up, MURs also completed.

As part of the MURs, pharmacists carried out asthma control and COPD assessment tests and recorded the results in an electronic system. An analysis of the recorded data showed:

- In relative terms, 40 per cent of people with asthma showed better asthma control during the time studied, while 55 per cent of COPD patients showed an improvement in symptom management.
- There was evidence of improved asthma control between the first and second MURs - at the second MUR there was a 40 per cent relative increase in the number of people achieving a test score representing good asthma control. This increase was statistically significant.
- There was evidence of improved COPD management following the intervention - at the second MUR more people achieved test scores indicating a less severe impact on their lives from COPD. The improvement was statistically significant.
- Analysis of data on emergency asthma and COPD admissions showed a positive association between the introduction of the project and changes in emergency hospital admissions.

SIMPLE (acronym - Stop smoking, Inhaler technique, Monitoring, Pharmacotherapy, Lifestyle and Education) approach to ASTHMA management (LEICESTER):

http://system.improvement.nhs.uk/ImprovementSystem/ViewDocument.aspx?path=Lung/National/website/Case_studies/Leicester_Lung_Case_Study.pdf.

This service is based on that fact that only two-thirds of patients with asthma have a routine asthma review each year, although research has shown that the delivery of regular structured reviews of people with asthma can reduce their day-to-day symptoms and reduce the burden of providing emergency care on the NHS. This service utilises the community pharmacy as an additional place

for patients with asthma to access expert advice and receive a structured review of their disease, working in collaboration with the GP practice. The service has been evaluated robustly, demonstrating outcomes over a 6-month period.

- 125 patients (mean age 57.5 years, 60% female, 63% South-Asian).
- 63% patients returned for a follow-up appointment and review of their asthma after three months. 40% of the patients returned for a follow-up at three and six months.
- 42% of patients had not had an asthma review at their GP practice in the last 12 months.
- 56% had not had their inhaler technique checked in the last year. 40% of those patients who had attended their medical practice for an asthma review had not had their inhaler technique checked during the review.
- 19 patients (15%) owned an asthma action plan at baseline.
- Significant improvements in patients asthma controlled (measured by the Asthma Control Test (ACT) questionnaire) ($p=0.002$). Intention-to-treat analysis confirmed significance ($p<0.001$). 40% of patient's ACT score increased by a score that would be clinically important.
- Patients who had not had an asthma review at their GP practice within the last year showed a significant improvement in their asthma control.
- Patient quality of life improved significantly (measured by mini-AQLQ) ($p=0.03$)
- Inhaler technique was checked by the pharmacist in 99% of cases. Patient inhaled technique improved significantly ($p<0.001$).
- Medication adherence - both self-reported and adherence scores calculated by prescription re-fill data from the pharmacy computer system showed improvements. The results showed a significant reduction in the collection of prescriptions for SABA and a highly significant increase in the prescription refill of ICS ($p<0.001$). 92% of patients at the end of six months collected at least 80% of their ICS inhalers.

-
- The pharmacist completed and provided a personalised asthma action plan for 80 patients (78%).
 - 32% reduction in the number of visits to the GP for an asthma-related issue over the study period ($p=0.053$).
 - 40% reduction in hospital admission data (this must be interpreted carefully as the sample size was small and the result was not statistically significant)

APPENDIX 2

Community Pharmacy Futures Project:

The Community Pharmacy Future (CPF) project is collaboration between Boots UK, The Co-operative Pharmacy, LloydsPharmacy and Rowlands Pharmacy. We have worked with the Department of Health, PSNC, NHS Employers and independent pharmacy in the development and implementation of three service models. The aim is to develop CPF as a service platform to reduce risks, enhance patient quality of life and demonstrate the value of pharmacy interventions using validated outcome measures.

Working with NHS clinical experts, COPD was identified as an area with a poor quality of life and high dependency on the proper use of medicines. Respiratory disease is a key area in the NHS Outcomes Framework. With around 900,000 diagnosed and up to 2.8m undiagnosed patients in the UK, COPD has substantial direct costs to NHS (£900m/yr)¹ and huge impact on patients, especially among those who smoke. Active public health interventions to reduce smoking will have the biggest impact. Exacerbations also significantly affect quality of life. Patients' ability to use inhalers correctly and their medicines adherence determine the effectiveness of their therapy.

Wirral was chosen as an area to pilot the service which aims to reduce exacerbations through improved medicines adherence and supports patients to manage their condition better and improve quality of life, including using rescue packs (steroids and antibiotics) when necessary.

Patients were advised on their medicines, on good inhaler technique and helped with issues they identified (breathing, sleeping). Risk factors were reduced through appropriate services (smoking cessation, flu vaccinations).

Patients get regular, tailored support when they collect their repeat medication. Outcomes were measured using validated scoring tools (Morisky medicines adherence³, COPD assessment test [CAT]⁴, MRC dyspnoea scores⁵ and EQ-5D quality of life⁶).

- 34 pharmacies in the Wirral recruited 306 COPD patients
- The service launched on 17th September 2012. Data collection for six months of service interventions finished on 30th June 2013. Patients continue to receive clinical support under a more streamlined service

Patients saw clear benefits from pharmacist interventions, starting with improving inhaler technique, arranging rescue packs and receiving health and lifestyle advice.

"Knowing when to use the inhalers and when not to, I'm finding it very good actually and definitely feel better in myself" - COPD patient

Highlights of the results after six months show:

- Significant increase in medicines adherence
- Reductions in overall NHS resource use by patients
- Significant improvement in patients quality of life

Patients saw a general improvement in health. Patients were more satisfied with the management of their condition. Quality of life was improved for patients, such as gaining confidence to leave the house, sleeping better, greater ability to do housework, walking further and having reduced chest pain. They were reassured by being able to pop in to ask for advice.

PRICE (Pharmacist Re-admission Intervention for COPD Exacerbation):

A six month self-controlled case series study of hospital re-admission rates due COPD exacerbation after the introduction of a pharmacist to the multi-disciplinary team was carried out. The pharmacist provided evidence based, patient orientated medication and education to people admitted with an exacerbation of COPD. Such interventions included inhaler technique counselling, smoking cessation advice and treatment, optimisation of prescribed therapy and provision of patient action plans in the event of future exacerbations. A total of 319 participants received 1313 medication or educational interventions by the pharmacist. The mean hospital re-admission rate per patient due to COPD exacerbation significantly reduced from 2.22 in the six months prior to the introduction of the pharmacist to 1.14 in the six months post-introduction ($p<0.001$). In addition, there were significant increases in: mean inhaler technique score (across all inhaler types) from 4.3 to 6.3 (max score 7, $p<0.001$) and compliance with national guidance from 45.1% to 76.5% of patients compliant ($p<0.001$). Financial savings on drug expenditure of £52,125 per annum were made.

Name:	John Britton
Job Title:	Professor of epidemiology and consultant respiratory physician
Organisation:	UK Centre for Tobacco and Alcohol Studies (UKCTAS)
Region/location:	University of Nottingham, Nottingham UK
Capacity in which you are replying to the inquiry	As Director of UKCTAS, a UKCRC-funded strategic network of 21 tobacco and alcohol researchers from 12 UK and 1 New Zealand universities

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

Yes, in relation to management of chronic respiratory disease, and given current known opportunities to prevent or modify disease. Medical services can always be improved but I think that basic care provision is adequate. There are marked variations in access to services for lung cancer but the impact on life expectancy of reversing these is likely to be modest in relation to the investment involved.

Investment in population- and individual-level interventions to prevent much chronic respiratory disease, by preventing/treating smoking, obesity and low levels of physical fitness are grossly inadequate, but this is also true of services for many or all of the ‘killer’ diseases listed above.

I cannot comment on resources for specialist services such as lung transplantation.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

The key priority is to prevent smoking. Smoking causes over 80% of deaths, and over 80% of hospital admissions for COPD and lung cancer. Continued smoking increases the rate of progression of COPD and asthma. Historically high smoking rates in the UK explain our currently high but declining mortality from COPD and lung cancer. Passive smoking causes around 41,000 new cases of asthma, wheeze and lower respiratory infection in children, generating over 140,000 GP consultations and nearly 6000 hospital admissions, in the UK each year. Smoke-free legislation has substantially reduced hospital admissions for asthma in children. Smoking cessation is the only intervention known significantly to reduce the rate of progression of COPD. Preventing smoking uptake, promoting smoking cessation, and preventing passive

smoke exposure are thus the key priorities in preventing morbidity and mortality from respiratory disease in the UK. Although much has been achieved in this respect, the fact that 10 million people in the UK still smoke is testimony to the sustained inadequacy of the political and medical response to the tobacco epidemic.

Obesity exacerbates chronic respiratory disease, causes asthma, and is responsible for a majority of obstructive sleep apnoea.

Development and implementation of primary and secondary prevention strategies for obesity through population and individual strategies to modify energy intake and promote physical activity is inadequate at almost all levels.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

At government level, a failure fully to implement policies that will reduce smoking, including substantial tobacco tax rises and minimum pricing, tackling illicit supply, retail licensing, preventing secondary advertising and promotion, standardised packaging, mass media health promotion campaigns, integrating cessation interventions into health and social care, extending smoke-free policies and harm reduction.

Among the medical professional at individual level, failure to learn or deliver effective smoking cessation interventions; and at organisational level, failure to implement cessation interventions and smoke-free policies as systematic components of medical care.

For obesity, a similar failure to implement primary or secondary prevention policies.

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

Smokers are by far the largest group of people at high risk of respiratory disease, and this group will generate most cases of lung cancer and COPD. They are at high risk because they smoke.

Obese people are at high risk of obstructive sleep apnoea, chronic respiratory failure and asthma, and obesity exacerbates disability in all respiratory disease. Obesity results, ultimately, from a sustained imbalance of energy intake and consumption.

5. What can the Government and the NHS in England do to reduce respiratory deaths?

The Government by implementing the policies outlined under (3) above.

The NHS should also be implementing smoking cessation interventions, and smoke-free policy, in line with (3) above; including full implementation of NICE guidance PH48 on smoking cessation in secondary care settings, and implementing measures to prioritise the identification and treatment of smokers throughout the care pathway.

Many healthcare professionals are in desperate need of training and education in identifying and treating smokers.

For obesity there is a need for radical overhaul of policy to promote modification of diet and physical activity.

Asthma Questions:

1. What are the most important factors contributing to asthma deaths?

Respiratory infections, ambient pollution (and particularly tobacco smoke pollution), smoking, poor compliance with medication, damp homes, obesity, possibly paracetamol use.

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

Highly allergic individuals, and those exposed as in (1) above

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

None for medical care. Services and population strategies for smoking and obesity are inadequate.

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

The epidemics of asthma deaths in the 1960s appear to have been driven by overuse of beta agonists. This effect, which also probably applies to reliance on long-acting beta-agonists, appears to be prevented by inhaled steroid use. Self management and education programmes that encourage appropriate use of medication, and self-referral for help during exacerbations, improve quality of life and should reduce mortality.

5. What can the Government in England do to reduce asthma deaths?

Prevent smoking and increase smoking cessation, improve housing, prevent obesity, reduce outdoor pollution

6. What can the NHS in England do to reduce asthma deaths?

Prevent smoking and increase smoking cessation, prevent obesity, promoted physical fitness, ensure delivery and monitoring of effective therapies

7. Do you have any other comments relevant to this inquiry?

Chronic Obstructive Pulmonary Disease (COPD) Questions:

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

Smoking accounts for most cases of COPD. Industrial exposure to dust and fumes, and ambient pollution account for much of the rest. COPD risk is also determined by fetal development and birthweight, which are also heavily influenced by maternal smoking and to a lesser extent passive smoking, nutrition and other determinants of fetal development.

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

Failure to implement effective smoking prevention policy and treatment.

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?

Promote smoking cessation and smoke-free policy

4. What could the Government in England do to reduce premature mortality from COPD?

Prevent smoking

8. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

COPD mortality tracks smoking prevalence with an approximate 25 year lag. Declining mortality from COPD in the UK reflects the trend in smoking 25 years previously. So, reducing smoking successfully reduces deaths from COPD, and preventing smoking would prevent at least 80% of them.

5. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

Diagnosis would be improved by routine spirometry. Barriers include lack of suitable equipment and expertise to make and interpret the measures.

6. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

Provision of home COPD support appears to be extremely effective as a means of preventing admission to hospital, and facilitating early discharge.

9. Do you have any other comments relevant to this inquiry?

The UK has failed to deal adequately with the epidemic of tobacco smoking that peaked in the mid 20th century, and is failing to address the current epidemic of obesity. This reflects a wider imbalance in emphasis in the NHS on treating rather than preventing disease. Respiratory disease would, more than most areas of ill health, benefit from a rebalance of investment towards prevention.

APPG on Respiratory Health - Questions

Personal Information:

Name:	Richard Pitt
Job Title:	Public Affairs and Patient Advocacy Manager
Organisation:	Boehringer Ingelheim Ltd
Region/location:	UK
Capacity in which you are replying to the inquiry	On behalf of Boehringer Ingelheim
List of any supplementary information attached (if any)	

Respiratory Disease Questions: Please provide as much or as little information as you wish, up to a maximum of 300 words per question.

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

No. Respiratory Disease was one of the last major diseases to receive a National Service Framework to support the improvement in management and care in England, when the Outcomes Strategy for COPD and Asthma was published in 2011. Recent NHS changes have slowed the implementation and uptake of the recommendations within the Strategy and in many areas the implementation programmes have now stalled. Funding for regional COPD leads came to an end in March 2013 which curtailed many planned activities aimed at improving the care of this vulnerable patient group.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

- Earlier diagnosis of COPD will improve long term care
- Better education for health care professionals in identifying the signs and symptoms of respiratory disease
- Understanding that lung disease is not always caused by smoking, so it is not missed in non-smokers
- Increased awareness of appropriate diagnostic tests for differential diagnosis of lung disease, such as spirometry and HRCTs to identify the cause of lung crackles
- Better patient education - in terms of risk factor avoidance,

how to manage their condition once identified

- Motivation for patients to adhere to the medicine prescribed.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

- Recognition of symptoms by both HCPs and by patients themselves leading to a delay in diagnosis
- Lack of specialist support services, for example respiratory specialist nurses, respiratory physiotherapists
- HCP unfamiliarity with more complex lung diseases, treating presenting patients for COPD or asthma can cause a delay of more than 6 months in diagnosing other terminal lung conditions
- Lack of understanding of the severity of certain lung conditions amongst HCPs, as well as patients, families and carers

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

- Smokers/Ex-smokers - if their lung disease is smoking related they are likely to have smoked enough to make their disease present. They are also statistically more likely to be suffering from chronic co-morbidities
- Children and adolescents - if asthmatic, they may be at risk of fatal attacks while in settings where they do not have access to their inhalers e.g. school. If they are children of smoking parents/carers they will be exposed to smoke in confined spaces such as their homes and cars. Their clothes are also likely to be contaminated by smoke particles, even if they are 'clean'
- Families of smokers - as above.

5. What can the Government and the NHS in England do to reduce respiratory deaths?

- Reignite the focus on respiratory disease that was growing before April 2013 when the highly successful DH respiratory team was disbanded. This team was beginning to demonstrate success in driving out variation in healthcare by sharing tools such as the Atlas of Variation; driving up standards particularly in COPD and asthma care through a concentration on the outputs of the Outcomes Strategy for COPD and Asthma that was published in 2011
- Improve opportunities for treating the whole person rather than their single conditions
- Reviewing QOF to be patient outcome focused rather than disease management focused

Asthma: Please provide as much or as little information as you wish, up to a maximum of 300 words per question.

Background

Over 4 million people in England are affected by asthma⁸ and, on average, three people die every day from their asthma. We know three quarters of these deaths are amongst people aged 65 or over, and evidence suggests 90% of all asthma deaths are preventable if managed properly.⁹ In 2010 the UK death rate from asthma was one of the highest in Europe.¹⁰

In February 2012, the National Review of Asthma Deaths (NRAD), led by the Department of Health, began a review into all deaths from asthma across the UK for one year. The review aims to reduce the number of asthma deaths and the findings will be published in April 2014.

Questions

1. What are the most important factors contributing to asthma deaths?

- Poor symptom control. This is caused by a number of factors. Physicians not understanding what symptom control means and clarity on the goal they are aiming to achieve; patients downplaying the severity of their symptoms or developing coping mechanisms to deal with their symptoms; ‘it’s only asthma’ attitude; lack of realisation that an asthma attack can occur at any moment and kill.

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

-

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

- Lack of understanding amongst health care professionals of the true risks of an asthma attack.
- Early diagnosis of symptomatic patients and the primary care workload this may generate in the short-term.

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

-

5. What can the Government in England do to reduce asthma deaths?

Include in the Mandate a clear need to define the goal of treating asthma and propose targets to the NHS for achieving this goal.

6. What can the NHS in England do to reduce asthma deaths?

- Clearly define the goal of treating asthma - e.g. patients should live symptom free.
- Incentivise HCPs to meet this target in all asthma patients registered in practice registers/QOF.
- Develop clear criteria that allow the HCP to identify the impact of Asthma on a patients day to day life.

- Ensure that the Quality Standard for asthma is implemented by all CCGs as quickly as possible
- Ensure that all people with asthma have action plans and receive quality information about their condition
- Ensure that HCPs understand what symptom control really means for patients, why it is important, what questions to ask to find out if patients really achieve it, and what to do if they are not
- Incentivise outcomes through QOF and CCG outcome indicator sets (CCG OIS) rather than inputs

7. Do you have any other comments relevant to this inquiry?

- There is a need to raise patient and HCP awareness of the extent to which patients are normalising symptoms and the impact on quality of life that patients experience from these symptoms and going out of their way to avoid triggers.
- There is also scope to raise expectations of the goal of treatment to aim for patients being symptom free, but there is work to do to convince both patients and HCPs that this is a realistic goal.

Chronic Obstructive Pulmonary Disease (COPD) Questions: Please provide as much or as little information as you wish, up to a maximum of 300 words per question.

Background

COPD kills about 25,000 people a year in England and Wales. Recent figures showed that COPD accounted for 4.8% of all deaths in England between 2007 and 2009. It is the fifth biggest killer disease in the UK after cancer, heart, stroke, and liver disease. Premature mortality from COPD in the UK was almost twice as high as the European (EU-15) average in 2008 and 1 in 8 people over 35 has COPD that has not been properly identified or diagnosed.¹¹

Questions

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

- Late diagnosis of disease and no incentives for case-finding programmes
- Feeling of guilt amongst patients who have smoked which leads to late presentation to a HCP
- Poor understanding by HCPs of the importance of treatment interventions as early as possible in the disease
- Lack of suitable programmes for pulmonary rehabilitation (PR)
- Varied provision of PR across the country

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

- Same as in question 1

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?

- Re-establish respiratory networks to provide a focus for driving improvements in respiratory services across regions
- Incentivise outcomes in QOF and CCGOIS rather than inputs
- Establish and implement (including fund) national programmes for spirometry accreditation and pulmonary rehabilitation programmes
- Early identification to allow interventions that manage the symptoms experienced

4. What could the Government in England do to reduce premature mortality from COPD?

- Action on tobacco control e.g. plain packaging on cigarettes
- Increase further the tax on tobacco
- Understand the link between poverty and COPD - housing, fuel, food
- Develop initiatives with education services to stop smoking before it starts
- Introduce legislation to outlaw smoking in confined spaces, such as in cars

8. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

5. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

- Opportunistic screening and case finding programmes in community based settings on the back of well publicised campaigns has been shown to drive up diagnosis rates. Barriers may exist in terms of adequate resource and education to follow up these additional diagnoses.
- We were approached by two LPCs in 2011 to assist them in setting up accredited spirometry services in retail pharmacies. However, a conflict arose between the local GPs and retail pharmacies meaning that the service couldn't move forward. Issues such as this may now resolve themselves with contracts for GPs and Pharmacists now being held by NHS England.

6. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

- Boehringer Ingelheim have worked in partnership with several CCGs to identify patients with COPD in the community through a programme called Know it, Check it, Treat it. When this was run for a week in Hertfordshire in September 2013, 10% of the people who were screened during the campaign were found to have COPD. National funding for this kind of project could have enormous impact on reducing the number of people undiagnosed with COPD, and therefore have an impact on quality of life, unplanned hospital admissions and even premature mortality.

9. Do you have any other comments relevant to this inquiry?

¹ The Burden of Lung Disease: Report 2, British Thoracic Society, 2006.

² UK mortality from respiratory disease is 5th worst in the EU, after Denmark, Ireland, Belgium and Hungary. ERS White Book - the Burden of Lung Disease, Figure 1. Last accessed on October 2013. <http://www.erswhitebook.org/chapters/the-burden-of-lung-disease/>

³ Department of Health, *England level data by programme budget*. Downloaded from: <https://www.gov.uk/government/publications/2003-04-to-2010-11-programme-budgeting-data>. Accessed on 01/10/2013

⁴ 7,500 lives could be saved in England when total deaths were 23,000 per year from COPD. Outcomes Strategy for Asthma and COPD: NHS Companion Document, Department of Health, May 2012.

⁵ Partridge M, Self care plans for people with asthma. The Practitioner 1991, p 715-21

⁶ Health Survey for England 2001. The Scottish Health Survey 2003. Welsh Health Survey 2005/2006. Northern Ireland Health and Wellbeing Survey 2005/2006. Population estimates from Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics & Research Agency

⁷ Outcomes Strategy for Asthma and COPD: NHS Companion Document, Department of Health, May 2012.

⁸ Health Survey for England 2001. Population estimates from Office for National Statistics

⁹ Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics & Research Agency

¹⁰ OECD, Deaths - *International comparisons, all ages*. Downloaded from <http://stats.oecd.org/> Accessed on 02/10/2013

¹¹ All references in this paragraph: An Outcomes Strategy for COPD and Asthma, Department of Health, July 2011.

APPG on Respiratory Health - Questions

Personal Information:

Name:	IAN CULLIGAN
Job Title:	LEAD PHYSIOTHERAPIST
Organisation:	WIRRAL UNIVERSITY HOSPITALS NHS TRUST
Region/location:	WIRRAL, NORTH WEST
Capacity in which you are replying to the inquiry	Specialist Physiotherapist

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

Absolutely not. There is less investment on the ground in respiratory specialists (Doctors, Nurses, AHP's) and less recognition of the disease burden. Fewer pulmonary rehab programmes compared to cardiac rehab and this is similar in the charitable field with many more cardiac / stroke charities compared to respiratory.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

Improve investment and training of staff, make it more appealing.
Increase public awareness in COPD and other respiratory conditions and develop an effective smoking campaign which works on a large scale.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

Poor socio-economic factors, poor patient education, lack of specialists and joined up working between healthcare providers. Insufficient attempts at helping people quit smoking.

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

Poor socio-economic due to lack of education and occupational factors

5. What can the Government and the NHS in England do to reduce respiratory deaths?

Invest in respiratory services which are effective

Chronic Obstructive Pulmonary Disease (COPD) Questions:

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

Lack of patient and staff education
Smoking
Poor acute respiratory management and a lack of specialists at first point of contact (A+E)
Lack of relationships between primary and secondary care
Inconsistent information given to patients

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

Social and behavioural factors
Staff attitudes and quality of training / dissemination of knowledge
Unglamorous
Not in public eye

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?

Prevention and Detection
Improve stop smoking services
Improve public campaigns
Upskill clinicians (GP /PN) to spot early signs and intervene sooner
Increase Pulmonary Rehab investment

4. What could the Government in England do to reduce premature mortality from COPD?

Plain packaging cigarettes if proven benefit
Continue investment in NHS

1. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

Pulmonary Rehab

5. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

Upskill clinical staff
Increase awareness and campaigns
Barriers - social psychology / education / behaviour

6. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

Integrated COPD service on Wirral is excellent example of MDT working
Pulmonary Rehab is desperately underfunded

2. Do you have any other comments relevant to this inquiry?

Name:	Dr Gwyneth Davies
Job Title:	Clinical Senior Lecturer & Respiratory Physician
Organisation:	ABMU Health Board
Region/location:	Swansea, Wales
Capacity in which you are replying to the inquiry	Respiratory Physician

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

No. Respiratory services are underfunded, particularly in relation to those for ischaemic heart disease relative to the health burden posed. This is exemplified by poor ratios of specialist to patient ratios for different specialties across the UK, in comparison to RCP recommendations. Inequity in service provision is mirrored by the proportion of research funding associated with different conditions.

The *Burden of lung disease* (BTS, 2006) documents that respiratory diseases kill one in four people in the UK, with the standardised mortality ratio for respiratory diseases showing a threefold difference across social classes. More people die from respiratory disease than from ischaemic heart disease and the UK has one of the highest mortality rates for respiratory disease in Europe (nearly twice the European average). Respiratory diseases are the most common cause of long-term illness in children, result in the highest levels of consultations with general practitioners and are the second most common reason for emergency hospital admission. Examples of the severity of the situation are as follows:

- respiratory disease kills one in four people
- respiratory disease has the steepest socio-economic mortality gradient of any disease area
- respiratory disease is the most common reason for general practitioner consultation
- the only countries in Europe with a worse mortality rate from respiratory disease than the UK are Ireland, Malta, Kyrgyzstan, Tajikistan, Kazakhstan, Uzbekistan and the Republic of Moldova
- 5-year survival from lung cancer is <8% (only pancreas is worse, 7000)

- cases/year)
- asthma is the most common chronic illness in children and pregnant women

References

Stephen T Holgate, on behalf of the UK Respiratory Research Strategy Committee. Priorities for respiratory research in the UK. *Thorax* 2007;62:5-7 doi:10.1136/thx.2006.073882

http://www.brit-thoracic.org.uk/Portals/0/Library/BTS%20Publications/burden_of_lung_diseases.pdf

The burden of lung disease. ERS white book.

<http://www.erswhitebook.org/chapters/the-burden-of-lung-disease/>

2. What changes can be made to improve outcomes for all or most respiratory conditions?

- Patient education e.g. early signs of lung cancer; self-management of asthma/COPD
- Effective smoking cessation campaigns - unbranded packaging; funding of smoking cessation counsellors
- Adequate resource so that appropriate specialists see patients; expand consultant numbers to meet minimum RCP targets
- Adequate resource so that specialists with appropriate expertise see patients, with appropriate access to multidisciplinary specialist teams e.g. difficult asthma services, allergy services.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

As for 2

- Patient education
- Effective smoking cessation
- Inadequate resource so that appropriate specialists do not see patients; insufficient consultant numbers to meet minimum RCP targets

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

Smokers

Lower socioeconomic groups - poorer education on risks, reduced access to health care

Psychosocial morbidity - e.g. for asthma deaths and generally in terms of accessing healthcare and concordance with medication.

5. What can the Government and the NHS in England do to reduce respiratory deaths?

As above:

- Patient education e.g. early signs of lung cancer; self-management of asthma/COPD
- Effective smoking cessation campaigns - unbranded packaging; funding of smoking cessation counsellors
- Adequate resource so that appropriate specialists see patients; expand consultant numbers to meet minimum RCP targets

Asthma Questions:

1. What are the most important factors contributing to asthma deaths?

Will be informed by NRAD

- Psychosocial factors
- Poor concordance with treatment
- Food allergy

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

Risk markers include those with psychosocial morbidity, poor concordance, food allergy.

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

- Effective education to patients that need it most
- Effective education to health care providers; interface between primary/secondary care; dissemination across health care providers
- Effective multidisciplinary working e.g. the role of pharmacists in the effective Finnish asthma programme
- Limited resource to support asthma care, in particular difficult asthma services: consultants, specialist asthma nurses; clinical psychologist

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

Not deaths but the Finland national asthma programme showed remarkable benefits in terms of healthcare utilisation e.g. a 54% reduction in hospital days.

5. What can the Government in England do to reduce asthma deaths?

- Ensure that appropriate asthma related targets are used in primary and secondary care
- Provide adequate resource to support asthma care, in particular difficult asthma services
- Reduce inequity across social classes which contributes to worse

education and health care access

- Fund appropriate research to reduce asthma deaths

6. What can the NHS in England do to reduce asthma deaths?

- Ensure resources are distributed to where they are most needed
- Develop 'at risk' registers of asthma patients who can be targeted with intervention to reduce risk of death and hospitalisation
- Improve education to patients and healthcare providers
- Facilitate smooth interfacing and effective communication between community/primary/secondary care
- Work with researchers to identify risk factors for deaths and ways to address these in terms of effective interventions

7. Do you have any other comments relevant to this inquiry?

Name:	Graham Devereux
Job Title:	Professor of Respiratory Medicine Honorary Consultant Physician
Organisation:	University of Aberdeen Aberdeen Royal Infirmary
Region/location:	Aberdeen, Scotland
Capacity in which you are replying to the inquiry	Respiratory Physician who deals daily with respiratory disease 23 years experience of respiratory disease Researcher into the natural history and risk factors for asthma and COPD
List of any supplementary information attached (if any)	Reid et al 1998 Jones et al 1999 Both papers describe the major inaccuracies in the certification of asthma deaths in the UK

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

Respiratory diseases are the poor relation to the big killers, however lung cancer is the greatest cause of cancer death in the UK and services are lamentable, in Aberdeen we have one lung cancer nurse for 400 patients a year, with 70% of patients dying within a year, in contrast there are 6 breast cancer nurses for 300 patients a year.

There is a general opinion by politicians, NHS managers and unfortunately patients themselves that they deserve lung disease because they smoked, this is grossly unfair as nearly all diseases have a lifestyle component.

Respiratory diseases affect the most disadvantaged groups of our society and the least vociferous, the patients seem to accept their lot in life, most of them are too ill or die too quickly to campaign.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

Prevention is always better than cure. Invest in smoking cessation, reduction, avoidance, legislation, education.

Invest in education to teach smokers for what symptoms to look for, there is much educational effort put into bowel and breast cancer

Invest in research to identify environmental factors into the aetiology of disease and intervention. The huge amounts of money spent on identifying genes and molecules in mice will never prevent asthma that has a huge environmental component that can be manipulated.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

The patients are from the most disadvantaged groups of our society
There is a general resignation that they deserve their lung disease because of smoking
Continued smoking
Many patients from the most disadvantaged groups view the NHS with distrust as a 'big brother' organisation that tells them what to do.

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

Lower social class
Smokers
Poor diet
Maternal smoking during pregnancy
Maternal grandmothers smoking during pregnancy
Obese
Dusty occupations
Certain occupations associated with occupational asthma

5. What can the Government and the NHS in England do to reduce respiratory deaths?

Prevention, prevention, prevention

Asthma Questions:

1. What are the most important factors contributing to asthma deaths?

The majority of asthma deaths in the over 65s tend to be in patients with COPD, essentially many of the deaths are incorrect diagnoses of asthma in people with COPD or in people with a life long history of untreated asthma that is essentially behaving like COPD. David Hendrick in Newcastle investigated asthma death certification in the 1990s (European Respiratory Journal 1998; 12(5):1079-83, Respiratory Medicine 1999; 93(12):923-7) and noted that 43% of asthma deaths never had asthma and that the majority (>75%) of asthma deaths in the >65s were incorrect and 45% of the asthma deaths in the <65s were incorrect. Overall 64% of deaths attributed to asthma were incorrect. In addition it was noted that many of the precipitant causes of death in people with asthma were unrelated to asthma (septicaemia, gastric aspiration, illicit drug use) or were a consequence of co-morbidities such as heart disease. Recently as part of NRAD, I was invited to complete two forms for patients of mine labelled as 'asthma deaths,' in fact, one had died of COPD and one had died of a myocardial infarction. This raises concerns about the accuracy of NRAD. In my 25 years as a chest physician I have never seen an asthma death in hospital, I have heard of 2-3 anaphylactoid type asthma deaths in young people outwith the hospital in that time

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

Patients with poorly controlled asthma, those with poor socio-economic

circumstances, psychological co-morbidity, smokers, those on beta-blockers, those with egg/peanut allergy.

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

When I worked in England a major challenge was the prescription fee, if an asthma patient has to use 4 inhalers a month, this works out as very expensive and they tend to go for as many as they can afford and the one that they think gives them the most relief. I have not encountered this since the prescription fee was abolished in Scotland.

Patient compliance with medication is a major issue, when patients with life threatening asthma have psychological issues and a chaotic lifestyle eg son/daughter drug addict, lost job, being divorced, their asthma is the least of their problems, hence they tend not to take their medication.

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

Finland

5. What can the Government in England do to reduce asthma deaths?

Abolish the prescription fee for asthma medication
Legislate against smoking, this will reduce the number of children developing asthma (maternal/grand maternal smoking during pregnancy is a risk factor for asthma), passive smoking makes asthma worse and smoking prevents corticosteroid (preventer) inhalers from working.

6. What can the NHS in England do to reduce asthma deaths?

Promote the correct diagnosis of asthma and the correct certification of deaths in people with asthma

7. Do you have any other comments relevant to this inquiry?

How about a bit of perspective, the risk of dying from asthma is very low 1000-1500 deaths a year from a patient population of 5 million, I would argue from David Hendrick's work that actual deaths are 500-800. Compare this with 28,000 deaths from COPD and 35,000 deaths from lung cancer. There are 2,000 deaths a year from road traffic accidents, 5,000 from 'injuries'

Chronic Obstructive Pulmonary Disease (COPD) Questions:

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

We are reaping the consequences of our industrial past: in certain areas of the population 70-80 years ago. Children born and brought up in socially disadvantaged areas have reduced lung function due to a combination of air pollution, parental smoking, poor diet. If these children smoke they are far more likely to develop COPD (their lungs have never reached their maximal potential). There are strong associations between low birth weights 60-70 years ago and COPD mortality, notably in the former industrial areas of the north west and north east. The usual comment is that a smoker in Glasgow is far more likely to develop and die of COPD than a Southern European, most probably because of the adverse effects

of poor early life exposures and poorer lifestyle choices (many of which are outwith their control).
Additional contribution from our industrial past include dusty occupations and air pollution.

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

Many patients with COPD continue to smoke
Considered to be a smokers disease 'what do they expect' apathy on the part of public health, politicians
Patients are from the most disadvantaged groups of society, they are embarrassed and accepting of their fate.
Poor services especially pulmonary rehabilitation
Relatively ineffective drugs to treat COPD
High rates of co-morbidity in the UK population (industrial past issues)

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?

Smoking cessation
Improve lifestyle choices
Research prioritise COPD medication development

4. What could the Government in England do to reduce premature mortality from COPD?

Smoking legislation

8. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

Current medications do not impact on mortality

5. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

Education, provision of open access spirometry
Outreach clinics whereby hospital chest physicians see patients in General Practice to confirm/refute diagnosis

6. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

Negligible investment in pulmonary rehabilitation
Continuous pressure from NHS management to reduce the spend on respiratory drugs

9. Do you have any other comments relevant to this inquiry?



A confidential enquiry into certified asthma deaths in the North of England, 1994–96: influence of co-morbidity and diagnostic inaccuracy

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To understand more fully the nature of events leading to asthmatic death, we conducted a confidential enquiry prospectively throughout 1994–96 among the surviving relatives and respective general practitioners of subjects whose deaths could be attributed to asthma, whether wholly or partly. We also reviewed relevant hospital records and autopsy reports, and we submitted all the gathered information to an enquiry panel for evaluation. The subjects were identified from death certificates issued in five districts of the Northern Health Region of England (population 1 million) on which asthma was recorded as the primary cause of death.

The enquiry panel agreed that asthma had been a critical factor in causing death in only 33 of the 79 certified cases for which there were sufficient data. The level of concordance was substantially greater for subjects aged <65 years (76%) than for those who were older (17%). In 16 of the 33 cases asthma alone appeared to be responsible for death, but in 17 cases a wide variety of additional, co-morbid, disorders appeared to have contributed. They included, during the 24 h preceding death, gastric aspiration, septicaemia, a single dose of a beta-blocker, the abuse of organic solvents or illicit drugs and possibly, an inadvertent exposure to horse allergen. More chronic causes of co-morbidity included ischaemic heart disease, chronic obstructive pulmonary disease (COPD), thoracic cage deformity and alcohol abuse. There were possible errors of judgement in two cases by the supervising physician (6%) and in three cases by the patient (9%). Poor compliance and psychosocial disruption probably exerted an additional adverse influence in nine cases (27%).

We conclude: (1) that asthma death certification in subjects aged 65 years or more is very unreliable, (2) that for approximately half of the deaths in which asthma exerted a critical role there were critical co-morbid disorders and (3) that errors of judgement, poor compliance, or psychosocial disruption are likely to have exerted an additional adverse influence in an important minority of cases.

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Introduction

Asthma mortality has provoked much debate over the past two decades, chiefly in relation to its prevention but also because of doubts concerning the accuracy of reported statistics. Evidence of both false positive and false negative diagnostic labelling has complicated the evaluation of factors which may exert an important influence, and this may have hampered the development of effective strategies for prevention (1–5). It has become evident, nevertheless, that in many asthmatic deaths in Britain, potentially preventable factors probably exerted a critical influence

(6). This has stimulated a need to better understand the characteristics of those who die and the circumstances of their fatal asthmatic episodes.

Severity of the disease itself and marked variability of its clinical expression are of clear major importance, and the concept of 'brittle' asthma has been helpful in identifying asthmatic patients at particularly high risk. There are also clear differences in the use of medication if asthmatic subjects who die from exacerbations of their disease are compared with those who survive. An increased risk of death is associated with an excess use of bronchodilators (not necessarily a causal association) and a diminished regular use of inhaled steroids, and there are additionally links with the use of tranquillizers, cocaine and other illicit medications (7–9). Thus, as many as 17% of subjects dying from asthma in one North American series had histories of drug abuse (10). Other factors attracting recent concern have included the ease of contact between patient and healthcare professionals (e.g. availability of medical

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advice/assistance, geographic distance, telephone communication, transport), the level of perception by both patient and physician that exacerbations may be of life threatening degree, the adequacy of emergency medical care and a variety of psychosocial issues (11–14).

In order to evaluate the wide variety of potentially relevant factors and to obtain a measure of perspective, there is a role for confidential enquiries among surviving relatives and the healthcare professionals who were involved in managing the individual cases. Such enquiries may allow information of relevance to emerge more readily and more fully than would otherwise be possible. A confidential approach was consequently adopted by the Mortality and Severe Morbidity Working Group of the U.K. National Asthma Task Force when it was formed in 1991 with support of the National Asthma Campaign, the British Thoracic Society, the Royal College of Physicians and the Royal College of General Practitioners. Its primary aim was to review certified asthma deaths in subjects aged less than 65 years, in whom inaccuracy of death certification was thought not to be a major problem.

The present paper reports the findings from one of the contributing regions, the Northern Region of England, but it considers certified asthma deaths at all ages and it particularly reviews the accuracy of the certified cause of death in relation to the nature of the events leading to death.

Methods

The enquiry reviewed the circumstances leading to death, for which asthma was certified to be the direct cause, during the 3 yr period 1st January 1994 to 31st December 1996. The parent population comprised approximately 1 million people living in five districts (three rural, two urban) within the Northern Health Region of England—Northumberland, Newcastle upon Tyne, North Tyneside, East Cumbria and West Cumbria.

The study was prospective in nature and involved a number of phases, all under the understanding of strict confidentiality: (1) identification of cases from death certificates and a reporting network, (2) informal contact with the patient's general practitioner followed by a more formal interview and the completion of a standardized questionnaire, (3) review of hospital case notes and autopsy details whenever available, (4) interview and questionnaire completion with the patient's closest surviving relative whenever possible and appropriate and (5) an annual assessment of new cases by an enquiry panel of two consultant respiratory physicians, a senior lecturer in primary healthcare, two general practitioners, a practice nurse and a research nursing sister. Inevitably full details were not always obtainable, particularly concerning the deaths of the more elderly subjects.

The panel first separated the cases into three groups according to whether asthma was judged to be the sole cause of death (uncomplicated asthma death), whether asthma contributed critically to death but another disorder (or disorders) contributed also (complicated asthma death),

or whether asthma did not contribute to death (non-asthma death). Particular attention was paid to the age at death, since the accuracy of asthma death certification has been reported to differ before and after the age of 65 years.

Results

A total of 80 cases were identified for which the death certificate reported asthma to be the primary cause of death, and sufficient data were obtained for 79 for the enquiry panel to make a judgement as to whether or not asthma had played a critical role. By 'critical' the panel considered that had it not been for asthma, death would probably not have occurred. Table 1 shows the distribution by age according to the panel's judgement. The panel agreed that asthma had been critical to death in 25 of the 33 cases with age <65 years (76%) but in only eight of the 46 with age ≥65 years (17%). This age difference in the level of concordance between the panel and the physician certifying death was highly significant ($\chi^2 = 24.2$, $P < 0.0001$).

UNCOMPLICATED ASTHMA DEATHS

The panel considered that in 16 cases death was a consequence of asthma alone (48% of the 33 deaths in which asthma had been critical). Seven of the subjects were male (44%), 13 were aged <65 years (81%) and 11 underwent post mortem examination (69%). The following case histories provide illustrative examples:

Case 1: A 36-year-old man with asthma since the age of 1 year died in his car shortly after having dinner with his girlfriend. He had appeared normally well at that time, and there was no recognized immediate provoking trigger. He had had several admissions to the local general hospital because of acute attacks of asthma, but had failed to attend a number of nurse-run Asthma Clinics within the general practice. Furthermore, he had only recently returned from holiday in Greece where he had not expected to need his inhaler medication (salbutamol and high dose beclomethasone). He had not, consequently, taken this with him. Autopsy showed over-inflated lungs with mucus plugging

TABLE 1. Distribution of certified asthma deaths by age and asthma death category

Age	Panel classification of death category		
	Uncomplicated	Complicated	Non-asthma
<65 years (n=33)	13	12	8
≥65 years (n=46)	3	5	38
Total (n=79)	16	17	46

of the smaller bronchi. The heart appeared normal and no other abnormality was found.

Case 2: A 55-year-old nurse, who attended the local general hospital's Chest Clinic regularly with well documented atopic asthma and aspirin sensitivity, died suddenly in an asthma attack. Her asthma had been regarded as 'brittle' by her supervising respiratory physician and she had required treatment with high doses of inhaled steroid, frequent intermittent courses of oral steroid and, at times, maintenance oral steroid. She was thought to be a 'poor perceiver' of breathlessness. Her outpatient supervision and her clinic attendance appeared exemplary.

In only one case was longstanding asthma in a never-smoker associated with severe and progressive fixed airways obstruction and cor pulmonale, though in several a high-risk for asthmatic death was readily evident.

COMPLICATED ASTHMA DEATH

The panel considered that in 17 of the 33 cases of asthma death (52%) there was a relevant 'co-morbid' disease which was also critical to death. Eleven of the subjects were male (65%), 13 were aged <65 years (76%) and 14 underwent post mortem examination (82%). The following case histories provide illustrative examples:

Case 3: A 57-year-old man with atopic asthma since childhood was found dead, slumped over the bedroom floor apparently trying to use his nebulizer. Two days previously he had phoned a friend to say he was feeling too unwell to visit. Post-mortem examination showed both lungs to be moderately hyperinflated but additional findings included severe kyphoscoliosis and an 80% stenosis of his left anterior descending coronary artery, as well as severe atheromatous change in other coronary vessels. It seemed unlikely that asthma alone was responsible for death, though it probably contributed to it.

Case 4: A 61-year-old woman, not known to have asthma but having neglected diabetes, hypertension, obesity and previous cardiac failure, became acutely breathless and was found to be dead on arrival at the nearest hospital. Post-mortem examination showed long tenacious plugs in her bronchi and severe left ventricular hypertrophy, but the pathology report made no mention of pulmonary oedema. Again, it seemed unlikely that asthma had been the sole cause of death. Although she had been in respiratory distress, her death was sudden and unexpected, and may have been precipitated by a cardiac dysrhythmia consequent to the metabolic effects of the acute asthmatic attack and, perhaps, the diabetes.

Case 5: A student aged 19 years had become unduly anxious over college examinations. He consulted a new general practitioner, and reported mild asthma which was only intermittently troublesome. At the time he was using no regular asthma medication. The practitioner considered the use of beta-blocker to be justified, but an hour or so after the first dose the student became wheezy and moderately distressed. He sought assistance at a local cottage hospital which had limited facilities for emergency care. Another practitioner was summoned and went

directly from her horse stable to administer intravenous and nebulized bronchodilator therapy, but the student deteriorated and died before he could be transferred to the nearest general hospital. By an unfortunate chance he was allergic to horses, which might possibly have been a further contributory factor to his death.

Case 6: A 13-year-old asthmatic boy, treated with regular inhaled steroid, had been hill-climbing during the day, but then collapsed suddenly and died during the early evening. Post-mortem examination showed hyperinflated lungs with extensive mucus plugging. There was also evidence of minor aspiration of gastric contents and a blood sample taken at the autopsy suggested that solvent abuse had probably occurred. This possibly stimulated vomiting, aspiration and the fatal asthmatic episode.

One death was associated with the use of illicit drugs, one was associated with alcoholism and one was the result of septicaemia following lung transplantation for severe asthma.

NON-ASTHMA DEATH

The panel considered that in 46 cases asthma had neither caused nor contributed to death. Eighteen of the subjects were male (39%), eight were aged <65 years (17%), and nine underwent post-mortem examination (20%). In five cases the panel considered that COPD was the primary cause of death, with or without a cardiac component, in one, death appeared to have been a consequence of pneumonia and in another (an infant), post-mortem examination favoured bronchiolitis as the probable cause of death, not asthma. In many of the older subjects (the great majority) the immediate cause of death was not evident from the information available, though this was sufficient for asthma to be considered improbable. The following histories provide illustrative examples:

Case 7: An 84-year-old man had first been diagnosed as having asthma when aged 76 years, which the general practitioner later reported 'was always well controlled'. He had also been thought to have farmer's lung, but there was no available smoking history. Increasing breathlessness led to an emergency hospital admission where investigation revealed cardiac failure, atrial fibrillation and pulmonary oedema, together with mild renal failure and a raised level of cardiac enzymes suggesting a small infarction. At discharge, following appropriate treatment, there was still radiological evidence of heart failure. Two subsequent emergency admissions within 4 months culminated in death. Severe cardiac failure and uncontrolled atrial fibrillation during the terminal admission resisted intensive therapy (including intravenous steroids because of the history of 'possible asthma') and a very high level of serum cardiac enzymes was measured. The admission summary recorded three diagnoses—myocardial infarction, ischaemic heart disease and COPD—but gave no respiratory data. The death certificate nevertheless recorded asthma as the primary cause of death.

Case 8: A 56-year-old woman, who smoked heavily, was noted in the general practice records to have 'bronchitis' in

1986 and 'asthma plus chest infection' in 1990, at which time peak expiratory flow measurements varied from 140 to 180 min⁻¹. In 1991 she was noted not to have benefited subjectively from prednisolone and nebulized salbutamol. In 1992 she was seen by a local respiratory physician who diagnosed 'chronic bronchitis and emphysema'. The precise circumstances of her death in 1995 were uncertain but were thought to have followed a gradual deterioration.

ERRORS OF JUDGEMENT, POOR COMPLIANCE, AND PSYCHOSOCIAL DISRUPTION

Among the subjects whose death the panel attributed to asthma (whether wholly or partly) there were a number of additional factors, apart from co-morbidity, that may have exerted an important influence.

Patient error of judgement probably contributed to the deaths of three subjects. They comprised a 54-year-old woman with recognized brittle asthma who went home to use her nebulizer after developing a severe asthma attack while shopping, rather than seek emergency care from the nearest hospital as she had been advised; the 36-year-old man who died soon after returning home from an overseas holiday where he had discontinued his inhaler medication because he had felt so well; and a 63-year-old man who had suffered increasing nocturnal respiratory discomfort but had apparently not wished to disturb his wife by calling his general practitioner until he had lapsed into an extreme and irrecoverable state. His death occurred a week after his daughter had delivered stillborn twins after 37 weeks of pregnancy, and this had already caused his wife (and the rest of the family) considerable stress.

In two cases, including that of the student given a beta-blocker, there was a suggestion of judgement error by the supervising physician. The other case involved a 62-year-old man, apparently known to have had asthma for several years, who had died from an asthmatic attack just nine months after being prescribed no more than a dose of a bronchodilator inhaler as required. There was no evidence that he had received any functional assessment or regular supervision, but nor was there evidence that he had sought further advice when his symptoms deteriorated.

In five cases there were clear written references to poor compliance with medication or to multiple failures to attend clinic appointments, and in four emotional stress or social factors were prominent. One man had just left the family home as a consequence of marital disruption and had his fatal episode within the unfamiliar environment of a Salvation Army hostel.

Discussion

The enquiry helped clarify three major issues of interest. Firstly, it suggested that the certification of asthma death in subjects aged 65 years or more is associated with a substantial degree of inaccuracy. Secondly, it revealed that for the majority of deaths in which asthma is likely to have

played a critical role, a variety of co-morbid disorders played a critical contributory role. Thirdly, it identified among the cases of both uncomplicated and complicated asthma death, a meaningful minority for which errors of judgement, poor compliance, or psychosocial disruption are likely to have exerted an important adverse influence.

The panel agreed that asthma had played a critical role in causing death in only 33 of the 79 cases of certified asthma death over the 3 yr surveillance period, for which there were sufficient data. This implies an annual mortality rate from asthma of about 11 million⁻¹, but it ignores false negative certification. The rate of 11 million⁻¹ (approximately a third of that recorded nationally) therefore represents a minimum. False positive certification appeared particularly common in subjects aged 65 years or more, thereby supporting the conclusions of other investigations that asthma death certification is very unreliable in this age group (4,5). It is only when there is confidence in accepting asthma as the cause of death, whether it be the sole or partial cause, that meaningful strategies for prevention can be considered.

In fact asthma was judged to be the sole cause of death in 16 of the 33 cases (48%). For the majority, co-morbid disorders were considered to have exerted a critical contribution. Most prominent were other common chronic disabling diseases, ischaemic heart disease and COPD, but the investigation was notable for identifying a variety of additional sources of co-morbidity—thoracic cage deformity; aspiration of gastric contents; septicaemia; abuse of alcohol, organic solvents and illicit drugs; anxiety and the prescription of a beta-blocking drug; and (possibly) inadvertent exposure to horse allergen.

In two of the 33 cases (6%) there were possible errors of judgement by the supervising physician (the prescription of a beta-blocker, and the failure to prescribe regular inhaled corticosteroids), and in three cases (9%) errors of judgement could be attributed to the patients. Poor compliance and psychosocial disruption probably exerted an additional adverse influence in nine cases (27%). Among those managed according to current guidelines, the proportion of cases in which death might readily have been prevented was small. This is reassuring from the viewpoint of the guidelines, but disturbing in the sense that the guidelines were not always followed nor were they fully effective. Strong dissatisfaction with the healthcare services was expressed by a few of the surviving relatives, and it was evident that the possibility of death had been poorly perceived by the relatives and physicians of some of these subjects.

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Age-dependent inaccuracy of asthma death certification in Northern England, 1991–1992

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Age-dependent inaccuracy of asthma death certification in Northern England, 1991–1992.
D.W.E.C. Reid, V.J. Hendrick, T.C. Aitken, W.T. Berrill, S.C. Stenton, D.J. Hendrick. ©ERS Journals Ltd 1998.

ABSTRACT: Asthma mortality appeared to increase two-fold in the UK from the mid-1970s to the early 1990s, but there is evidence of inaccuracy in asthma death certification and so a region-wide investigation was undertaken to assess whether this recorded statistical trend might have been partly or wholly artefactual.

A total of 35 respiratory physicians, distributed in panels of three, systematically reviewed the hospital and general practice records of 210 subjects with physician-diagnosed asthma who died in 1991 and 1992. The death certificates indicated that asthma was considered to be the primary cause of death in 103 (group 1), a contributory cause in 70 (group 2) and not relevant in 37 (group 3).

There was agreement within the panels that 43% of the subjects had probably never suffered from asthma. Discordance between the panels and the certifying physicians over the correct death certification category was high for group 1 (45% for those aged <65 yrs, 75% for those aged ≥65 yrs and 64% overall) and group 2 (67%), but much less for group 3 (22%).

This study concludes that asthma death certification provides a markedly inaccurate picture of asthma mortality, particularly in elderly subjects. Thus, it is speculated that if the magnitude of this source of inaccuracy has increased over the last two decades, the apparent recent increase in asthma mortality may be largely artefactual.
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Asthma morbidity in England and Wales appears to have increased in recent decades, despite advances in therapy, and this is widely attributed to increasing asthma prevalence. This increase has not, however, been fully reflected by mortality trends, and in children and young adults, there have been no clear changes. In adults aged ≥45 yrs (in whom >85% of current asthma deaths are recorded), mean annual mortality doubled between the mid-1970s and the early 1990s in both sexes [1, 2]. The rate of change and the degree of annual fluctuation increased with age, and the apparent increase was most evident in those aged ≥65 yrs.

The cause of the marked increase in recorded asthma deaths in this age group is uncertain. If correct, it could reflect improved diagnostic recognition, an increase in asthma prevalence, an increase in disease severity or an adverse effect of medication. The 1979 and 1984 changes in international coding practice (International Classification of Diseases (ICD) 9, implementation of rule 3) artificially increased the mortality rate in those aged <45 yrs and >75 yrs, respectively, but this provides insufficient explanation for the observed trends [2–4].

Alternatively, the increase may be largely artefactual. The accuracy of death certification is known to decline with advancing age, and there is concern that recent trends, especially in the elderly, may be attributable to diagnostic transfer [5, 6]. An audit investigation in the period 1980–

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1989 in one district of the Northern Health Region of England suggested that the majority of certified "asthma deaths" had occurred in elderly smokers who had neither died from asthma nor suffered from it [7]. Other studies have suggested that asthma death certification for the whole population may overestimate the number of true asthma deaths by 13–47%, with the degree of inaccuracy in certification rising in the elderly to 39–80% [8–10].

The recorded asthma mortality rates of 3.94 and 3.64 per 100,000 for the Northern Health Region (population 3.07 million) for the years 1991 and 1992, respectively, closely reflect the national figures for England and Wales of 3.67 and 3.48 (total population 51 million). Therefore, experience within the northern region as a whole is likely to be representative of the national picture. The aim of this study was, consequently, to estimate the magnitude of any inaccuracy in death certification for asthma within this region, and hence, to assess whether the apparent increase in asthma mortality in the elderly could have occurred, at least partly, as a result of diagnostic transfer.

Methods

Subjects

Permission was obtained from 13 of the 16 local Health Authorities for a review of death certificates for the years

1991–1992. Those that included the word "asthma", either as the direct cause of death (part 1 of the certificate) or as a contributory cause (part 2 of the certificate), were identified. In addition, a random sample was sought from Regional Health Authority records of patients who had died within these districts over the same period and who had a diagnosis of asthma recorded in their hospital records, but whose death certificate did not mention asthma. Hospital and general practice records were sought for all cases.

We identified 375 relevant death certificates and for 215 of these the full hospital and general practice records were obtained. There was additional information from *post mortem* examinations for 41 of these cases. The failure to retrieve both hospital and general practice records in 160 cases was not associated with any obvious bias of relevance to death certification with regard to age or sex, although those included were more likely to have died in hospital than the 160 who were not included (69 *versus* 37%). In 67% of these 160 cases, either the hospital records or the general practice records were available for review, but not both, and so we decided to investigate only those for which there were full records from both sources. As a consequence, an unknown number of cases were excluded because there had been no hospital referrals and hence no hospital records.

Study groups, case batches, and sentinel cases

Of the 215 cases with both hospital and general practice records, the initial 210 were classified into three groups: group 1, asthma certified as the direct cause of death (103 cases, 49%); group 2, asthma certified as a contributory but not direct cause of death (70 cases, 33%); and group 3, asthma not mentioned on death certificate but recorded in hospital records as an active problem (37 cases, 18%). Of these 210 cases, 204 were drawn together into 17 batches of 12, each batch containing at least one case from each death certification group. The six other cases, two from each death certification group, had been selected at random as "sentinel cases" to assess consistency and repeatability among the reviewers. They were distributed in two sets of three cases (one from each certification group). One set was included in all odd numbered batches, and the other in all even numbered batches, so that each reviewed batch of 15 cases contained 12 regular cases for single review and three sentinel cases for multiple review. The remaining five of the 215 cases were insufficient to form a batch and so were not included in the investigation.

Reviewer panels

Each batch of 15 cases was reviewed by a panel of three respiratory physicians, two trained consultants and a registrar trainee. New panels were constituted as each case batch was prepared, so that the task was shared as evenly as possible. All regional consultants and trainee registrars were invited to participate and almost all did so, *i.e.* 23 consultants and 12 registrars, each reviewing one to three (usually two) batches of cases. Each physician reviewed the data independently without seeing the death certificates, and without knowledge of the distribution of cases by certification group or sentinel status. It was known, however, that all three death certification groups would be represented.

Systematic reviews

A standardized questionnaire was used to aid the physicians summarize their reviews of the hospital and general practice records. They were then asked to conclude whether: the subject had asthma, asthma directly caused death or asthma contributed to death if it was not the direct cause; they were also asked to identify the level of probability associated with each conclusion: most unlikely, *i.e.* <10%; probably not, *i.e.* 10–29%; conceivable but unlikely, *i.e.* 30–49%; more likely than not, *i.e.* 50–69%; probably, *i.e.* 70–89%; or almost certainly, *i.e.* ≥90%. They were also invited to identify any other disorder that they considered was the direct or a contributory cause of death.

Analytical methods

The primary method of analysis, leading to a "consensus" conclusion, was based on the categorical result from each reviewer; *i.e.* was the answer to a given question probably yes (≥50% probability) or probably no (<50% probability)? The agreement of at least two of the three reviewers was required for each nonsentinel case, and a majority of at least two thirds among the many reviewers for each sentinel case. As an alternative method of analysis, the mid-points within each probability range (*i.e.* 5, 20, 40, 60, 80, 95%) were used to obtain a score from each reviewer, thereby taking account of the reviewer's individual levels of confidence. Providing that at least two panel physicians were able to offer a score, the panel conclusion for each question was then expressed by the "mean panel score". A mean score ≥50% indicated a positive (yes) answer to the question posed.

Results

Demographic data

Of the 210 cases, 91 were males and 119 were females. Of the males, 35 (38%) were aged <65 years, and 56 (62%) ≥65 yrs. Of the females, 33 (28%) were aged <65 yrs, and 86 (72%) ≥65 yrs.

Asthma diagnosis

The panels agreed by consensus with the diagnosis of asthma in 120 (57%) of the 210 cases (unanimously in 78, by majority in 42), and disagreed in 89 (unanimously in 52, by majority in 37). In one case, there was insufficient information to permit a consensus conclusion, two reviewers disagreeing with each other and one abstaining because the data were considered inadequate. The percentage of subjects thought to have had asthma was similar in all death certification groups: group 1, 55%; group 2, 57%; and group 3, 59%. However, the percentages differed significantly between those aged <65 yrs and those who were older (70 *versus* 50% respectively; $\chi^2=5.986$; $p<0.05$).

Asthma mortality

The reviewing panels were able to reach a conclusion about the cause of death in 191 of the 210 cases (unanimously in 61% and by majority in 39%). Their conclusions, by the consensus method, are shown in table 1. The

Table 1. – Conclusions by consensus on relevance of asthma to death, by certification group

Panel conclusion	Death certification			
	Group 1 direct	Group 2 contri- butory	Group 3 irrele- vant	Total
All subjects	86	67	37	190
Direct	31	1	4	36
Contributory	13	5	4	22
Not relevant	42	61	29	132
Subjects aged <65 yrs	31	15	14	60
Direct	17	0	3	20
Contributory	5	2	2	9
Not relevant	9	13	9	31
Subjects aged ≥65 yrs	55	52	23	130
Direct	14	1	1	16
Contributory	8	3	2	13
Not relevant	33	48	20	101

Values are numbers of cases.

panels agreed with the certifying physicians that asthma was the direct cause of death in only 31 of the 86 (36%) cases so certified in group 1, and that it was of some relevance (*i.e.* direct or contributory cause) in only 50 of the 153 (33%) cases in which the word "asthma" appeared on the death certificate (groups 1 and 2 combined). They agreed with the certifying physician that asthma was not relevant to death in 29 of the 37 (78%) group 3 cases.

There was a high level of agreement among the reviewing physicians over the relevance of asthma to death in the six randomly chosen sentinel cases (table 2). Agreement was almost unanimous (>95%) in five of the six cases and by a clear majority (70%) in the other. Despite this, there was agreement between the panels and the certifying physicians in only half of these cases.

Five panel physicians unknowingly reviewed a set of three sentinel cases twice, thereby providing 15 duplicated reviews. Identical results were obtained for all but two of the 15 pairs. One reviewer considered that asthma was not relevant to death initially, but decided that there was insufficient information to judge when the case was reviewed the second time. Another initially considered asthma to be a contributory cause of death, but the direct cause at the second review.

Almost all of the group 3 subjects had died in hospital (this had no doubt helped the Health Authority to identify

Table 2. – Sentinel cases: number of respiratory physicians recording the relevance of asthma to death in each possible diagnostic category, by certification group

Physicians' conclusions	Death certification		
	Group 1 direct	Group 2 contri- butory	Group 3 irrele- vant
Odd batches	Case O1	Case O2	Case O3
Direct cause	24	0	26
Contributory cause	0	0	0
Not relevant	0	24	1
Even batches	Case E1	Case E2	Case E3
Direct cause	1	16	0
Contributory cause	0	4	0
Not relevant	23	3	24

For odd batches, there were 27 reviews and for even batches, 24. In some cases, the individual reviewer did not consider that there was sufficient evidence to offer an opinion.

them), but the sites of death (hospital or community) of the group 1 and 2 subjects were distributed much more evenly. The independent importance of place of death and age to the likelihood of discordance between panels and certifying physicians was assessed using logistic regression analysis. Discordance over the cause of death in the group 1 cases was significantly more likely with increasing age (75% for those aged ≥65 yrs *versus* 45% for those aged <65 yrs, the odds of disagreement increasing by 3.6% per year of age difference; $p=0.028$) and there was more discordance over the group 1 and 2 cases together than over the group 3 cases (67% *versus* 22%, odds ratio= 11.7; $p<0.001$). Whether death occurred in the community or hospital (*i.e.* whether the certifying physician was a general practitioner or junior hospital doctor) exerted no influence (odds ratio=1.12; $p=0.8$). The internal disagreement between panel physicians was also greater for the group 1 and 2 cases than for the group 3 cases ($p<0.001$, one-way analysis of variance (ANOVA)), but the age at death did not exert any influence on their ability to reach a conclusion or on the level of internal disagreement.

Mean panel scores

The supplementary analysis using the mean panel scores gave almost identical results to those obtained categorically by consensus. Of 209 cases for which both methods could be used to assess the diagnosis of asthma, only eight gave a positive outcome for one but a negative outcome for the other. For 191 cases, at least two panel physicians were able to offer a score for the cause of death (table 3), and for 190 of these, the results could be compared with the results of the consensus method of assessment. Inconsistencies were noted in only three, all from group 3. In one, asthma was considered a "contributory" cause of death by consensus but "not relevant" by mean score, and in another the converse occurred. In the third case, asthma was considered a "contributory" cause by consensus but the "direct" cause by mean score.

Cause of death identified by panels

In the 55 group 1 cases where the panels disagreed with the certifying physician that asthma was the direct cause

Table 3. – Conclusions by mean score on relevance of asthma to death, by certification group

Panel conclusion	Death certification			
	Group 1 direct	Group 2 contri- butory	Group 3 irrele- vant	Total
All subjects	87	67	37	191
Direct	31	1	5	37
Contributory	13	5	3	21
Not relevant	43	61	29	133
Subjects aged <65 yrs	31	15	14	60
Direct	17	0	3	20
Contributory	5	2	1	8
Not relevant	9	13	10	32
Subjects aged ≥65 yrs	56	52	23	131
Direct	14	1	2	17
Contributory	8	3	2	13
Not relevant	34	48	19	101

Values are numbers of cases.

of death, the true cause was thought to be smoking-related chronic obstructive pulmonary disease (COPD) in 28 (51%), both COPD and cardiovascular disease in six (11%), cardiovascular disease alone in six (11%), an alternative respiratory disorder in three (sarcoidosis 2%, pulmonary embolism 4%) and a variety of other diseases in 10 (18%). In two cases, the panels were unable to identify the probable direct cause of death, although in one, asthma probably contributed.

Discussion

It is well recognized that death certificates may be inaccurate, the degree of inaccuracy being greatest in the elderly, for whom there are often multiple pathologies and a natural reluctance to obtain a necropsic diagnosis. Despite this, mortality trends derived from asthma death certifications have exerted a considerable influence during recent decades, and the apparent steady rise in older age groups has led to fears that treatment may be ineffective or may have unsuspected dangers [11–14].

Our investigation suggests that inaccuracies in attributing death to asthma are likely to be substantial, although it should be recognized that the physicians certifying death may have possessed additional information of relevance to that available to the reviewing panels. Differences in opinion between certifying physicians and panel physicians do not necessarily mean, therefore, that the errors lay with the former rather than the latter. Furthermore, approximately one third of the panels' conclusions were reached by majority, not unanimous, verdict, and by corresponding mean scores in the most uncertain probability range, *i.e.* 30–69%. This implies that diagnosing asthma and assessing its relevance to death are often difficult tasks, although the panel physicians did not appear to find this more difficult in the older subjects, despite the frequency of other disorders of possible relevance. We consequently assessed the overall concordance between panels and certifying physicians by considering whether asthma was likely to have been relevant to death (*i.e.* direct or contributory case), since this would minimize differences of opinion over quantitative issues, while still allowing an assessment of the fundamental qualitative issues.

In fact, the levels of concordance were of a similar order, whether asthma was assessed specifically as the direct cause of death (*i.e.* group 1 cases only) or more widely as a factor of relevance (*i.e.* groups 1 and 2 combined). Thus, concordance proved to be poor for group 1 and 2 cases where asthma was certified to be relevant, but good for group 3 cases where the death certificates did not mention asthma. Although panel conclusions were not always clear cut, the six randomly selected sentinel cases usefully indicated that the panel physicians as a group showed a high level of consistency in assessing the cause of death, as did the five individual panel physicians who provided duplicate reviews. This was despite the poor level of concordance (merely 50%) between the panels and the certifying physicians for these sentinel cases. There was also a high level of consistency between the consensus conclusions of the panel physicians and their conclusions derived from mean probability scores. This suggests that the results did fairly reflect the considered opinions of practising respiratory physicians rather than the method of analysis.

Almost every respiratory physician in the region contributed to the investigation and no one physician contributed to excess. Furthermore, all three possible death certification groupings were known to be represented in each batch of cases, although in unknown proportions. It is doubtful, therefore, whether any important systematic biases were operating, and we think it is likely that the findings do indicate a substantial "false positive" inaccuracy in asthma death certification.

The discordance between panel physicians and certifying physicians in assessing the direct cause of death in the group 1 cases was much greater (and significantly so) in the older subjects, being 75% in those aged ≥ 65 yrs but 45% for the remainder. However, internal disagreement within panels was not related to age (or place of death). This suggests that the increasing discordance between panels and certifying physicians with increasing age was a consequence of differences in diagnostic opinion rather than a lack of information.

The effect of patient age on agreement about the cause of death is important as most certified deaths from asthma (about 60%) occur in this older population, and national statistics are unduly weighted by them. If the false positive certification rate was of the order of 75% nationally in this older population in the early 1990s, there would have been 800–900 false positive certifications annually in England and Wales, enough to account for the apparent overall increase in asthma mortality since the mid-1970s. The recent trend in this older group may consequently have been entirely artefactual. For this to be so, there would have been about 300 true asthma deaths among the total of 1,100–1,200 certified in the early 1990s in subjects aged ≥ 65 yrs, and also about 300 among the total of 500–600 certified annually in the mid-1970s. This would imply an increase in the false positive rate of asthma death certifications from about 50% (approximately the rate that we have found in 1991–1992 for subjects aged < 65 yrs) to 75%, which seems plausible though is entirely speculative. It would imply, in addition, that if asthma prevalence has increased without any increase in overall mortality, the risk of death in an affected individual must have decreased. Recently developed management strategies may, therefore, have been more successful than has been suggested.

Diagnostic transfer from COPD appeared to be responsible for many of the false positive asthma death certifications, a phenomenon noted in other studies [5, 6, 10, 15]. There is an increasing tendency to treat patients suffering from fixed airflow obstruction (which may occasionally be a consequence of long-standing asthma) with the same medications that are used for asthma, and as such patients may perceive some benefit from this treatment, it may be that the diagnostic terms COPD and asthma have come to be used interchangeably, at least in some subjects. This is especially likely in patients who are not referred to respiratory medicine clinics and who do not, consequently, undergo adequate diagnostic tests of lung function. During an era in which there has been increasing awareness of asthma by public and physicians alike, it may have become the preferred diagnosis and so have appeared subsequently, though erroneously, on death certificates. For the particular population in the present study, the panels concluded that there was insufficient evidence from either the general practice records or the hospital records to sustain a

diagnosis of asthma in a substantial proportion (42%). Again, this percentage was significantly greater in subjects aged ≥ 65 yrs (50%) than in those who were younger (30%).

The investigation was aimed primarily at assessing the accuracy of group 1 and 2 death certifications, *i.e.* an assessment of false positive inaccuracy. The group 3 cases were included to lessen the possibility of bias during the reviewing process. Reviewers might have been prejudiced by suspecting that asthma mortality had been exaggerated or underestimated. However, they would have known that any individual case could have come from any one of the possible death certification groups, and that other reviewers would also assess each case. The number of group 3 cases was insufficient for a meaningful assessment of false negative inaccuracy in asthma death certification, and they were not selected from any particular death certification grouping. We cannot estimate, therefore, how many true asthma deaths are hidden among the statistics relating to death from COPD, cardiovascular disease, or any other causes. We noted, nevertheless, that of the 37 group 3 cases, the panels concluded that asthma was the direct cause of death in four and a contributory cause in a further four. By coincidence, a very recent investigation of asthma mortality in the 16–64 yr age group suggested that false negative certifications had occurred in four of 22 cases (18%; 95% confidence interval 5–40) [16].

In view of the high prevalence of asthma within the population at large and the large number of deaths attributed to COPD (or to alternative diagnostic terms) and cardiovascular disease, the cumulative potential for false negative certification of asthma deaths is formidable. Underestimation of asthma mortality through this phenomenon is, consequently, likely to counteract, to some degree, the probable error towards overestimation that we have identified in this investigation. Unrecognized asthma deaths are not, however, likely to invalidate our suggestion that recent trends of increasing asthma mortality in the elderly may be, primarily, a consequence of artefact (increased "false positive" certification) because it is improbable that there would have been increases in diagnostic transfer in opposite direction simultaneously.

We conclude that recent statistics of asthma mortality are seriously flawed by false positive certification. This results from diagnostic transfer from other diseases, principally chronic obstructive pulmonary disease, but it is not closely related to whether death occurs in hospital or in the community, and so to whether the death certificate is completed by junior hospital doctors or general practitioners. We speculate that recent trends suggesting an increasing risk of death from asthma in older age groups are partly (or even wholly) artefactual and that, if asthma prevalence is actually increasing, recently developed management strategies (and current medications) have been more successful than has been suggested.

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Name:	Iolo Doull
Job Title:	Consultant in Paediatric Respiratory Medicine
Organisation:	Children's Hospital for Wales, Cardiff
Region/location:	Wales
Capacity in which you are replying to the inquiry	President of the British Paediatric Respiratory Society

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

I can only comment on issues concerned with respiratory disease in children, but nevertheless I believe that services for respiratory diseases are not as well resourced as for those with cardiac or oncological disorders. We estimate that in England approximately 170 children per year die of respiratory condition, 150 per year of cardiac condition and 220 from cancer. Although the numbers are broadly similar, the resources are not.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

The most important change would be to decrease smoking. This should include means to decrease smoking in pregnant women, decreasing the uptake of smoking in children and young people, improving smoking cessation in children and adolescents and decreasing children's exposure to environmental tobacco exposure (usually from their own families). We would also advocate the benefits of healthy eating to decrease the effects of obesity on respiratory health, and the benefits of regular activity.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

Smoking

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

In England we estimate that approximately 170 children die of a respiratory cause each year, but in addition approximately the same number of children with other conditions, often children with complex health needs, will also die due to respiratory problems.

5. What can the Government and the NHS in England do to reduce respiratory deaths?

Decrease smoking and discourage its uptake.

Asthma Questions:

1. What are the most important factors contributing to asthma deaths?

There are approximately 15-20 deaths due to asthma per year in children in the UK. Major

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

Smoking is the biggest amenable risk factor, but there is a complex inter-relationship between psychological factors, family dynamics and appropriate treatment and concordance with treatment

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

Ideally there should be standardised and incentivised care in primary and secondary care

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

The Finnish asthma programme has significantly decreased asthma morbidity

5. What can the Government in England do to reduce asthma deaths?

Decrease smoking

6. What can the NHS in England do to reduce asthma deaths?

Decrease smoking

7. Do you have any other comments relevant to this inquiry?

Any actions to highlight the burden of respiratory disease in children is to be welcomed.

Name:	Dr Patrick Flood-Page
Job Title:	Consultant Chest Physician
Organisation:	Aneurin Bevan Health Board
Region/location:	Wales
Capacity in which you are replying to the inquiry	As NHS respiratory clinician As Chair of British Lung Foundation in Wales.
List of any supplementary information attached (if any)	

Chronic Obstructive Pulmonary Disease (COPD) Questions:

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

Smoking: Smoking and secondary environmental exposure to cigarette smoke are most important.

- Smoking rates have fallen since the early 1970's but are unchanged over the last 8 years at around 20% of the population.
- Overall smoking rates disguise an increasing socio-economic divide between manual and professional/managerial groups. Smoking rates in the manual group remain above 30% whilst those in managerial/professional have fallen to under 10%. In areas of socioeconomic deprivation smoking rates are higher still.
- Many adult smokers started when they were children. Smoking rates in the under 16 have fallen to 10% but remain twice as high in those with parents in manual economic groups (Am J Pub Health 2006). Nicotine addiction in children associated with passive (environmental) exposure to cigarette smoking may be an important factor underlying the differential rates.
- Most smoking cessation attempts are unsuccessful. Despite large investment in smoking cessation services across the UK 1 year quit rates are only 15% (BMJ 2013)
- This compares poorly with cessation services in other countries where different approaches to smoking cessation have shown 1 year quit rates above 50% (Mayo Clin. Proc. 2013)

Late diagnosis:

- COPD is often diagnosed late when much permanent damage has already been done.
- Earlier diagnosis and earlier smoking cessation and earlier institution of COPD therapy may save lives.

Sub-optimal Care:

- Optimal COPD care reduces mortality: smoking cessation, Inhaler therapy (TORCH Study NEJM 2007); the effective treatment of comorbidities for example diabetes; vaccination; pulmonary rehabilitation (Respiratory Res 2005); Nasal and mechanical ventilation during the acute exacerbation; oxygen therapy and lung transplantation have all been shown to reduce mortality.
- Access to this care is not available to all patients in the UK.

Research:

- Understanding the genetic and cellular basis of COPD may lead to new treatments and may explain susceptibility and so target smoking cessation and other therapies.
- Investment in COPD basic science research has lagged behind other prevalent chronic conditions such as coronary heart disease and diabetes.

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

Smoking adoption:

- Children exposed to passive cigarette smoke become nicotine dependent (Cosci et al 2008)
- This dependency, parental and other role model example and ready access to cigarettes all increase the likelihood that a child from a smoking household will become a habitual smoker in adulthood.
- Measures such as banning cigarette smoking in cars where children are present (CTUMS 2012) and the introduction of plain cigarette packaging (BMJ 2013) are starting to show an important impact.

Smoking cessation services:

- Smoking cessation services are not properly integrated with healthcare services with the result that they are not set up with a focus on those most at risk - those with disease.
- Cessation services are slow to adopt current evidence base: there is little central coordination in the dissemination of new approaches with piecemeal adoption of best practice.
- There is no benchmarking of services and little culture of excellence.

Inequality of access to services:

- Even where most components of optimal COPD care are available in a healthcare environment, through a lack of awareness or lack of education and lack of integration these services are not accessed consistently for all patients.
- Through better education and integration between primary and secondary care services this can be overcome.

Lack of robust evaluation of existing services:

- Services which fail to achieve their primary objective whether reduction in hospital admissions/readmissions or length of hospital stay for community COPD services; QOL or exercise capacity for pulmonary rehabilitation often continue without change to content or personnel.
- Failure to collect or to act upon adverse audit data, local inertia to change, vested interests or lack of leadership may underlie some of these issues.
- Poor quality services are associated with excess COPD mortality.
- Local overall and service specific COPD mortality figures are not routinely collected.
- There is little formal benchmarking of similar services.

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?

- Screening spirometry for all smokers aged over 50 years to be integrated with effective smoking cessation services.
- Rethink smoking cessation services to accommodate current evidence on what works, to integrate more effectively with healthcare services and to give more leadership in the development of cessation services in the future.
- Encourage more robust evaluation of existing services with reorganisation around what works
- Publication of COPD service quality markers for example smoking rates and cessation service quit rates, admission and readmission rates, pulmonary rehabilitation waiting list and completion rates.
- Benchmarking of services between comparable healthcare organisations, sharing and adoption of good practice.

4. What could the Government in England do to reduce premature mortality from COPD?

- Legislate to ban smoking in cars and homes where children are present, the introduction of plain cigarette packaging.
- Sponsor further good quality research on addiction of children exposed to cigarette smoke
- Encourage the principle of good quality local and national audit.

5. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

Reduction in mortality has not been shown in the short term in association with the introduction of good quality local COPD services. Smoking cessation and optimal care have been shown to reduce mortality as outlined above. Services offering these to all patients would therefore be expected to reduce mortality over time. Such

services offer the best way to reduce mortality for COPD at the current time. See below for examples of services.

6. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

Spirometry screening of smokers over 50 and improved recognition of those at risk for example the opportunistic screening of those with recurrent chest infection and risk factors for COPD integrated with effective cessation services.

7. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

Primary Care Education Project

- The primary care education project in Gwent, South Wales offered training to GP practice nurses both in optimal COPD care and as well as in the availability and appropriateness of referral to community and secondary care COPD services for their patients.
- 90 % of COPD patients are looked after exclusively in primary care and usually by practice nurses who rarely receive formal training.
- By achieving improvements in COPD care practiced by the majority, equality of access to optimal COPD care was achieved in a way not possible with services based around the consultant outpatient clinic (Flood-Page et al., ATS 2012)

The Gwent COPD Audit

- Hospital admissions and readmissions are a surrogate for good quality care and associated with mortality reduction.
- COPD services were introduced piecemeal across Gwent with each LHB (local health board) practicing a different model of care for demographically similar populations but with the same objective of reduction in hospital admissions.
- Evaluation of these local projects showed that most effective were integrated between primary, secondary and community. Those working in isolation primary, secondary or community were associated with either no change or, in the case of community based COPD services organised around primary care practices, a substantial increase in hospital admission rates. (Flood-Page et al Thorax 2011)
- This last model of care is the commonest practiced across the UK.
- Services have since been reorganised around the integrated model and COPD hospital admissions/readmissions have fallen by 30%. (Flood-Page et al., BTS Winter meeting 2011)

Do you have any other comments relevant to this inquiry?

Name:	Professor Stephen T Holgate CBE FMedSci
Job Title:	MRC Clinical Professor of Immunopharmacology
Organisation:	University of Southampton, Faculty of Medicine
Region/location:	South Central
Capacity in which you are replying to the inquiry	Individual and Chair of BLF Scientific Committee

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

In some places, respiratory services are excellent, but in others it is very poor. Much seems to depend upon having a local lung disease champion. There are also problems in new ways of delivering a high quality service by closer integration of primary and secondary care. Early diagnosis of lung cancer and children's services are especially problematic. It should also be said that the risk factors for chronic lung disease have been especially high in the UK (tobacco, pollution, occupational) on account of our past industrial heritage.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

- Greater integration of primary and secondary care.
- Improved focus on children's health
- More community-based preventative measures (walking groups for older people e.g. green and blue gyms, more focus on exercise in children).
- Improved diet for less obesity and greater anti-oxidants
- More integration between cardiovascular, metabolic and pulmonary medicine.
- Greater engagement of the community regarding what healthy lungs mean.
- Children's smoking remains a problem: both active and passive (e.g. in cars)

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

In the UK we have far too many different organisations that are

engaged in lung health and illness with a real lack of a joint enterprise:

- Professional Societies: BTS, BPA, BALR, PCRG, ARNS, ARTP, Soc Occup Med etc etc. + all the Regional ones and Devolved Admin (Scotl, Wales, N Ireland)!
- Medical Charities: BLF, AUK, CF Trust, CRUK, BHF, Mesothelioma etc etc
- Royal Colleges: Child Health, O and G, Physicians, Surgeons etc
- Devolved Health Ministries (Engl, Scotl, Wales, NI etc)
- Lack of research funding
- Persisting and even widening health inequalities (Soceo-economic factors, N/S divide)

The net result of all of this is lack of a **national strategy** for lung disease, duplication of efforts and patchy research. Also low effort on public health, children's health and translation of research for patient benefit

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

Children and the elderly

5. What can the Government and the NHS in England do to reduce respiratory deaths?

Produce a coordinated joined up approach. We desperately need a single strong professional society (not mostly clinicians) with all the different groups feeding in. % years of the UK Respir Res Collab was starting along this road, but the time has now come to all join forces in a single organisation. A National Clinical and Research Strategy needs to be developed with EVERYONE involved

Asthma Questions:

1. What are the most important factors contributing to asthma deaths?

Lack of a joined up health and research strategy
Low attention on prevention
Too lung-centric

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

Those in SE deprived areas, those with adolescent problems

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

Lack of joined up strategies across the whole of lung health

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

The Finnish and most recently the S.Ireland experience (joined up care+ prevention)

5. What can the Government in England do to reduce asthma deaths?

Concentrate effort on high risk groups.

6. What can the NHS in England do to reduce asthma deaths?

7. Do you have any other comments relevant to this inquiry?

Asthma is only part of the problem. Lung health generally needs a higher [profile in the UK. Can we all now join forces in this (please).

Chronic Obstructive Pulmonary Disease (COPD) Questions:

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

Smoking
Industrial Pollution
Poor diet

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

Lack of a joined up NATIONAL STRATEGY across the field

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?

Stop and prevent children smoking
More attention to weight reduction, diet and exercise

4. What could the Government in England do to reduce premature mortality from COPD?

Create incentives for an integrated joined up approach
Concentrate effort on early diagnosis (including cancer)

8. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

Patchy success across UK e.g. Leicester

5. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

Screening in primary care (spirometry)
Better public awareness
Community engagement

6. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

No not especially.

9. Do you have any other comments relevant to this inquiry?

Just a desperate **plea** to bring together all the many groups involved in lung disease and health to engage in a **single joined up approach**. We really do not need all the different professional groups as long as their interests were all looked after. Call it the **British Society of Lung Health or British Respiratory Society** (Thoracic as in BTS is very dated and organ-centric).

APPG on Respiratory Health - Questions

Personal Information:

Name:	Richard Hubbard
Job Title:	Respiratory Epidemiologist (Current project funded by the British Lung Foundation)
Organisation:	University of Nottingham
Region/location:	East Midlands
Capacity in which you are replying to the inquiry	Request from APPG
List of any supplementary information attached (if any)	Powerpoint used during inaugural session of APPG on Respiratory Health

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

No - research into screening for lung cancer lags behind that for breast cancer and colorectal cancer even though lung cancer kills more people each year than both of these two diseases combined

2. What changes can be made to improve outcomes for all or most respiratory conditions?

Decreased smoking prevalence

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

Failure to address the smoking prevalence sufficiently

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

Smokers - because smoking is the most important cause of lung cancer and COPD and is an important factor in death from pneumonia and asthma

5. What can the Government and the NHS in England do to reduce respiratory deaths?

Help the process of reducing the smoking prevalence

Asthma Questions:

1. What are the most important factors contributing to asthma deaths?
Avoidable causes are smoking and adherence to medication
2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?
Smokers and socially deprived people
3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?
A need for emphasis on smoking cessation
4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?
There has been a large reduction in asthma deaths in the UK - which may relate to the use of inhaled steroids
5. What can the Government in England do to reduce asthma deaths?
Emphasise smoking cessation, implement care programmes in primary care
6. What can the NHS in England do to reduce asthma deaths?
Emphasise smoking cessation, implement care programmes in primary care
7. Do you have any other comments relevant to this inquiry?

Chronic Obstructive Pulmonary Disease (COPD) Questions:

1. What are the most important factors contributing to the current high level of premature mortality from COPD?
Smoking and childhood poverty
2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?
Failure to address the problems of smoking and childhood poverty
3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?
Smoking cessation access and emphasis
4. What could the Government in England do to reduce premature mortality from COPD?
Smoking cessation access and emphasis
8. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?
The reduction in deaths from lung cancer in people under the age of 55 in the uk related to smoking cessation has been an important success

5. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

Increasing the emphasis on recording smoking habit in primary care

6. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

The new leaf campaign for smoking cessation in Nottingham has a high social presence

9. Do you have any other comments relevant to this inquiry?

Patterns, causes and effects of lung disease

Richard Hubbard

BLF Professor of Respiratory
Epidemiology



Remit

- Why are so many people dying from lung disease
- Scale of the problem
- Why is respiratory different to other things
- Its about the breadth
 - Cancers
 - Airways disease
 - Interstitial lung disease
 - Acute and chronic infection
 - Sleeps
 - ITU
 - Structural issues



Deaths – England and Wales

- In 2011 404,367
- 1 in four due to lung disease
- 1 in four due to cancer
- Same as for heart disease



deaths

- Lung cancer – 30,148
- Out of a total cancer deaths of 143,181
- Lung cancer just under 1 in 5 cancer deaths,
- breast 1 in 14 and colorectal 1 in 10
- 5 year survival figures



Other important ones

- Asthma 1,019
- IPF 3,794
- COPD 25,246
- Pneumonia 25,344



Admissions and bed days

- Lung 1,310,865 con epi and 4,905,892 bed days
- Lung is 1 in 13 con episodes
- Bed days 1 in 10 are respiratory
- 50% more con epi and 75% more bed days than heart disease



Causes of lung disease

- Smoking – 85% of all lung cancers most COPD
- Also a role in pneumonia
- Social deprivation and childhood poverty
 - COPD
 - Lung cancer
- Occupation
- Access to care



Smokers

- Nearly all adult smokers became addicted as children
- Everyday we do nothing people die
- Simple things work
 - Price up – sort niche cheap cigarettes
 - Plain packaging
 - Sort film and TV
 - Media campaigns

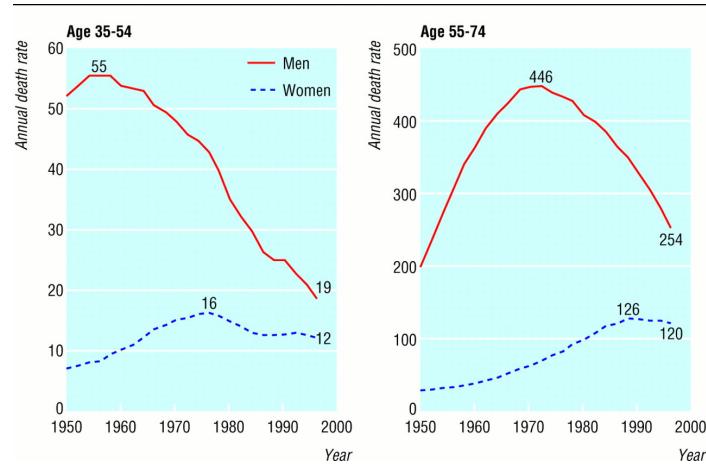


Spending on cancer research

- NCRI figures for last 11 years
- Breast leads the way on 352 million
- Colorectal in 3rd place on 213 million
- Lung cancer in 6th place with 90 million
- Which is 8 million a year for our most lethal cancer
- Breast 3200 per death, colorectal 1383 per death and lung 272 per death



Lung cancer mortality



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How much can be prevented

- 25,000 lung cancer deaths – 1950 to 2000 mortality rate from lung cancer fell by 60% in 35 to 54 year olds
- 15,000 COPD deaths
- 750 asthma deaths
- Pneumonia - harder



Summary

- Respiratory disease is enormous problem
 - 1 in 4 deaths
 - 10% of all bed days
- Lung cancer, COPD and Pneumonia = 80% deaths
- Smoking explains at least a half of these
- Deprivation is also hugely important
- Access to services – particularly cancer – needs to be optimised for all



Harm reduction

- In 5 years e-cig market now exceeds all of NRT
- Need to push harm reduction
- Health care workers – treat smoking like high blood pressure or glucose



All Party Parliamentary Group on Respiratory Health: Invitation to submit written evidence to the inquiry into respiratory deaths

Name:	Dr Richard Iles
Job Title:	Consultant Respiratory Paediatrician with specialist interest in asthma, Addenbrooke's Hospital, Cambridge Clinical lead for Paediatric Asthma - Maternity Newborn, Children and Young People Strategic Clinical Network NHS England, East of England
Organisation:	Addenbrooke's Hospital, Children and Young People Strategic Clinical Network NHS England
Region/location:	
Capacity in which you are replying to the inquiry	Individual
List of any supplementary information attached (if any)	Correspondence with CCG.

With reference to - Paediatric Asthma Deaths

Dear Group

I am a Paediatric Respiratory Specialist working in Addenbrooke's Hospital, Cambridge. I have been in this post for 17 years. For the last 15 years I have been involved in a the East of England Confidential enquiry into asthma deaths, which as published on the risk factors for which has published on the "Risk factors for childhood asthma deaths" – [attached](#). My area of responsibility up until 12 months ago was Paediatric Cystic Fibrosis, but from Jan 2013 I took on the lead for Severe and difficult to control paediatric asthma, this has allowed me to revisit both my own service and the interface with primary care with new eyes.

For the last six months I have been the Clinical lead for Paediatric Asthma - Maternity Newborn, Children and Young People Strategic Clinical Network NHS England, East of England, and have interfaced with Primary, secondary care and CCGs, trying to find a method to implement a high impact change model. The East of England has a diversity of protocols and practice for its management, consequently there is a great deal of variation in treatment and acute attendance and admission rates. This project crosses boundaries between primary, secondary and tertiary care to improve augment professional education in all areas, and standardizing asthma management protocols, and improving care to the 127,000 children with asthma in the region.

I have attached a number of papers – but it is also worth reading the article from J Paton, in arch dis child this year. – [attached](#):

I am happy to share my experiences. This is my personal view –

"There are known knowns: These are things we know that we know.

There are known unknowns: That is to say, there are things that we know we don't know.

But there are also unknown unknowns. There are things we don't know we don't know."

Donald Rumsfeld

Where the system is failing; (But there are also unknown unknowns. There are things we don't know we don't know.”)

- The majority of paediatric asthma can be managed in Primary care. There are examples of good if not outstanding practice – but when it goes wrong the scenario is often templatable
 - Under-recognition of disease severity or disease itself
 - Under-treatment, recognition by family and health care professionals
 - Under-instruction - No acute or emergency action plan
 - Safe Guidance is not followed
- 60% of the admissions and 90% of the deaths are preventable.
- Primary care is swamped with demand, and clinicians cannot see the wood for the trees.
- 40% of Primary care clinicians have 6 months training in paediatrics at an early stage of their career pathway, many less will have specific respiratory training.
- There is little awareness of BTS, NICE or other guidance in Primary and some secondary care.
- There is little time or understanding of how to instruct patients on medications or inhaler technique – please look up how to use your inhalers on “youtube”, has happened and thought to be adequate advice by some GPs under certain circumstances. There are in some practices there are limitations on prescribing which do not allow this instruction to take place.
- The default providers of respiratory expertise are the respiratory nurse specialists, who are usually part time.
- The majority of respiratory nurse specialist training is adult based, but many RNS lack confidence, particularly with Children, aged 5-12, who are the more mature group! (**attached**)
- BTS sign guidance is excellent, but referral to specialist opinion is based on the prescribing of high dose medication, not disease control. There are a lot of children who are not referred from primary care due lack of appreciation of disease severity. Our own figures are approx
 - Paediatric Population EoE 1.4M
 - With asthma 127K
 - With severe asthma (BTS 4/5) 1.3K
 - If 50 % go to London 600
 - Presently CUH and others see approx 150
 - Approx 350 children with difficult to control asthma have not been referred
- There is poor recognition of the acutely sick child, and treating the complexities of treating chronic “difficult” to control asthma, which is paired with the common belief that children do not die of asthma.
- Practices are not always aware of guidance, or equipped with oxygen and acute medications to prevent deterioration whilst waiting for ambulance.

What the barriers to good practice are; (There are known unknowns: That is to say, there are things that we know we don't know.)

- Primary care does not have to adhere to NICE guidance
- There is a lack of standardisation of asthma care within Primary and secondary care
- There is limited sharing of good practice within a primary care practice or amongst practices within a CCG, and little integration with secondary care – mistakes are not identified and shared.
- There is little time set aside for either GPs or RNS for CPD, and this is poorly organised
- There is confusion as to QOF. Does it apply to paediatric asthma
- QOF does not result always in quality improvement and can be instead just a method of income generation.
- CCGs are looking for minimal impact and low cost solutions which prove to be ineffective.

What policy changes are needed to reduce respiratory deaths (There are known knowns: These are things we know that we know.)

- GPs practices need to adhere to NICE guidance
- QOF payments need to be reviewed – particularly with reference to children
- CPD needs to be protected credit given those who achieve.(kite marking)
- Standardisation of asthma management, with accountability.
- Further integration of secondary care paediatrics with primary care family practice, with focus on “good” and “shared” practice.
- Referrals from education, who can be more aware of the child’s school performance, or lack of attendance.
- The establishment of well child clinics as per lancet paper – **attached** – where chronic and common diseases can be reviewed with expertise.
- Please also look at designing and commissioning Services for CYP asthma – **attached**, this needs to be adhered to!
- Lastly - Change is possible – please see data from Finland- **attached**

Hope this is helpful

Yours sincerely

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RESEARCH PAPER

Risk factors for childhood asthma deaths from the UK Eastern Region Confidential Enquiry 2001-2006

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Abstract

Background: Confidential enquiries into asthma deaths can identify inadequacies in medical management and factors which contribute to patients' death.

Aims: To identify risk factors for paediatric asthma deaths over a 6-year period.

Methods: Observational case-series study of paediatric asthma deaths between 2001-2006 in the UK Eastern Region. Hospital, primary care and post-mortem data were obtained for every child (≤ 17 yrs) with asthma recorded on the death certificate, and a detailed questionnaire was completed. Information was obtained on asthma severity, medications, hospital admissions, GP and hospital follow-up, adherence, psychosocial / behavioural factors, allergies, details of the terminal attack and precipitating factors.

Results: 20 children (10 male; 8-17yrs; median: 11.5yrs) died of asthma between 2001-2006. 9/20 had mild to moderate asthma (BTS/SIGN criteria), 10/20 had severe asthma and 1 child was not known to have asthma. 13/20 were clinically atopic. Only 3 had undergone allergy assessment. 10/20 died between June and August. 12/20 children had adverse psychosocial and behavioural factors. 7/20 children were on non-combination long-acting β_2 -agonist (LABA) treatment without inhaled corticosteroids (ICS).

Conclusions: Almost half the deaths occurred in children with mild/moderate asthma. We recommend that allergic factors and seasonal allergy should be identified early, non-combination LABAs avoided, and speculate that overuse of short-acting β_2 -agonists (SABAs) may indicate non-adherence with ICS. Asthma deaths in children can be avoided if risk factors are identified early.

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Keywords asthma, deaths, allergy, inhaled corticosteroids, LABAs, SABAs, seasonal, adherence, behavioural, psychosocial, children, paediatric, risk factors

See linked editorial by Stephenson & Shields on pg 13

Introduction

In the UK, asthma mortality peaked in the mid 1960s and again in the late 1970s and early 1980s.¹ In response to these worrying statistics, a Confidential Enquiry into asthma deaths in children and adults was started in Eastern England in 1988. Initially, only deaths in the Norwich Health District were investigated, but in 1992 the Enquiry was extended to East Anglia (Norfolk, Suffolk and Cambridgeshire). In 2001 the Enquiry was further extended to include the whole of the Eastern Region of the UK.

Data from the Office of National Statistics (ONS) show that

rates of childhood mortality from asthma have been on the decline since the epidemic of asthma deaths in the mid-1960s, when they reached 10 per million among children aged under 5 years and 14 per million among 5-14 year-olds. Between 1990 and 2000, asthma-related deaths among children aged under 5 years and those aged 5-14 years remained uncommon at around 2 per million each year.²

Previous UK Eastern Region Confidential Enquiries into asthma deaths in children and adults < 65 years old have identified behavioural and psychosocial factors as well as seasonal allergic factors as contributing to the patient's death. In two-thirds of asthma deaths medical management failed to

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comply with national guidelines.³⁻⁵ A number of previous studies from different parts of the world have also reported on risk factors contributing to asthma deaths.⁶⁻¹³

The aim of this observational study was to identify risk factors contributing to asthma deaths in children during a 6-year study period (2001-2006). The Eastern Region population is approximately 5.5 million, 22% of whom (1,276,000) are children below the age of 18 years.¹⁴ This is the first report on asthma deaths in children in the Eastern Region of the UK.

Methods

The methods used during the 2001-2003 period have been reported previously,⁵ and the same methodology was used for the remainder of this six-year study (2001-2006). In brief, the Chair of the Confidential Enquiry requested patient details from the ONS relating to deaths in patients < 18 years old in the Eastern Region of the UK in the previous 12 months (each year for the six years of the study) with asthma recorded in the first part of the death certificate. The Eastern Region of the UK consists of the counties of Norfolk, Suffolk, Cambridgeshire, Bedfordshire, Essex and Hertfordshire, and the Unitary Authorities of Peterborough, Luton and Southend-On-Sea. The Enquiry excluded the area within the M25 London orbital motorway.

Each patient's details were distributed to two members of the Confidential Enquiry Working Group – a respiratory physician/paediatrician in the District General Hospital (DGH) nearest to where the patient lived, and a general practitioner (GP). The respiratory physician/paediatrician obtained the local hospital notes and in conjunction with the child's paediatrician completed a detailed proforma related to the patient's asthma and overall asthma care. The proforma included information on asthma severity, medication, hospital admissions, GP and/or hospital follow-up, compliance with medication, psychosocial and behavioural factors, allergies, details of the terminal attack and suspected precipitating factors.

A GP from the Working Group obtained the general practice records and made a detailed review of the patient's notes. The results of all available post-mortem examinations were also reviewed. Patients were excluded from the enquiry at this stage if the hospital and/or general practice records or the post-mortem report revealed that the main cause of death was not asthma. The GP member then contacted the deceased's GP before completing a proforma detailing all aspects of asthma management, including the number of prescriptions issued for each asthma medication, how often appointments were missed, whether the patient attended for asthma review regularly, whether or not a management plan had been issued, and how often peak flow measurements had been recorded.

Asthma severity was classified by the working group members using the British Thoracic Society (BTS)/Scottish Intercollegiate Guideline Network (SIGN) stepwise guidelines for asthma treatment: mild (BTS steps 1-2), moderate (BTS step 3)

and severe (BTS steps 4-5).¹⁵ Admissions to hospital or visits to the Accident and Emergency department for the previous 12 months were also taken into account when assessing severity (i.e. severe asthma = BTS steps 4-5 or at least two hospital admissions in the previous year). Allergy testing for asthma is not routinely carried out in the UK and only a limited number of patients had results of skin testing recorded in either the primary care or secondary care notes. Therefore only limited data were available on atopy, known allergies and possible anaphylactic precipitating factors.

Socioeconomic data were derived for each patient based on their home address/permanent place of residence. A Multiple Deprivation Score Index (MDS index) was calculated from seven weighted domain scores using the following: Income (22.5%), Employment (22.5%), Health Deprivation and Disability (13.5%), Education, Skills and Training (13.5%), Barriers to Housing and Services (9.3%), Crime (9.3%) and Living Environment (9.3%). An MDS index close to 1 suggests a good socioeconomic status.¹⁶

A Summary Form – incorporating all the relevant information obtained from the records, post-mortem examination and interview with the deceased's GP – was then completed following discussion with members of the Working Group. National guidelines on asthma management¹⁵ were used to define standards and to make judgements on the appropriateness of medical care received by the patient.

Ethics approval was not required for this study.

Results

Between 2001-2006, 20 children (10 males) died from asthma in Eastern England. Ages ranged between 8-17yrs (median age 11.5yrs). Patient characteristics are shown in Table 1.

Asthma severity

Using BTS/SIGN guidelines to assess severity, 9/20 children had mild to moderate asthma (BTS steps 1-3). Of these, three children had previous hospital admissions (although none in the previous 12 months). 10/20 children were graded with severe asthma (BTS steps 4-5) and of these nine had admissions to hospital in the previous year (one admitted to the intensive care unit (ICU)). One child had no prior recorded history of asthma before death, and died suddenly with asthma recorded as the cause of death which was confirmed by post-mortem examination. (see Figure 1).

Health care factors

Five out of the 10 children with severe asthma were managed solely in primary care and had never been seen in hospital by a respiratory specialist. One of these children had been referred to hospital two months prior to death but had not been seen by the time of death. None of the five had a written asthma management plan. In total, only 6/20 children had a record of a written asthma management plan. Only 5/20 children had a peak flow measurement recorded (either in primary or secondary care) within a year of death. Spirometry was recorded in only

Table 1. Characteristics of the 20 paediatric patients who died from asthma, Eastern Region, 2001-2006.

Age	Sex	Severity/ BTS step guidelines	ICS	Non combination LABAs	Oral prednisolone	Previous admissions	Atopy	Adherence	Social	Asthma plan	PF	Anaphylaxis/SD
11	F	Mild-2	Yes	No	No	No	NK	Poor	-	No	No	SD
15	M	Severe-4	Yes	Yes	No	Yes	Dog allergy	Good	Domestic problems	No	No	Suspected anaphylaxis (dog walk prior to death)
10	M	Severe-5	Yes	Yes	Yes	Yes	NK	Poor	-	No	No	Gradual deterioration over 24h
15	M	Mild-1	No	No	No	No	NK	Good	-	No	No	SD
8	F	Severe-5	Yes	Yes	Yes	Yes	Eczema dog allergy	Good	-	No	Yes	Gradual deterioration over 24h
16	M	Severe-4	Yes	No	Yes	Yes	Allergic rhinitis aspirin	Poor	Family discordance	Yes	No	Suspected anaphylaxis New pet (rat)
12	F	Not known asthma	No	No	No	No	NK	-	-	-	-	SD
11	M	Severe-3	Yes	No	No	Yes	+ve SPT to HDM	Good	Family discordance	No	Yes	SD
10	M	Severe-3	Yes	No	Yes	Yes	Eczema Nut allergy	Good	Unable to recognise severity	Yes	Yes	Suspected anaphylaxis (nut)
9	F	Mild/ moderate-3	No	Yes	No	No	Eczema Animal allergy	Poor	?	?	?	Suspected anaphylaxis (guinea pig exposure)
16	F	Moderate-3	No	Yes	No	No	NK	Poor	-	?	?	SD
12	F	Severe-2	Yes	No	No	No	NK	?	-	No	No	SD
8	M	Severe-3	Yes	Yes	No	Yes	Dog allergy	?	-	?	?	Suspected anaphylaxis Dog exposure
15	F	Moderate-3	Yes	Yes	No	No	Eczema	Poor	Domestic violence	?	?	SD
15	F	Moderate-3	Yes	No	Yes	Yes	Seasonal asthma Hay fever	Good	-	Yes	?	SD Thunderstorm
17	M	Moderate-3	Yes	Yes	No	Yes	Seasonal asthma	Poor	Denial	No	?	Unwell for 3 days Thunderstorm
10	F	Moderate-3	Yes	No	No	No	Seasonal asthma Hay fever Eczema	Good	-	Yes	Yes	SD Thunderstorm
9	M	Severe-4	Yes	No	Yes	Yes	Severe eczema Milk + Peanut allergy	Good	-	Yes	?	SD
9	M	Moderate-3	Yes	No	No	Yes	Eczema	Poor	Denial	Yes	Yes	SD
10	F	Severe-3	Yes	No	No	Yes	Eczema	Poor	Neglect	No	No	SD

ICH= inhaled corticosteroids; PF= peak flow; LABAs= long acting β-agonists; NK= not known; SD= sudden death; SPT= skin prick test; HDM= house dust mite

?= information not available; +ve=positive

7/20 children (6/7 suffered from severe asthma). In 6/20 GP practices there was a respiratory nurse specialising in asthma (each specialist nurse had attended a recognised training course for asthma within the last two years).

For 8/20 children, follow-up for their asthma was considered inadequate. Only 7/20 children were under regular review in an asthma clinic (either hospital or primary care) during the year preceding their death.

One child with severe asthma was seen 16 hours prior to death by a GP and was misdiagnosed as croup: no treatment had

been given. The child was seen again 4 hours prior to death by a different GP who diagnosed an asthma attack, gave nebulisers and oral prednisolone but did not refer the child to hospital.

Four children had co-existing medical conditions (ADHD, epilepsy, neurofibromatosis disease type 1, and autism with learning difficulties).

Drug treatment and adherence

Of the patient cohort, 9/20 children were poorly compliant with prescribed medication and 6/20 children had poorly controlled asthma despite taking their recommended treatment (which was

Figure 1. Asthma severity including number of children with previous hospital admissions in each group (mild, moderate, severe)

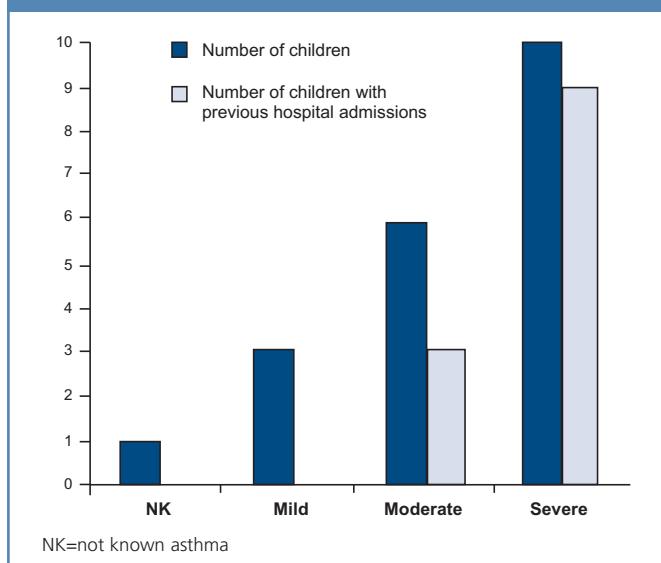


Figure 2. Number of asthma deaths in different months; there is a clear peak in the months of June/July/August which most likely represents seasonal asthma

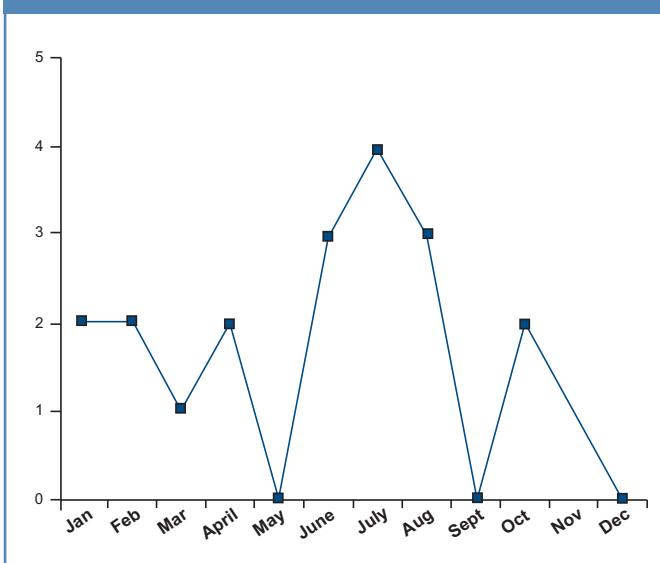


Table 2. Health-related risk factors – doctor, practice or hospital – for paediatric asthma deaths, number of patients (%)

No record of peak flow monitoring over last year prior to death	15 (75%)
No record of written asthma management plan	14 (70%)
Inadequate follow up	8 (40%)
Delayed or no referral to specialist	5 (25%)
Follow up in hospital asthma clinic at time of death	7 (35%)
Inadequate doses of inhaled corticosteroids or delayed doses of oral prednisolone	8 (40%)
Number of patients on non-combination LABAs without prescribed ICS	2 (10%)
Number of patients prescribed non-combination LABAs and ICS but non-compliant with ICS	4 (20%)

therefore considered to be inadequate). Seven children had been prescribed non-combination LABAs and of these six were not taking ICS – two children had not been prescribed ICS and four children were not taking their prescribed ICS. 8/20 children were on inadequate doses of ICS or were not commenced on oral prednisolone in time (see Table 2).

Adherence to treatment was defined as the extent to which patient behaviour matched the health professional's recommendation. Poor adherence was defined as taking less than 50% of the recommended inhaled medication or omission of all inhaled medication for one week or longer over the previous six months.

Adverse behavioural/psychosocial factors

Overall, 12/20 children had psychosocial or behavioural factors which may have contributed to their death. 6/12 children came

from dysfunctional families or families with serious domestic problems. 2/12 children were in denial about their asthma, and therefore did not recognise the severity of their disease and the need for regular treatment. 5/12 children displayed poor adherence with their medication and attending appointments.

Two of the children were smokers. No information on parental smoking was available.

Four out of the 20 children were taken to hospital in the parent's car and died on route while stuck in traffic. In two cases an ambulance was refused by the parents who preferred to use their own transport.

Analysis of the socioeconomic data of our patient cohort revealed a distribution that was similar to the socioeconomic profile of the Eastern region with less than a third of patients belonging to the 'deprived' group.

Allergic and seasonal factors

At least 13/20 children were likely to be atopic with a clinical picture consistent with atopic disease, but only three had had a formal allergy assessment in an allergy clinic to confirm this. There was insufficient information on atopic status on six out of the remaining seven children – the seventh child was not known to have asthma and no data were available on atopy either.

In 4/20 children, animal exposure was a likely allergic trigger before death (a dog in two cases, guinea pig in one, and a newly-acquired rat in one). One child who was known to be allergic to nuts had documented exposure to nuts shortly before the fatal attack and another child had aspirin sensitivity but there is no evidence that NSAID ingestion contributed to his death. There were no data available regarding allergies to medication on any other patients.

Ten of the 20 children died between June and August. Two had mild asthma and both suffered sudden death, implying an

acute allergic trigger (see Figure 2). Three deaths during this period occurred during a thunderstorm. In a further five children there was evidence of allergen exposure shortly prior to death – in four cases exposure to an animal or pet, and in one case exposure to nuts. None of these children had a post-mortem serum measurement for tryptase.

Discussion

Main findings and interpretation in relation to previously published work

Severity of asthma is an important risk factor for paediatric asthma deaths: half of the 20 children who died in the Eastern Region of the UK between 2001-2006 were considered to have severe asthma. Five of these 10 were on BTS/SIGN treatment steps 4 or 5 and the rest were under-treated but had at least two hospital admissions within the previous 12 months. A number of risk factors were identified in this severe group including use of non-combination LABA inhalers, inadequate health care, under-treatment with ICS, delayed referral to a specialist, and under-estimation of disease severity by close family members and in some cases medical staff. Psychosocial factors are common in this group, but poor compliance was less common than in those considered to have mild/moderate asthma. Furthermore, 7/10 children with severe asthma were atopic but only two of them had undergone formal allergy assessment.

It is of interest that almost half the deaths occurred in children with mild to moderate asthma. Our results are in accord with the Victoria study in which the majority of deaths could not be classified as "high risk", with 33% judged to have a history of trivial or mild asthma and 32% no previous hospital admissions for asthma.¹⁷ In our study, nine children had been prescribed treatment from BTS/SIGN steps 1-3 and were therefore considered to have mild to moderate asthma. This group displayed a different cluster of risk factors. Six were clinically atopic but the atopic status of the other three could not be determined. Other risk factors included seasonal asthma (3/9), poor compliance with medication (6/9), and use of non-combination LABA inhalers (4/9). Seasonal asthma often remains unrecognised in patients considered to have 'mild' asthma, who can suddenly become unwell when they receive a large allergen load during the pollen or fungal spore seasons. Other allergic triggers such as pets and foods – especially nuts – can cause severe or even fatal asthma in patients with poorly controlled disease or bronchial hyper-reactivity due to seasonal allergen exposure.¹¹

Peak flow measurements were poorly recorded in the primary care notes in our patient group. It is important that objective measures of lung function are recorded routinely in children with asthma at each follow-up appointment. These measures provide a basis for comparison during times of illness and are essential for evaluating the severity of disease.

Spirometry was recorded in only a minority of cases, and an assessment of asthma severity based on symptoms and

treatment was often inaccurate. Baseline spirometry is known to give an accurate "snapshot" of asthma severity, and the FEV₁ derived from spirometry is linearly related to the severity of airways obstruction.¹⁸ Ramsey *et al.* also suggest that FEV₁/FVC is a useful indicator of asthma severity in children.¹⁹ Spirometry is reproducible, with most children able to perform acceptable spirometry with 50% success by the age of 6 and with 85% success at age 10. Methods and results are standardised and spirometers widely available.^{19,20}

Overall, only 6/20 children had any record of a written asthma management plan and this may have contributed to poor compliance or confusion with treatment leading up to death. A recent review has shown that there is strong paediatric evidence that the addition of a written action plan significantly improves outcomes.^{21,22} During acute exacerbations a written record of the best treatment options is likely to be particularly useful – and therefore all children should have a detailed management plan which is updated on a regular basis.

Seven of the asthma deaths occurred in children prescribed non-combination LABA inhalers, and none of these had a written asthma management plan. In at least half of these cases there was evidence of a lack of compliance with ICS treatment. In asthma, the overuse of β₂-agonists combined with under-use of anti-inflammatory medications is associated with increased mortality.²³ Recent studies have suggested that LABAs may increase severe and life-threatening asthma exacerbations as well as asthma-related deaths, especially when used without regular ICS.^{24,25} Therefore, non-combination LABA inhalers should not be used in asthma. In addition it is essential for primary care to have a system that flags up patients who use excessive amounts of SABAs.

A significant proportion of the children had psychosocial or behavioural factors which may have affected compliance with medication and attendance at appointments. This finding is in line with other studies investigating risk factors for fatal asthma: domestic problems, family discordance, neglect, smoking, denial, non compliance with medication, failure to attend appointments and delay in seeking medical help, have all been shown to contribute to adverse outcomes.⁶⁻¹³ These factors must be taken into account when children are seen and assessed for asthma, and a special effort should be made to improve compliance.

Two of our subjects were known smokers. There is strong evidence that cigarette smoking in asthma is associated with poor symptom control, and smokers have more severe symptoms and are more likely to be admitted to hospital compared with non-smokers with asthma.^{26,27} Active smokers also present impaired short-term therapeutic responses to corticosteroids: the underlying mechanism remains unresolved but could result from alterations in airway inflammatory cell phenotypes, changes in the glucocorticoid receptor alpha to beta ratio, and increased activation of pro-inflammatory transcription factors or reduced histone deacetylase activity.^{28,29}

In four out of the 20 deaths, children were taken to hospital in the parent's car and died on route whilst stuck in traffic. It is possible that these deaths could have been averted by the rapid arrival of a paramedic in an ambulance where oxygen-driven nebulisers and adrenaline are readily available. Previous studies have suggested that delay in receiving medical help affects outcome.^{8,12}

In the UK, children with asthma do not undergo routine allergy testing and atopy remains unidentified. Therefore, amongst these 20 children there was a lack of recorded information on allergic status. However, we found that asthma deaths peaked between the months of June and August. Researchers in Denmark who reviewed 108 asthma deaths in children aged 1-19 years old in the years 1973-1994 also noticed a similar peak in mortality in the summer months in patients who were more likely to be atopic, had fewer asthma symptoms, and who were not under regular review for their asthma.⁹ Of the 10 seasonal deaths, at least half the children were clinically atopic but no information on atopy was available for the rest. Only two of the 10 had a record of an asthma management plan. None of them was under hospital review for their asthma, although 6/10 were under GP follow-up once a year but not necessarily prior to the onset of the pollen season. Five of the 10 seasonal deaths occurred in patients on LABAs with four of them not compliant with regular medication. Children with seasonal asthma are at high risk as they are usually asymptomatic out of season, remain unprotected by ICS treatment, and increase their use of SABAs or LABAs when they suddenly receive a large allergen load.

In four children there was documented animal exposure prior to death. One child was playing with a guinea pig belonging to a friend and another child was exposed to a newly acquired pet rat. Two other children were in contact with dogs at the time of death. In all the above cases exposure to the pet may have been the allergic trigger. None of these children was ever assessed formally for pet allergy and no skin testing results were available for any of them. In one case there was documented exposure to nuts prior to death (the patient was known to be nut allergic). Acute severe asthma due to anaphylaxis as a cause of sudden death may be underestimated. A group of researchers in Sweden who evaluated 37 children and young adults who died of asthma noted that a significant proportion of deaths were probably caused by food allergy and that for 8/37 of the subjects death was associated with exposure to pet dander.¹¹ In a recent US study, children admitted to a paediatric ICU for asthma exacerbation were significantly more likely to report food allergy compared with children admitted to a regular paediatric ward or seen in ambulatory care. The researchers concluded that self-reported food allergy is an independent risk factor for potentially fatal childhood asthma.³⁰ Therefore, not only is poorly controlled asthma a risk factor for deaths due to food allergy, but food allergy in an asthmatic child is a marker for a potentially fatal outcome.

In three cases, asthma deaths occurred during a thunderstorm. All three children suffered from seasonal asthma

and two of them also suffered from hay fever. Thunderstorm-related asthma is increasingly recognised in sensitised, atopic individuals before a sudden, large allergen exposure particularly consisting of fungal spores such as *Alternaria alternata*. Thunderstorm-related asthma usually occurs at a time and location during an allergen season in which large numbers of patients with asthma are outdoors.³¹

Strengths and limitations of this study

This is a retrospective, uncontrolled, observational study and therefore has inherent limitations. The amount of information available for each patient is limited by the quality of record-keeping in both primary and secondary care. Patient records in GP practices and hospitals are either electronic or handwritten, and the clinical details are variable. Self-reported data from GPs (when missing from the patient's chart) may have introduced some bias and could not be substantiated because relatives were not interviewed. The determination of social dysfunction was not standardised, allowing for the possibility of incorrect classification. The use of ICS prescribing data from GP records may have resulted in under-reporting of non-adherence.

However, in most cases, a combination of primary and secondary care records, as well as post-mortem results, provided sufficient insight to enable conclusions to be drawn – with a remarkable degree of consistency – into the circumstances surrounding these asthma deaths. There can be an element of subjectivity when clinical data are interpreted, but this was minimised by detailed discussion and the need for consensus amongst the large number of professionals on the Working Group; this is a strength of this study.

Implications for future research, policy and practice

Children with severe asthma are at high risk of asthma exacerbations and should have shared care in both primary and specialist secondary care. There is also a need for prompt referral to hospital for children who have frequent asthma exacerbations and specialist follow-up for children after hospital admission. Recognising the symptoms and seeking prompt medical help during an exacerbation can affect outcome.

As part of their regular management and follow-up, all children with asthma should have received training in the use of a peak flow meter (once they are of an age where their peak flow technique is reliable and reproducible) and use of their inhalers, and should have received an individual asthma management plan. Both the child and the family should be educated on how to recognise acute exacerbations and respond appropriately.

Our results suggest that determination of atopic status and specific allergic sensitisation is an essential part of the management of all children with a diagnosis of asthma. We recommend that children with asthma undergo formal allergy assessment to identify allergic triggers and be provided with a written management plan. Their annual review should take place before each season and in many cases seasonal increases in prophylactic therapy will be required.

A serum sample for tryptase should be taken in all sudden,

Childhood asthma deaths

unexplained, anaphylactic or asthmatic deaths. None of our subjects with documented allergen exposure prior to death had a post-mortem serum measurement for tryptase. Tryptase is a useful marker of mast cell degranulation and can be taken up to 72 hours after death.³²⁻³⁴

Conclusions

In this case series of paediatric asthma deaths, a number of important risk factors have been identified. Psychosocial and behavioural factors can lead to poor-compliance with medication. The use of non-combination LABA inhalers contributes to confusion with treatment and underuse of ICS particularly without a written management plan. Seasonal and allergic triggers remain unrecognised particularly in patients with less severe asthma as there is no routine allergy testing for asthma patients in the UK. The risks associated with disease severity and non-adherence with ICS are well recognised; however, these could be anticipated with the routine use of spirometry and a system for identifying those patients who use excessive SABAs or who fail to attend appointments. Many of the above risk factors are likely to be preventable if asthma is phenotyped, triggers identified early, and patients educated to self-manage their condition.

Handling editor Maureen George

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Conflicts of interest The authors declare that they have no conflicts of interest in relation to this article.

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Begin forwarded message:

From: ***** ***** (NHS WEST SUFFOLK CCG)
<*****.*****@nhs.net>
Date: 2 January 2014 15:45:43 GMT
To: Richard Iles <richard.iles@doctors.org.uk>, ***** ***** (NHS WEST SUFFOLK CCG) <*****.*****@nhs.net>
Subject: RE: High Impact change Paediatric Asthma

Richard,

I'm glad you are getting some traction with this. As ***** alluded we find it hard to get GPs practices to take on new pathways/material/guidelines. It's a symptom of the large volume of information sent out to primary care. I have tried to encourage my own GP partners and nurses to take up various tools but again they give a sincere response but it does not result in much substance.

Not to be gloomy so early in the New Year I am happy to help disseminate your feedback forms to our 25 practices in the ***** CCG and I can at least make sure my own respiratory nurses and GPs give some feedback. I think gradually with time we should be able to embed the use of these asthma plans/guidelines as part of normal practice.

Best wishes,

Dr *****

From: Richard Iles [richard.iles@doctors.org.uk]
Sent: 01 January 2014 11:49
To: ***** ***** (NHS WEST SUFFOLK CCG)
Cc: ***** ***** (NHS WEST SUFFOLK CCG)
Subject: RE: High Impact change Paediatric Asthma

Hi *****

The concept behind the asthma management plans is that they standardise assessment and treatment in all areas, so perhaps confused the original question. The request was originally to have a look at the materials and trial them within the practice with the respiratory nurses, fellow GPs and patients.

To bring you and ***** up to speed:

They are being trialed in the *****H and Addenbrookes outpatients with very positive feedback.

Addenbrookes A&E have trialed, and again with very positive feedback, and one or two comments (additional resuscitation information, and might need to be a bit simpler)

We decided to delay the *****H A&E department as it is relatively dysfunctional, but hopefully will be more stable in the new year. After reflection and discussion this may be a good area to see if we can get comments and adoption.

The Suffolk Respiratory nurse group have also passed comment with very positive feedback, and are using in 2 practices.

CAMHealth and 4 Cambridgeshire practices are also trialling, again with very positive initial comments.

So a slow trickle of patients will be appearing in practices, with the plans.

In Jan we will be sending out a feedback form, so if you could even casually ask the opinion of the respiratory nurse and fellow GP that would be helpful.

All the best for the New Year

Richard

Name:	Warren Lenney
Job Title:	Professor of Respiratory Child Health
Organisation:	Keele University, UHNS Stoke-on-Trent
Region/location:	West Midlands
Capacity in which you are replying to the inquiry	Expert respiratory paediatrician with experience in adult as well as paediatric respiratory diseases
List of any supplementary information attached (if any)	None attached but my team has just finished a Cochrane-like review of factors in childhood which increase the likelihood of COPD development in adult life. We are attempting to get this published

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

Absolutely not!

Lung cancer research is poorly funded, many cardiac deaths occur through respiratory causes and COPD is one of the few major diseases still increasing in prevalence and increasing its contribution to our national mortality figures. Too little consideration is paid to respiratory compared with cardiac or oncological issues in adults. Virtually no consideration is given to the fact that diseases such as COPD, asthma and other chronic respiratory diseases have their origins early in childhood and if there is genuine interest in reducing their prevalence and severity, research must take place very early in life. There is no point waiting for the disease to become established before studying it in depth.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

Increase research funding for adult and particularly paediatric respiratory issues. Reclassify respiratory disease as a high DoH priority and encourage more trainees to enter respiratory training programmes. There is an acute lack of paediatric respiratory training posts as well and a shortage of paediatricians in training wishing to follow a respiratory career pathway.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

COPD and lung cancer are regarded as preventable if people didn't smoke. Therefore there is still the belief it is the fault of the individual and his/her life-style. This is far too simplistic. The same could be said about heart disease but for some reason the stigma is not present to the same degree.

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

Multiple causes ranging from genetic through to social disadvantage, poor diet, in-utero issues, premature birth, early infantile viral chest infections, air pollution, environmental tobacco smoke (before and after birth) and bronchial hyper-responsiveness.

5. What can the Government and the NHS in England do to reduce respiratory deaths?

Recognise the above and reclassify respiratory diseases as high priority

Asthma Questions:

1. What are the most important factors contributing to asthma deaths?

Lack of understanding of the underlying mechanisms. Lack of training and education of carers, patients and families. Lack of realisation that asthma is a disease which has been poorly controlled for decades.

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

The national asthma death audit should give an excellent guide to this aspect when it is published

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

Any increase in primary care support for asthma may result in reducing support for other diseases. Our obsessions with national targets and national league tables detract from enabling innovation and incentives at a regional or more local level.

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

The classic study is the one from Finland. The BLF study just starting in N Staffordshire and the Grampian region is based on the Finland experience.

5. What can the Government in England do to reduce asthma deaths?

Re-instate respiratory as a disease category as important as cardiac and cancer

6. What can the NHS in England do to reduce asthma deaths?

Encourage well planned projects and if the results are positive ensure roll out throughout the rest of the country.

7. Do you have any other comments relevant to this inquiry?

Chronic Obstructive Pulmonary Disease (COPD) Questions:

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

Our inability to alter lifestyles and the environment

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

Lack of effective educational and training programmes nationwide

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?

Emphasise the need to look at influencing the development of COPD as early in life as possible- hopefully before school entry

4. What could the Government in England do to reduce premature mortality from COPD?

Ensure COPD is as high a governmental priority as are cardiac or cancer issues.

8. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

No

5. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

Lack of recognition that early signs can be detected in childhood as can populations at higher risk of COPD development

6. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

The review we have undertaken will hopefully enable further research to progress

9. Do you have any other comments relevant to this inquiry?

Name:	William MacNee
Job Title:	Professor of Respiratory and Environmental Medicine/Honorary Consultant Physician
Organisation:	University of Edinburgh/Lothian Health
Region/location:	Lothian, Edinburgh
Capacity in which you are replying to the inquiry	Consultant Respiratory Physician

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

Resources for treatment of respiratory diseases are at a lower level than those of other services despite the common nature of these conditions and their high morbidity and mortality. The profile of respiratory diseases is low in comparison to many other chronic killer diseases, particularly in relation to COPD which is considered to be a self-induced condition related to cigarette smoking.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

Respiratory conditions becoming a national priority. Early and accurate diagnosis and appropriate treatment to prevent progression of disease.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

Education about respiratory conditions, recognition of at risk groups, rapid access to specialist care, shared care between community and secondary care.

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

Smokers.

5. What can the Government and the NHS in England do to reduce respiratory deaths?

Recognise respiratory conditions as an area of disease priority; proactive approach to early identification, diagnosis and

intervention; ensure access to accurate diagnostic spirometry to confirm diagnosis; ensure people receive evidence-based treatment; offer smoking cessation support; identify and treat exacerbations promptly; promote healthy lifestyle changes such as regular physical exercise.

Chronic Obstructive Pulmonary Disease (COPD) Questions:

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

Late diagnosis and inappropriate treatment.

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

Recognition of COPD as an important cause of morbidity and mortality, appropriate diagnosis and treatment; early identification and treatment of exacerbations; smoking cessation support for people with COPD who smoke; identifying patients who may require specialist treatment such as NIV and in domiciliary settings and those who develop respiratory failure and their need for long-term home oxygen therapy.

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?

Early diagnosis and appropriate treatment, early identification and management of exacerbations of the disease.

4. What could the Government in England do to reduce premature mortality from COPD?

The diagnosis and identification of COPD patients, evidence-based treatment, early identification and prompt treatment of exacerbations.

1. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

[Redacted]

5. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

Recognition by healthcare professionals of symptoms related to COPD in appropriate risk groups, case findings in these groups of at risk patients, speedy access to accurate spirometry.

6. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

[Redacted]

2. Do you have any other comments relevant to this inquiry?

[Redacted]

Name:	DR NIGEL MASTERS
Job Title:	MEDICAL ADVISOR TO CCG COPD/ASTHMA PROJECT /RETIRED GENERAL MEDICAL PRACTITIONER
Organisation:	Chiltern CCG
Region/location:	SOUTH WEST ENGLAND
Capacity in which you are replying to the inquiry	Have had an interest in respiratory care for over 30 years with low cost innovation at the primary care coalface.
List of any supplementary information attached (if any)	www.smokingpackyears .com www.clinicalindications.com www.copdprojectpack .co.uk

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

Respiratory health checks failed to be included in the NHS Health checks and this reflects the focus of the NHS on cardiovascular and diabetic health. Recommendation :detailed numerical smoking recording in primary care(see comment 3) and use of Copd screening FEV1 devices at the health check with referral to respiratory teams where needed .

2. What changes can be made to improve outcomes for all or most respiratory conditions?

1. Drug company Respiratory education is too focused on inhalers when holistic thinking is required .e.g. cardiovascular screen in COPD . Recommendation : Better computer templates for primary care which cover these areas. Use of clinical indications by prescribers on all repeat prescriptions .
2. There are too many respiratory inhaler types on the market causing confusion in use : Recommendation this should be simplified by the use of tight local formularies. This is especially important in asthma care .
3. The use of pulse oximetry as baseline measurement in new COPD and in respiratory emergency care by all medical staff is essential . ie the fifth vital sign . Recommendation : Pulse oximeters for all frontline health staff.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

Poor inadequate recording of individual smoking history is a barrier to good care . Read codes are descriptive but **numerical** smoking codes are urgently needed . Then need to be made visible on the computer screen . Recommendation : A small task force is set up to deliver smoking recording standards across the NHS England with clear instructions for computer suppliers .. Each 'ever smoker' needs smoking status , years smoked and pack years . This then needs to be visible at every patient contact . A useful screening cut off is 15 years smoked or 15 pack years . This will also allow effective searches for many diseases. eg lung cancer screening in the future. E -cigarette Read codes should also be developed .

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

Ever smokers are at increased mortality and morbidity outside their respiratory disease and their smoking histories should be a key focus of data collection in primary care.

5. What can the Government and the NHS in England do to reduce respiratory deaths?

The Chiltern CCG Project has the consistently lowest admission rates for COPD in England and some of the above ideas reflect important issues which the team believe are important for effective respiratory care.

Name:	Colin Michie
Job Title:	Consultant Paediatrician
Organisation:	Ealing Hospital ICO
Region/location:	West London
Capacity in which you are replying to the inquiry	Request from your Committee

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

No. In paediatrics respiratory disease is common. However specialists are a scarce resource, as are community nurses of high calibre. As a consequence many patients present late; some die at home- an avoidable situation. Those interested in allergy - and causes the majority of asthma in children - have published on the lack of trained staff to deal with the patients, educate them and their families. As far as I am aware this has had no perceptible impact on paediatric allergy management at the coalface.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

Employ more community or school based nurses to educate parents, patients and teachers about the potential risks of respiratory diseases, particularly asthma. It has been shown that doctors are not the best staff to carry out educational and awareness work, which has to be based in a patient's home, school and workplace.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

Expertise in educating parents and providing appropriate care pathways. The majority of children do not have rapid access to informed primary care services either through the general practitioners or the urgent care centres. The asthma deaths in children of which I am aware could all have been avoided if more expert attention had been provided rather than routine uninformed care from basic services. Countries in which patients can select a specialist or specialist nurse deliver more effective care to paediatric respiratory patients.

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

The response to this question is the same as to many other aspects of paediatrics: poor health access is worst among those that do not speak English, have not been in the UK for a long time and who live in those areas of greatest health inequalities. Exposure to cigarette smoke is another critical risk factor to pregnant mothers and children.

Examples of good work under the more specific umbrellas of tuberculosis and allergy have been carried out - by APGs - but these do not appear to have resulted in any change on the ground. One might therefore cynically respond that as long as health inequities persist at the level seen in the UK, respiratory disease will persist at unacceptably high frequency with an unacceptably high avoidable mortality.

High rates of smoking in adolescents is evident in Hospitals, but there are no specific systems or people in place for us to tackle this. In our paediatric department or our antenatal clinic there is no information for patients or potential mothers to explain the risks. The lack of enforcement of any smoking regulations in Hospitals means all our entrances are surrounded by cigarette butts, so the NHS appears to tacitly condone smoking.

5. What can the Government and the NHS in England do to reduce respiratory deaths?

Listen to those with expertise, prioritise some achievable goals, balance these against other avoidable causes of death and invest appropriately. Lessons need to be learned from the lack of success of APGs - e.g. tuberculosis and the achievements of others, e.g. continence.

NICE quality standards are particularly helpful, but commissioners need to be able to implement them. In my particular part of west London implementing any community-based initiatives such as the new NICE guideline is currently amazingly complex because we have lost so many good community nurses.

The recent DOH Strategy (COPD and Asthma) has been launched - how does the APG relate to this apparently parallel exercise?

Asthma Questions:

1. What are the most important factors contributing to asthma deaths?

From a paediatric perspective asthma deaths are often unexpected by families who do not grasp the severity of the disorder. Parent/family/school education in asthma is needed at a more effective level to prevent these.

There should be information available from NICE on this subject.

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

See answer to section 4 and 1 above

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

A lack of trained and motivated nursing / community staff

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

NICE implemented a quality standard relating to asthma in 2011: an audit of this should provide useful data.

School-based clinics in America have reduced the costs of all aspects of asthma control and treatment, improved school attendance and reduced parent absenteeism. These also help reduce smoking rates among those particularly at risk. We have no solid school-based health services in the UK to compare with these.

5. What can the Government in England do to reduce asthma deaths?

Examine the effect of the NICE quality standard for asthma, and the responses of patients to the NICE patient experience.

6. What can the NHS in England do to reduce asthma deaths?

Firstly stop degradation of community services - we are losing experienced staff at an increasing rate in west London as corrosive and unhelpful local changes in health care are implemented. Then invest in community services, particularly school-based ones.

7. Do you have any other comments relevant to this inquiry?

Given the launch of a recent DOH strategy it seems curious to overlap with another specific APG.

I should welcome evidence that previous APG work relating to tuberculosis and allergies had been taken into consideration. Paediatricians and infectious disease specialists have been very concerned about respiratory disease for some time; evidence has been presented to parliamentary groups and no action has resulted. We see children as the crucible of our species, but clearly we are not supported by policy makers!

Increasing rates of antibiotic resistance in chronic chest patients is a growing problem that makes one fear that there is little central coordination. Significant pathologies of the past manifest once more, as stated in your introduction. Evidence from the 'District General Hospitals' can only be ignored at the peril of the nation's health.

Chronic Obstructive Pulmonary Disease (COPD) Questions:

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

As a paediatrician I see very little illness defined as COPD, and cannot

comment meaningfully on this subject

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

As a paediatrician I see very little COPD and cannot comment meaningfully on this subject

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?

As a paediatrician I see very little COPD and cannot comment meaningfully on this subject

4. What could the Government in England do to reduce premature mortality from COPD?

As a paediatrician I see very little COPD and cannot comment meaningfully on this subject

8. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

As a paediatrician I see very little COPD and cannot comment meaningfully on this subject

5. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

As a paediatrician I see very little COPD and cannot comment meaningfully on this subject

6. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

My area of west London provides many cases of tuberculosis that will give rise to COPD in some. This is a significant health problem that has led experts in the field to publish, through an APG, a report (last April). This recommends investment in screening. There is no evidence this has been implemented.

Childhood obesity leads to adult obesity which compromises and in many cases can cause COPD. The NHS and political support for the obesity campaign directed through the Academy has been extremely poor.

9. Do you have any other comments relevant to this inquiry?

There are disturbing discrepancies between the delivery of health care on the ground, which is becoming progressively less expert and more chaotic in my experience of it, and that in other developed countries. For this reason the figures cited in the introduction to this survey are not surprising.

My presentations at international meetings suggest our service is often more akin to that in developing countries. Unless our significant health inequities are tackled on a broader front, the interest your group represents in respiratory health will be diluted and your diligence

wasted.

APPG on Respiratory Health - Questions

Personal Information:

Name:	Dr Gary Ruiz
Job Title:	Consultant Respiratory Paediatrician
Organisation:	King's College Hospital
Region/location:	London
Capacity in which you are replying to the inquiry	Consultant in Paediatric Respiratory Medicine at London Teaching Hospital for almost 20 years. Trustee of British Lung Foundations for 6 years

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

Depends on the respiratory disease. For COPD, certainly not. Treatments are still mainly palliative and we still do not know how to alter the long term course other than by smoking cessation. Sudden death from stroke or a heart attack is something with which the ordinary public can identify, fear and think worthy of investment in both treatment and research. If the public even know what COPD stands for, they would be less likely to concern themselves with a slowly progressive illness which could be regarded as self-inflicted from smoking. Asthma has a higher profile than COPD and there has been a much better investment in this disease. It is certainly much commoner than COPD (5.4 vs 1 million) but as a killer disease, asthma bears no comparison with COPD (1,000 deaths vs 25,000 deaths per year). Mortality from heart disease is declining at least partly due to widespread preventative strategies which are sadly lacking in COPD.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

Smoking avoidance or cessation remains the single most effective measure to prevent and improve respiratory conditions.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

- Lack of political will to implement public health measures to combat active and passive smoking compared to other countries
- Lack of investment in good research into COPD

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

Yes. Regarding respiratory disease in children specifically:

- Premature babies (airway damage from premature usage)
- Babies of mothers who smoked during pregnancy (growth retarded baby with smaller calibre airways which are therefore more likely to obstruct causing wheeze)
- Children from “atopic” families (higher risk of allergic sensitisation occurring in lungs and development of asthma)
- Unimmunised children (e.g. whooping cough, pneumococcal pneumonia)
- Children with underlying illness predisposing to respiratory infection: e.g. cystic fibrosis, immunodeficiencies, neurologically impaired children, sickle cell disease, etc
- Obese children (sleep-disordered breathing)

5. What can the Government and the NHS in England do to reduce respiratory deaths?

Although we have an unacceptably high death rate for asthma compared to other similar countries, the mortality is minuscule in relation to the morbidity it causes and is dwarfed by deaths from COPD. Effective measures to reducing COPD deaths would therefore have a much greater impact on overall respiratory deaths. These measures might include ensuring funding and support for:

- Identifying and targeting preventative strategies at high risk groups (currently smoking avoidance is main strategy but workplace exposures are increasingly recognised as another cause which may account for 15% of COPD)
- Developing management strategies for halting the progression of the disease in affected individuals at an early stage (currently smoking cessation remains the most important therapeutic measure but a 4 stage graded management strategy has been described by GOLD, involving immunisation, pharmacotherapy, etc.)
- Ensuring that severely affected patients are adequately supported e.g. long-term oxygen therapy can double survival in hypoxaemic COPD patients, noninvasive ventilation is an effective technique to get patient through a severe exacerbation, etc

Asthma Questions:

1. What are the most important factors contributing to asthma deaths?

Of the 1143 asthma deaths from asthma in the UK in 2010, only 16 were in children. Being a paediatrician, there may be others better qualified to comment on factors contributing the majority of deaths which occur in the older age group.

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

Patients who:

- Have required admission to intensive care or high dependency for acute asthma previously
- Require high amounts of treatment, particularly regular oral steroids
- Adhere poorly to prescribed treatment or management plans either through poor understanding (especially if English is not understood, which may account for racial differences) or carelessness
- Have poor recognition of symptoms
- Have severe asthma attacks but live remote from an emergency facility

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

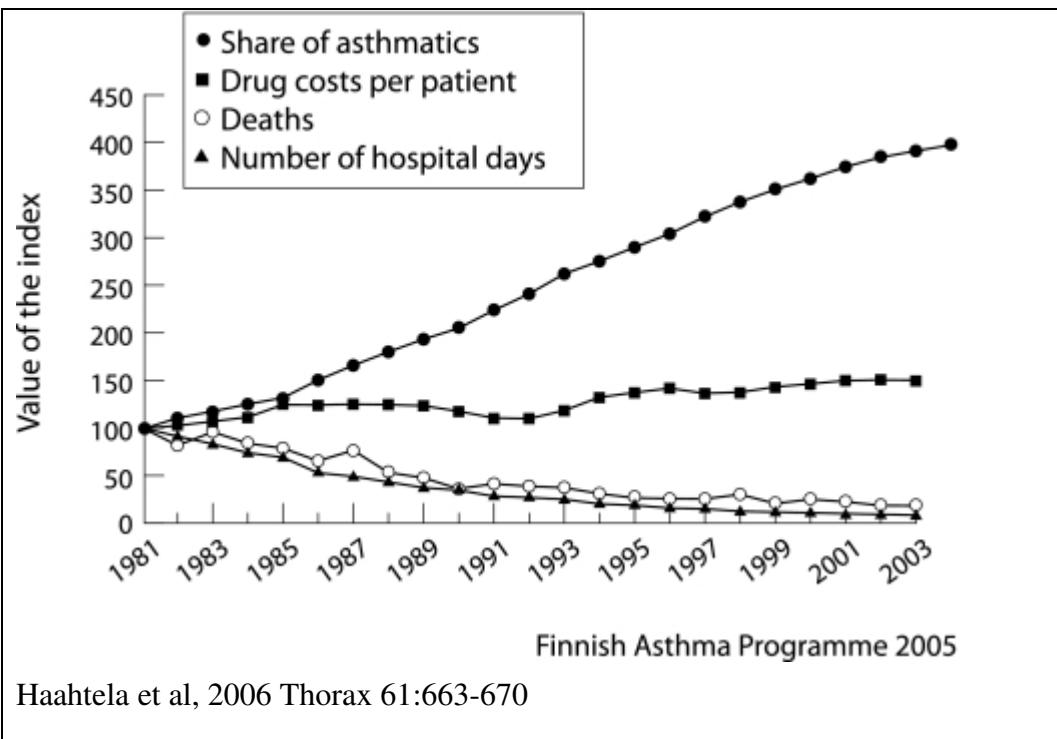
- Less fragmentation of services particularly if dealing with asthmatic children from the severe end of the spectrum requiring tertiary care
- Better education of professionals in asthma at all levels of care
- Improving knowledge about asthma in patients and carers

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

10 year national asthma programme in Finland (from 1994-2004) with the following goals:

- early diagnosis and active treatment
- guided self-management as the primary form of treatment;
- reduction in respiratory irritants such as smoking and environmental tobacco smoke;
- implementation of patient education and rehabilitation combined with normal treatment, planned individually and timed appropriately;
- increase in knowledge about asthma in key groups; and
- promotion of scientific research

This achieved a steady fall in mortality over the 10 years.



5. What can the Government in England do to reduce asthma deaths?
 - Support a national asthma campaign along the lines of the Finish model or other successful campaigns in other countries

6. What can the NHS in England do to reduce asthma deaths?
 - The National Review of Asthma Deaths initiative from RCP
 - Support research into causes and management of severe asthma

7. Do you have any other comments relevant to this inquiry?

Chronic Obstructive Pulmonary Disease (COPD) Questions:

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

I am a paediatrician and do not manage COPD

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?

4. What could the Government in England do to reduce premature mortality from COPD?

8. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

5. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

6. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

9. Do you have any other comments relevant to this inquiry?

We need to develop better ways of identifying and treating COPD. However there is clearly a need for more basic research into the causes of COPD. This will always be difficult to do in patients who already have the disease. The answer must lie in doing large prospective epidemiological/genetic studies in large cohorts of patients to identify people at risk on whom to target strategies to prevent the disease. Such a long term study needs to begin in childhood where the origins of COPD lie and where paediatricians can be the first to institute preventative strategies.

Name:	Nick Sargent
Job Title:	Consultant in Paediatric Emergency Medicine
Organisation:	Bristol Royal Hospital for Children
Region/location:	Bristol
Capacity in which you are replying to the inquiry	Lead for respiratory presentations within the Children's Emergency Department in Bristol (and as a member of the allergy team)

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

As a paediatrician it is difficult to comment based on the examples given in the question which are predominantly adult illnesses. Asthma does have a high profile within paediatric medicine but in my view children's asthma does not have a high enough profile within primary care. It appears that much of the routine asthma work has been devolved to practice nurses with a diploma. Unfortunately this diploma is very adult orientated and in particular does not arm the nurses with expertise in managing <5 year olds with recurrent wheeze.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

Unfortunately, it is a sign of the times that I think we need to financially incentivise GPs to focus on asthma and in particular children's asthma. There are few if any paediatric QOFs and I think this needs to change

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

Please see above - good primary care and a focus on prevention.

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

Ex-preterm infants and children with chronic lung or other preterm related chest illness. Also, atopic and allergic children - the UK

trails the rest of western Europe, North America and Australasia in terms of access to immunotherapy and allergy services in general.

5. What can the Government and the NHS in England do to reduce respiratory deaths?

See above

Asthma Questions:

1. What are the most important factors contributing to asthma deaths?

I can only comment on children's asthma:
Ineffective prevention of severe symptoms and in particular a lack of focus on wheeze in pre-school children. This mostly falls on primary care but all too often these children prevent recurrently to emergency departments and are patched up and sent home without much thought to long-term symptom control.

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

Atopic and allergic children - particularly those with food allergies.
Severe allergic/anaphylactic reactions in children often take the form of an asthma attack or include features of an asthma attack.

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

The need for investment in training and resources focused specifically at childhood asthma - particularly in primary care.

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

When I worked in Melbourne they used an online/electronic asthma plan generator that automatically printed off 3 copies (one each for the parents/patient, hospital notes and GP). Whilst I am not aware of any data to show it definitely reduced deaths this is clearly a good idea. I wonder if we could produce a generic asthma plan generator that could be used by all NHS institutions?

5. What can the Government in England do to reduce asthma deaths?

For children - focus on primary care prevention, increasing the number of specialist paediatric emergency medicine consultants (particularly in generic A&Es) and improving allergy services for children.

6. What can the NHS in England do to reduce asthma deaths?

Re-focus QOFs etc to prioritise asthma in children

7. Do you have any other comments relevant to this inquiry?

Name:	Dominick Shaw
Job Title:	Associate Professor and Honorary Consultant
Organisation:	University Of Nottingham
Region/location:	Nottingham, East Midlands
Capacity in which you are replying to the inquiry	Health care Professional, Academic, Member of the BTS specialist advisory committee on asthma.

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

Care and services are not on a par for several reasons:

Clinically, tests in respiratory disease are not as definitive as for other disease entities.e.g. there is no equivalent of a troponin to predict an exacerbation of airways disease. Furthermore as asthma is a variable condition it makes tests harder to interpret.

This lack of hard endpoint or outcomes makes it more difficult to coordinate services as there is no clear goal. Both stroke and cardiac medicine have successfully used “time is brain”/“time is heart muscle” (or door to needle times) to galvanise services around an (occasionally lacking) evidence based outcome.

Culturally, airways and respiratory disease tend to affect older people which has less of an economic and social effect. This, added to the occasional (misperceived) notion that patients have brought the disease on themselves makes airways disease less impactful from a societal and media perspective.

As an example in this media driven age, if one compares the celebrity role models who campaign for airways charities versus stroke or cardiac, an immediate difference can be seen in the celebrity kudos each charity attracts.

This is not aided by the terminology used; COPD and pulmonary rehabilitation are not patient friendly terms and should be ditched, or if kept an alternative should be sought for patient use as in the combination of myocardial infarct/heart attack. Lung attack is a good term and has been pushed recently.

Lastly aside from smoking, the respiratory community has underplayed the role of modifiable disease factors. In heart and stroke disease great play is made of diabetes, cholesterol, stress, exercise etc, but the respiratory community has not embraced this philosophy and has concentrated treatment on the underlying condition. This may be economic; allergy avoidance,

weight loss, anxiety management etc do not have easy drug targets.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

Better data capture is key; there is no point trying to change what you don't/can't measure.
Deciding/agreeing on what's important in the respiratory community is important.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

Lack of joined up care. The lack of a hard endpoint means that it is difficult to identify and concentrate on at risk individuals.

There is little point concentrating on the large majority of patients who will remain stable; patients at risk of a poor outcome should be identified and modifiable risk factors and underlying disease states treated aggressively.

As respiratory disease is such a prevalent condition it makes more sense to concentrate efforts on the small population who will do worse.

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

Low socioeconomic groups- causes are obvious- smoking, deprivation, education, etc.

5. What can the Government and the NHS in England do to reduce respiratory deaths?

Make proper management a mandated requirement for reimbursement.

Identify outlying areas of care based on admission and death rates and set up advisory task forces.

Raise public awareness; the recent stroke adverts on TV help force the hand of stroke services by increasing public expectation.

Asthma Questions:

1. What are the most important factors contributing to asthma deaths?

Poor compliance.
v. rarely truly refractory asthma.

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

Poorly compliant patients. Compliance is a complicated issue.
However, from memory, the vast majority of asthma deaths occur in older patients which may represent a comorbidity signal, or end stage of a long

chronic process.

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

As above- very prevalent condition, so at risk patients should be identified and then managed. The challenge is in the identification.
Also there has been a push to over diagnose patients- the diagnosis is hardly ever questioned, or re-evaluated. This means that other diagnoses get missed and the right patients are not concentrated upon.

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

Not when the rate of baseline death is already lowish.

5. What can the Government in England do to reduce asthma deaths?

Set up a rapid access breathlessness clinic that sees patients after their first course of oral corticosteroids. Modifiable risk factors can then be managed.

6. What can the NHS in England do to reduce asthma deaths?

Fund the above, or fund a pilot study- happy to be involved!

7. Do you have any other comments relevant to this inquiry?

Thanks for the invite. I have limited my specific comments to asthma, but the comments above about respiratory disease apply equally to COPD.

Name:	Susan Spence
Job Title:	Community COPD Specialist Nurse
Organisation:	South Tees NHS Trust
Region/location:	Hambleton and Richmondshire
Capacity in which you are replying to the inquiry	Health Care Professional
List of any supplementary information attached (if any)	

Chronic Obstructive Pulmonary Disease (COPD) Questions:

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

Late diagnosis, treatment and management.

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

Screening for COPD tends to be performed when symptoms of COPD develop. Primary care services already under a lot of pressure to be able to screen those smokers with no symptoms. (lung health checks). Patients not attending appointments. Funding for Community COPD support not in place in all areas. Self management plans too complex and not used by patients and health professionals.

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?

Support training health professionals in COPD screening in all smokers. Earlier intervention initiatives. Support more local cessation clinics. Pulmonary rehabilitation despite geographical location.

4. What could the Government in England do to reduce premature mortality from COPD?

As above plus better self management plans for patients that can more easily be followed.

1. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

Not from dying of COPD. Extended support of Outreach Services, Community COPD Nurse Services to manage exacerbations earlier reduce readmissions.

5. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

Improved screening for smokers. Pressures for achieving targets in all areas of health placed with Primary Care, not enough health professionals to take on extra screening and support programmes.

6. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

Outreach Service, Pulmonary Rehabilitation and Community COPD Nurse services available. Year of care pathway for COPD developed(to be updated) to provide Primary Care with guidance with the care and management for COPD in all stages and problems associated with COPD. Reduced admission rates into hospital. Would like to encourage screening for all smokers but pressure on services would not allow it.

2. Do you have any other comments relevant to this inquiry?

Routine screening in other illnesses in place, routine screening for smokers, regardless if symptoms are present should be more readily available.

Name:	Mike Thomas
Job Title:	Professor of Primary Care research
Organisation:	University of Southampton
Region/location:	SW
Capacity in which you are replying to the inquiry	Personal, professional and as Chief Medical Advisor to Asthma UK and a steering group member of the BTS-SIGN asthma guideline and NICE asthma guideline

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

No.

Funding for clinical services and research in respiratory diseases has lagged behind other disease areas. There has been an unfortunate perception that asthma is 'sorted out', whereas in fact there have been no improvements in deaths, admissions or symptoms in the last 15 years. COPD and lung cancer are often viewed as being 'self inflicted' by smoking and carry a stigma that other lifestyle-related conditions, such as diabetes, cirrhosis, heart disease, hypertension, do not carry. There are a number of rarer lung diseases such as IPF and sarcoid that cause immense hardship and distress that are poorly catered to in medical care. Outcomes of respiratory care show unacceptable variations between regions, and the poorest and most vulnerable sections of society often have the worst outcomes.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

We need a number of things.

1. Integrated care, so that consistent messages and seamless care pathways are provided
2. Supported self-management: patients need the information and support to make good choices about their own health. This includes better use of technology to allow people to receive care and support conveniently and efficiently
3. Better non-drug treatment provision- many lung conditions are long-term and incurable at present, so we need to support people and their families in coping with the consequences of chronic ill health
4. Individualised (stratified) care- everyone is different, and different treatments (drug and non-drug treatments) and effective in different people
5. New treatments- both drug and non-drug treatments
6. Better education and incentivisation of professionals to provide

high quality care

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

Smoking- we need better prevention and support services
Money- the investment in community services to keep people out of crisis and out of hospital must be adequate
Team-based integrated care- we need to sing of the same song-sheet
Education- professionals need to get better and providing people with the information they need in a form they can digest

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

Lower socio-economic and educational demographic groups, as more smoking and poorer nutrition and self care
Ethnic minority groups have poor respiratory outcomes, often as they have not engaged with health services

5. What can the Government and the NHS in England do to reduce respiratory deaths?

Support research
Incentives for high quality care
Audit
Listen more to patients

Asthma Questions:

1. What are the most important factors contributing to asthma deaths?

Non-adherence to medication
Professional complacency
Poor care

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

Socio-economically disadvantaged, and those with co-morbidities, partially psychological morbidity

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

Up-front investment in services.
Knowledge transfer
Cost pressures

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

Finland

5. What can the Government in England do to reduce asthma deaths?

Prioritise asthma care
Fund research
Note the lessons from NRAD and develop services

6. What can the NHS in England do to reduce asthma deaths?

As above

7. Do you have any other comments relevant to this inquiry?

Good luck!

Chronic Obstructive Pulmonary Disease (COPD) Questions:

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

Smoking
Delayed diagnosis
Inadequate treatment

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

Costs of services, including medication, hospital costs and pulmonary rehabilitation provision

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?

Better proactive care
Better early diagnosis
Better smoking services

4. What could the Government in England do to reduce premature mortality from COPD?

Cigarette advertising ban, including sport

8. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

Better detection in Scandinavia from screening programmes

5. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

Better screening and case-finding

6. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

We still lack adequate access to pulmonary rehabilitation

9. Do you have any other comments relevant to this inquiry?

Name:	John Warner
Job Title:	Professor of Paediatrics
Organisation:	Imperial College
Region/location:	London
Capacity in which you are replying to the inquiry	Personal but also as a member of the British Society for Allergy and Clinical Immunology and the British Thoracic Society
List of any supplementary information attached (if any)	My clinical and research interests have focussed on the early life origins of asthma and related allergic and respiratory disorders

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

No. Insufficient funding of services particularly to support specialist nursing, physiotherapy and dietician input

2. What changes can be made to improve outcomes for all or most respiratory conditions?

An increase in specialist allied health professionals to provide continuity of support particularly in the community.
The creation of networks to deliver integrated care between community and hospitals. This requires funding for education, training, meetings etc. and consultant delivered community clinics with GPs.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

Institutional barriers to integration of care; lack of funding and attention from CCGs.

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

From a paediatricians perspective there is a gathering time-bomb of neonatal intensive care graduates who will have a far higher risk of early onset COPD.

Obesity has profound effects on lung function and susceptibility to airway inflammation.
Smokers and other pollutant exposure...obvious but need to be integrated with an understanding of genetic susceptibility.

5. What can the Government and the NHS in England do to reduce respiratory deaths?

Give a higher priority and funding to support networks and integrated care.
Support more research.

Asthma Questions:

1. What are the most important factors contributing to asthma deaths?

Poor concordance with therapeutic recommendations mostly being a consequence of a lack of accord between physician and patient/carer.
No consistent allied health professional input in the community.
Virus infection super-imposed on allergic airway induced inflammation.

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

Those with associated food allergy often unrecognised and not diagnosed.
The more severe the asthma the greater the likelihood of allergy to inhalant and foods.
Poor socio-economic circumstances
Psycho-social problems
Previous hospital admissions with exacerbations

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

Lack of co-ordination of care as a consequence of so-many agencies from different organisations being involved.

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

The Finland national asthma programme has had spectacular effects on mortality, hospital admissions and has reduced costs.
My own team have recently implemented the paediatric allergy care pathways in 3 CCGs around St. Mary's hospital in NW London. This has already reduced hospital admissions for asthma in the 3 districts by 22% more than any other NW London districts.

5. What can the Government in England do to reduce asthma deaths?

Give it a higher priority such that CCGs are required to provide the funding to support an integrated service.

6. What can the NHS in England do to reduce asthma deaths?

Develop nationally agreed care-bundles.

Define competence to deliver which should be the basis of integrated care.

7. Do you have any other comments relevant to this inquiry?

See www.rcpch.ac.uk/acp and www.itchysneezywheezy.co.uk

APPG on Respiratory Health - Questions

Personal Information:

Name:

Job Title:

Organisation:

Region/location:

Capacity in which
you are replying to
the inquiry

List of any
supplementary
information
attached (if any)

PROFESSOR ROBERT WILSON
DIRECTOR LUNG DIVISION
ROYAL BROMPTON HOSPITAL
LONDON
CONSULTANT PHYSICIAN

Respiratory Disease Questions: Please provide as much or as little information as you wish, up to a maximum of 300 words per question.

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

- No. Although respiratory disease has been on the agenda as a priority for many years now, it has not had the same sort of commitment and investment - or seen a commensurate scale of improvements in outcomes - as other "big killers" such as heart disease, stroke, cancer or liver disease.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

- Implementing quality standards. A quality standard for COPD was published 2 years ago, one for asthma was published in February, one for smoking cessation in August, and several others are planned [for sleep disordered breathing, pneumonia, idiopathic pulmonary fibrosis and, for children, bronchiolitis, although clinical guidelines on which to base the standards need to be developed for most of these]. But they are having little impact in practice because of the lack of incentives to implement them, levers to drive their uptake, and systems to measure whether they are being adopted. So, for example, indicators need to be included in relevant performance management frameworks, and schemes that focus on the improvements that need to be made, for example CQUINS, should be developed and implemented.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

- Lack of investment in improving the data available for respiratory disease. This could be reversed by establishing a programme to agree on consistent outcome measures - including in primary care - and how the data should be collected. This will establish the baseline that is necessary to the development of levers and incentives, enable improvements to be measured, and help commissioners to understand that respiratory is a priority.
- Lack of infrastructure - and in particular the lack of future plans for networks for respiratory disease - which are important in developing and implementing the policy and actions that will drive improvements.

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

5. What can the Government and the NHS in England do to reduce respiratory deaths?

- Include relevant indicators in performance management frameworks such as the CCG Outcomes Indicator set.
- The long term conditions strategy that is being developed by NHS England should include examples of respiratory self-management projects with proper patient support, to help raise the profile of respiratory disease and demonstrate that it is a priority.
- Develop and disseminate discharge bundles for respiratory diseases through CQUINS, and develop and implement other, local, schemes that focus on the improvements that need to be made.

Asthma: Please provide as much or as little information as you wish, up to a maximum of 300 words per question.

Background

Over 4 million people in England are affected by asthma⁸ and, on average, three people die every day from their asthma. We know three quarters of these deaths are amongst people aged 65 or over, and evidence suggests 90% of all asthma deaths are preventable if managed properly.⁹ In 2010 the UK death rate from asthma was one of the highest in Europe.¹⁰

In February 2012, the National Review of Asthma Deaths (NRAD), led by the Department of Health, began a review into all deaths from asthma across the UK for one year. The review aims to reduce the number of asthma deaths and the findings will be published in April 2014.

Questions

1. What are the most important factors contributing to asthma deaths?

Confidential enquiries to date¹ have broadly identified the following factors as contributing to asthma deaths:

¹ An ongoing Confidential Enquiry into asthma deaths in the eastern region of the UK, 2001-2003, Harrison et al, Primary care Respiratory Journal (2005) 14, 303-313.

- *Disease factors*

The severity of a person's asthma affects their risk of a fatal attack. The people at the highest risk are those with severe asthma, though many people who die have mild asthma.

- *Behavioural or psychosocial characteristics of patient.*

Characteristics such as poor compliance with medication, failure to attend appointments, denial, depression, alcohol problems and smoking have been identified as risk factors for asthma deaths.

- *Medical management*

Inadequate medical care has also been identified as a risk factor for asthma deaths - principally inappropriate routine care, failure to prescribe (or prescribing an inadequate dose of) oral or inhaled steroids, lack or referral to a specialist chest physician and inadequate follow up, both by the hospital and GP following an exacerbation. Under-treatment may explain why so people with supposedly mild asthma die.

- *Allergy*

More recently allergy has been identified as a potential risk factor in asthma deaths.

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

As mentioned above:

- People with severe asthma.
- People with certain behavioural/psychosocial characteristics.
- People whose asthma care is inadequate.
- People (especially children) with asthma and allergy.

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

- Lack of infrastructure for respiratory disease, including asthma. The coverage of respiratory networks is patchy and their future uncertain. Sharing knowledge regionally and nationally about what works in driving up standards of care is not straightforward in a system where local organisations are responsible for commissioning healthcare. Respiratory disease should be top of the list when priorities for Strategic Clinical networks are next reconsidered..
- Asthma is battling for attention with a wide range of other conditions and priorities. We need to ensure that commissioners understand the benefits of improving asthma care in terms of, for example, the potential for reduced hospital admissions and associated costs, and improving performance against key performance indicators as well as the personal impact on people with asthma and their families.

Risk factors for childhood asthma deaths from the UK Eastern Region Confidential Enquiry 2001-6, Anagnostu et al, Primary Care Respiratory Journal, 2012; 21 (1):71-77.

A district confidential enquiry into deaths due to asthma, Wareham et al, Thorax 1993; 48:1117-1120 [This enquiry was incorporated into the eastern region enquiry]

A confidential inquiry into asthma deaths in Wales, Burr et al, Thorax 1999; 54: 985-989. Scottish Confidential Inquiry into Asthma Deaths (SCIAD) Bucknall et al, Thorax 1999; 54: 978-984.

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

- A recent study into health services for children in Western Europe looked at child mortality in Europe and considered various aspects of these services in different countries.² It suggests that Sweden's model of primary care may offer lessons in view of its achievement of some of the best outcomes for children in Europe (including asthma). In Sweden, GPs work closely with paediatricians and children's nurses with whom they are often co-located in health centres. Most GPs also receive at least 3 months specialist training in paediatrics. The authors suggest that such flexible models of primary care, with teams of professionals trained in child health working closely together might offer a way to balance expertise with access.
- However, we have to bear in mind that the way health systems deliver services in other countries may be the result of historical, cultural, social and financial factors that we cannot necessarily realistically expect to transplant here.
- Finland implemented a 10 year asthma programme in 1994. Although reducing the death rate from asthma wasn't one of its explicit goals, there was a reduction in the death rate in the duration of the programme [from 1.5654 per 100,000 of the population in 1996 to 0.9633 in 2004]. The programme focussed on early diagnosis and active treatment; guided self-management, implementation of patient education and rehabilitation, increasing knowledge about asthma amongst key healthcare professionals and reduction in respiratory irritants such as smoking/tobacco smoke through legislation. The key to implementation was considered to be an effective network of healthcare professionals given responsibility for asthma.

5. What can the Government in England do to reduce asthma deaths?

Improve the quality of asthma care by:

- Commissioning a comprehensive national audit to establish a baseline against which continuous improvements can be made to services.
- Including key parts of the quality standard for asthma (for example provision of asthma action plans) in performance management indicators such as the CCG Outcomes Indicator Set.

6. What can the NHS in England do to reduce asthma deaths?

- CCGs can improve asthma care by pledging to implement the Quality Standard in their area.
- CCGs and Area Teams in NHS England need to develop and implement local schemes to improve particular elements of care, for example CQUINS for hospital care and discharge arrangements and schemes along the lines of the old local enhanced services for follow up in primary care following hospital treatment.
- Primary care could implement risk registers to record people with severe

² Health services for children in Western Europe, Wolfe et al, The Lancet, 2013; 318:1224-34. See graph of mortality rate in children from asthma from this study on page 11.

- asthma and behavioural characteristics who are at greater risk of an attack so they can be monitored and reviewed.
- NHS England could appoint a National Clinical Director for Allergy to help ensure links are made between care for asthma and allergy.

7. Do you have any other comments relevant to this inquiry?

Chronic Obstructive Pulmonary Disease (COPD) Questions: Please provide as much or as little information as you wish, up to a maximum of 300 words per question.

Background

COPD kills about 25,000 people a year in England and Wales. Recent figures showed that COPD accounted for 4.8% of all deaths in England between 2007 and 2009. It is the fifth biggest killer disease in the UK after cancer, heart, stroke, and liver disease. Premature mortality from COPD in the UK was almost twice as high as the European (EU-15) average in 2008 and 1 in 8 people over 35 has COPD that has not been properly identified or diagnosed.¹¹

Questions

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?

4. What could the Government in England do to reduce premature mortality from COPD?

5. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

6. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

7. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

8. Do you have any other comments relevant to this inquiry?

-
- ¹ The Burden of Lung Disease: Report 2, British Thoracic Society, 2006.
- ² UK mortality from respiratory disease is 5th worst in the EU, after Denmark, Ireland, Belgium and Hungary. ERS White Book - the Burden of Lung Disease, Figure 1. Last accessed on October 2013. <http://www.erswhitebook.org/chapters/the-burden-of-lung-disease/>
- ³ Department of Health, *England level data by programme budget*. Downloaded from: <https://www.gov.uk/government/publications/2003-04-to-2010-11-programme-budgeting-data>. Accessed on 01/10/2013
- ⁴ 7,500 lives could be saved in England when total deaths were 23,000 per year from COPD. Outcomes Strategy for Asthma and COPD: NHS Companion Document, Department of Health, May 2012.
- ⁵ Partridge M, Self care plans for people with asthma. *The Practitioner* 1991, p 715-21
- ⁶ Health Survey for England 2001. The Scottish Health Survey 2003. Welsh Health Survey 2005/2006. Northern Ireland Health and Wellbeing Survey 2005/2006. Population estimates from Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics & Research Agency
- ⁷ Outcomes Strategy for Asthma and COPD: NHS Companion Document, Department of Health, May 2012.
- ⁸ Health Survey for England 2001. Population estimates from Office for National Statistics
- ⁹ Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics & Research Agency
- ¹⁰ OECD, Deaths - *International comparisons, all ages*. Downloaded from <http://stats.oecd.org/> Accessed on 02/10/2013
- ¹¹ All references in this paragraph: An Outcomes Strategy for COPD and Asthma, Department of Health, July 2011.

Name:	Stephanie Wolfe
Job Title:	Respiratory Nurse Specialist & Educationalist
Organisation:	Independent (Primary Care)
Region/location:	Norfolk
Capacity in which you are replying to the inquiry	as above and member PCRS-UK
List of any supplementary information attached (if any)	Provider of respiratory (mainly asthma, COPD, spirometry) services for over 20 years in Primary Care. Local and National speaker in respiratory disease

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

Respiratory disease services poorly provided for and significance/severity not recognised. Care can be patchy and a bit of a lottery.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

Provision of training and ongoing updates. Performance of spirometry which is done widely, is very poor and results inconsistent. Newer treatments not always known and therefore not tried when control of disease may be suboptimal.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

Severity may not be recognised by patients or health carers so treatment may be delayed or inadequate. Prescription charges may prevent some clients complying with treatment regimes as they can be costly (prescription charges)

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

Lower socio economic groups-relates to above.
Young (e.g teenagers) - may not accept diagnosis and/or treatments.

5. What can the Government and the NHS in England do to reduce respiratory deaths?

Improve training access/costs. Address prescription costs

Asthma Questions :

1. What are the most important factors contributing to asthma deaths?

delayed care- may be patient led, failure to seek help at appropriate time and/or poor treatment given in A/E depts

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

Lower socio economic groups, smokers. May not be aware that asthma can kill

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

cost and training

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

Finland

5. What can the Government in England do to reduce asthma deaths?

Provide consistent advise on asthma management to all health providers which in turn could educate general public.

6. What can the NHS in England do to reduce asthma deaths?

as above, consistency of good basic asthma care is needed

7. Do you have any other comments relevant to this inquiry?

Chronic Obstructive Pulmonary Disease (COPD) Questions:

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

diagnosed too late. Need greater lung health awareness & smoking

cessation services. Appropriate training in diagnosis and spirometry

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

Lack of time to be pro-active.

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?

Improve early diagnosis and smoking cessation. Public awareness of the disease-currently very poor. Lung cancer well known, COPD poorly understood by public

4. What could the Government in England do to reduce premature mortality from COPD?

as above

5. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

as before

6. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

7. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

Excellent provision of pulmonary rehab services but understanding of management of COPD in general practice and use of PR service. Too much focus on pharma management

8. Do you have any other comments relevant to this inquiry?

Guidelines out of date

Name:	Anonymous
Job Title:	Patient Representative (COPD)
Organisation:	Imperial College Healthcare NHS Trust and CLAHRC NWL
Region/location:	London NWL
Capacity in which you are replying to the inquiry	Both as patient rep and as patient suffering from long term respiratory conditions

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

Respiratory disease has not received the same amount of public campaign visibility as other diseases and to a large extent is subject to both ignorance and misinformation amongst the general public, and also amongst some healthcare professionals.

Perception is too often that of a minor ailment, with a quick fix -- the ubiquitous, badly prescribed and costly inhaler!!

I fully admire and support the admirable work done on cancer in the last 20 years to reduce taboos, misconceptions and improve diagnosis. Similar initiatives, interventions and sustained information campaigns need to be designed and implemented, with full coverage of all respiratory conditions.

One issue which is still a mystery to me is why COPD patients have access to community services, while those with other lung disease [ILD, aspergillosis, bronchiectasis, m-Kansasii, COP etc...] do not.

I have direct personal experience of this but also need to state that I am not "complaining" because I am extremely lucky to receive excellent care and treatment at Imperial College Healthcare NHS Trust's St Mary's Hospital Chest & Allergy Clinic. The point is that many patients are not as lucky as I am to access such a centre of excellence.

Patients not treated in the community:

- have no regular lung function/spirometry tests
- may not have access to home oxygen although such therapy would be beneficial
- are not included in their GP surgery's Risk Stratification Tool and hence not subject to

be considered for alerts, special care plans...

- may be refused flu vaccination if under the age of 65 [I was and had to enlist my secondary care chest physician's help to obtain jab...]

2. What changes can be made to improve outcomes for all or most respiratory conditions?

Active campaign to alert population to the seriousness of "breathlessness" symptoms and respiratory diseases which if not curable could at least be better managed, including self-managed, than they are now.

Implement effective community services with the collaboration of patients who have long term respiratory conditions and who can provide guidance to the real needs of patients, as opposed to assumed needs defined by non specialists, non clinicians. Peer to peer support groups should be at the core of such community service.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

Main barriers: lack of education [both general public and some HCP sections] and lack of communication between care settings.

Strong emphasis is placed on smoking cessation and this is, of course, correct and needs to continue. BUT many respiratory conditions are NOT related to direct smoking but to other conditions: poor housing, water contamination, pollution etc... These conditions need attention and solutions.

People should not die of asthma in this day and age, and yet 4 people die of the disease every day.

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

I do not have enough data to answer this question. My guesses would be that older people living in big cities with high level of pollution would be at higher risk. The housing conditions also need to be looked at.

5. What can the Government and the NHS in England do to reduce respiratory deaths?

- Implement and develop community services [including as mentioned above full collaboration of patients in the design of such services and the facilitation of peer to peer support groups]
- Seriously study the impact of housing conditions and enforce building regulations where non-compliance is the cause of respiratory illnesses, The present remit of environmental health officers is far too weak and basically totally ineffective.

Name:	Michaela Barnard
Job Title:	Lecturer in Children and Young People's Nursing
Organisation:	University of Salford
Region/location:	North west
Capacity in which you are replying to the inquiry	Patient with asthma

Asthma Questions

- What are the problems within the NHS that prevent a lot of people from receiving care that fully meets clinical standards? You can build on the experiences you shared at the Compare Your Care event.

Health professionals (particularly GP) knowledge on asthma including diagnosis, patient that doesn't fit the text book example and in particular lack of GP knowledge regarding BTS guidelines including step wise program, how to manage an exacerbation.

- What can the Government and NHS in England do to improve asthma care and ultimately reduce asthma deaths?

After 4 years of moderate asthma that has been quite difficult to treat, I still do not have a management plan. This SHOULD be my lifeline to reduce hospital admission never mind death. It's an easy intervention that helps patients understand when to seek treatment, step up treatment and what kind of intervention might be necessary. Management plans, checking inhaler technique and listening to the patient should be mandatory.

Improving primary care knowledge of asthma is key to this issue. Knowledge of the national guidelines for treating exacerbations is vital.

- Do you have any other comments relevant to this inquiry?

Having been in a preventable, acute life threatening admission to hospital situation, I know that patients need the tools and knowledge to equip them to seek assistance when necessary. I believe asthma management plans are a cheap and easy intervention, but knowledge and education of the health professional needs to come alongside this.

Name:	Molly Bennett
Job Title:	PR
Organisation:	Breathe Easy support groups
Region/location:	Hedge End Eastleigh
Capacity in which you are replying to the inquiry	As PR
List of any supplementary information attached (if any)	See forms

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

In varying respects yes , some services are behind others above IE late diagnosis.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

Attention to the causes, such as air pollution, industrial pollution, chemicals in foodstuffs , smoking, lack of exercise (usually because patients feel isolated through fear)

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

Obviously funding!

Not enough done on early diagnosis, educating patients to recognise when it is not a normal cold/chest infection.

More responsible actions from those causing the pollution in our areas, IE..industrial traffic- air quality/output monitoring of large industries - Funding to better educate people on the dangers around them. Especially children.

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

Those who work and live in heavy industrial areas, and those who have worked with many alien substances (asbestos etc) where symptoms do not present till later in life.

Children whose schools are close to a main rd are more likely to suffer from chest problems, which can later develop into a serious condition.

The use of chemicals in our food is I believe at a dangerous level, mostly used to prolong the shelf life of so many products .

Our farming industry is now a chemical mine field and people should be made aware of just what they are really ingesting!

5. What can the Government and the NHS in England do to reduce respiratory deaths?

Bring to the attention of all in government the dangers of pollution and take action to correct the situation now before the children of today become the patients of tomorrow, and we are faced with millions of people with a poor quality and much shorter life expectancy.

Educate them young so we don't have to treat them when old!

Chronic Obstructive Pulmonary Disease (COPD) Questions:

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

Air pollution/air quality

Smoking

Petrol fumes

Ingested chemicals in our food

Late diagnosis

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

Education on healthy life styles, especially for children

Not enough attention to air pollution
Children not being taught to cook healthy meals
More energy into reducing traffic fumes/better public transport
Serious reduction in the chemicals in our food and drink

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?

Educate and fund preventive measures, so people are not developing in the first place
Much more serious attention to address the traffic pollution, rapidly on the increase
Also air traffic pollution which is also on the increase!

4. What could the Government in England do to reduce premature mortality from COPD?

More funding into research to stop the ALARMING escalating problems of COPD

1. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

GP SURGERIES OFFER ADVICE /HELP on stopping smoking is some help, but we need to get the ideas of healthy eating and cooking fresh foods across to the younger generation
Pulmonary rehab courses are excellent, but not long enough, after which patients become isolated at home.
More groups like the one I started Up 5 years ago (after my rehab)To keep the exercises going and have a support group to help , we had to set up and fund the whole thing ourselves initially, until I got the local research team on board, who have been a tremendous help to us.

5. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

Regular testing by Gps for patients 'at risk' IE smoking
Working with industrial substances (I feel the larger companies should be a major part of funding this)
BETTER AIR QUALITY MONITORING to warn Gps of possible lung conditions presenting at surgeries, air quality to be available at every GP practice.

6. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

I am the PR for the local Breathe Easy group, we found our local surgeries could do more to refer patients to us ,

some are reluctant to keep our posters up letting rehab patients know we are here as a self help group, while others are very supportive!.

Our main support comes from the local research group at our hospital, and they keep us updated on what's going on.

2. Do you have any other comments relevant to this inquiry?

Many people are not going to their GP as they are worried about the constant 'lecturing' on their smoking habits .I feel this is the wrong approach, patients need to be encouraged to give up not made to feel degraded which many say they do.

There has to be a better way to get the message across, we have patients who smoked on joining but have since given up with the encouragement of others who have done it. a much more relaxed approach seems to work, good lesson here I feel?

APPG on Respiratory Health - Questions

Personal Information:

Name:	Lucy Falconer
Job Title:	N/A
Organisation:	Breathe Easy Aylesbury Vale
Region/location:	Southeast England
Capacity in which you are replying to the inquiry	Chair of Breathe Easy, and sufferer from severe respiratory disease
List of any supplementary information attached (if any)	

Respiratory Disease Questions: Please provide as much or as little information as you wish, up to a max of 300 words per question.

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

No. Heart disease and cancer in particular appear to have much higher profiles, and a range of services available to their patients that respiratory patients do not have. For example:

Coronary rehabilitation started locally long before pulmonary rehabilitation finally received a small amount of funding.

Coronary rehab sessions were held in the hospital gym using the range of equipment there, while pulmonary rehab mostly takes place in community halls where all the equipment (basically weights and steps) must be brought in by the physios and nurses who lead the sessions.

Cancer patients have a dedicated unit to themselves behind the hospital, with parking just a few yards from the door.

Chest clinics are held in two different out-patient locations in the main hospital, necessitating a long walk from the bus stop or parking space (disabled spaces are so few that they are hardly EVER available).

2. What changes can be made to improve outcomes for all or most respiratory conditions?

Better training for GPs so that diagnosis can be made earlier

Regular peak flow/spirometry testing for smokers aged 35+

Addition of peak flow/spirometry to routine Health checks for everyone aged 50+

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

Insufficient resources in the community and too much pressure on hospital beds, leaving many people feeling anxious and unsupported when chest infections go on and on, despite antibiotics and steroids

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

5. What can the Government and the NHS in England do to reduce respiratory deaths?

Make respiratory disease a higher priority

Fund research into causes and better treatments

Asthma: Please give your answers in no more than 300 words per question, including references where appropriate.

Background

Over 4 million people in England are affected by asthma⁸ and, on average, three people die every day from their asthma. We know three quarters of these deaths are amongst people aged 65 or over, and evidence suggests 90% of all asthma deaths are preventable if managed properly.⁹ In 2010 the UK death rate from asthma was one of the highest in Europe.¹⁰

In February 2012, the National Review of Asthma Deaths (NRAD), led by the Department of Health, began a review into all deaths from asthma across the UK for one year. The review aims to reduce the number of asthma deaths and the findings will be published in April 2014.

Questions

1. What are the most important factors contributing to asthma deaths?

2. Are there any particular groups at higher risk of dying from asthma? Why is this the case?

3. What practical challenges can you see in the NHS that prevent the delivery of better asthma care locally or nationally?

4. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from asthma?

5. What can the Government in England do to reduce asthma deaths?

6. What can the NHS in England do to reduce asthma deaths?

7. Do you have any other comments relevant to this inquiry?

Chronic Obstructive Pulmonary Disease (COPD) Questions: Please give your answers in no more than 300 words per question, including references where appropriate.

Background

COPD kills about 25,000 people a year in England and Wales. Recent figures showed that COPD accounted for 4.8% of all deaths in England between 2007 and 2009. It is the fifth biggest killer disease in the UK after cancer, heart, stroke, and liver disease. Premature mortality from COPD in the UK was almost twice as high as the European (EU-15) average in 2008 and 1 in 8 people over 35 has COPD that has not been properly identified or diagnosed.¹¹

Questions

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

Lack of awareness amongst the public and GPs

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

Being diagnosed with asthma and sent home with inhalers and left to get on with life

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?

Encourage TV presenters/programmes to focus on COPD more often

Educate everyone with lung disease about the benefits of pulmonary rehabilitation

Ensure every patient with lung disease has access to pulmonary rehabilitation and is encouraged to attend

4. What could the Government in England do to reduce premature mortality from COPD?

Fund research into treatments and prevention of COPD

8. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

Pulmonary rehabilitation?

5. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

Routine screening with spirometry for those over 35 who are at risk, i.e. smokers, people who worked around asbestos, etc.

6. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

We need more education for doctors and more empathy from them

Follow-up exercise classes after PR has finished

Re best practice, PR was initially only available in South Bucks, but is now available throughout the county. This is a big improvement.

9. Do you have any other comments relevant to this inquiry?

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- ¹ The Burden of Lung Disease: Report 2, British Thoracic Society, 2006.
- ² UK mortality from respiratory disease is 5th worst in the EU, after Denmark, Ireland, Belgium and Hungary. ERS White Book - the Burden of Lung Disease, Figure 1. Last accessed on October 2013. <http://www.erswhitebook.org/chapters/the-burden-of-lung-disease/>
- ³ Department of Health, *England level data by programme budget*. Downloaded from: <https://www.gov.uk/government/publications/2003-04-to-2010-11-programme-budgeting-data>. Accessed on 01/10/2013
- ⁴ 7,500 lives could be saved in England when total deaths were 23,000 per year from COPD. Outcomes Strategy for Asthma and COPD: NHS Companion Document, Department of Health, May 2012.
- ⁵ Partridge M, Self care plans for people with asthma. *The Practitioner* 1991, p 715-21
- ⁶ Health Survey for England 2001. The Scottish Health Survey 2003. Welsh Health Survey 2005/2006. Northern Ireland Health and Wellbeing Survey 2005/2006. Population estimates from Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics & Research Agency
- ⁷ Outcomes Strategy for Asthma and COPD: NHS Companion Document, Department of Health, May 2012.
- ⁸ Health Survey for England 2001. Population estimates from Office for National Statistics
- ⁹ Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics & Research Agency
- ¹⁰ OECD, Deaths - *International comparisons, all ages*. Downloaded from <http://stats.oecd.org/> Accessed on 02/10/2013
- ¹¹ All references in this paragraph: An Outcomes Strategy for COPD and Asthma, Department of Health, July 2011.

APPG on Respiratory Health - Questions

Personal Information:

Name:	M.Ginever
Job Title:	Chairman
Organisation:	Breathe Easy Nottingham
Region/location:	East Midlands
Capacity in which you are replying to the inquiry	As Chairman of Breathe Easy Nottingham support group for those living with lung disease. We are part of the British Lung Foundation, the national charity for any form of lung disease.
List of any supplementary information attached (if any)	

Respiratory Disease Questions: Please provide as much or as little information as you wish, up to a max of 300 words per question.

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

NO. Respiratory disease is the Cinderella of the main killers, despite its known impact in financial terms on the NHS and the quality of life endured by patients. It does not receive sufficient focus both at the highest level and within CCGs at primary care. There are defined pathways and processes for heart and cancer not evident to the same degree with respiratory conditions. This includes for example rehabilitation at secondary and local community level. Inconsistent diagnosis and treatment at GP level even within the same CCG. For example use of spirometry. There appears to be no minimum standard to which all must adhere. This leads to misdiagnosis and confusion especially between asthma and COPD. Public awareness of respiratory disease, thought to be caused by smoking and therefore self inflicted. Cardio vascular problems can also be caused by smoking but gets a sympathy vote. Levels of undiagnosed people with COPD are huge with little or no effort to find them. (The IN Force project in Nottingham City did attempt to do this). Do we have a time bomb which will impact on greater hospital admissions? Levels of mortality for asthma are tiny compared with COPD, yet my perception is that much greater weight is given to it.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

Development of rigorous pathways.
Earlier consistent diagnosis and treatment at all levels especially GPs.
Use of best practice models within CCGs and other units.
Contracts which have teeth to reinforce approach and performance,
e.g. QOFs and objectives linked to pay.
Focus on improving patient experience/quality of life rather than cost.
Education to address awareness issues.
Support for self help and support groups who can make a huge
difference to information and well being.
Keep GPs and other health professionals up to date.
Have a lead GP for chronic conditions within each CCG, and make
patients aware of this.
Increase patient involvement so that it is not lip service
Look at exercise programmes in the community, again often run by
support groups. (In Nottingham we are self funded from voluntary
contributions yet manage to put on an enjoyable exercise class
using a trainer who has both cardio and respiratory qualifications.
Focus on self management of chronic conditions to avoid unplanned
admissions e.g. at the start of an exacerbation.
Add respiratory as a category to CQC inspections
Use community nurse practitioners for an at home service, rather than
going to A & E.
Consistent pulmonary rehab programmes post diagnosis, with
subsequent follow up in the community. The heart model works
particularly well in this area. The community aspect does not exist
for respiratory here.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

Lack of effective performance measurement for health professionals
which features respiratory problems.
Audit / inspection to ensure that minimum standards are adhered to.
Keeping up to date or sharing best practice through 'Protected
Learning Time' is not enough.
Do not use premium rate or similar costing numbers which can be a dis-
incentive to call.
Build on the information BLF provides so plugging an information gap
Thinking more about pro-action rather than reaction, community based

approach to minimise unplanned admissions. E.g. respiratory nurses accessible directly by a patient
System is still heavily dependent on a health professional's personal interest in respiratory disease. Always have someone accountable for the service so as to avoid a lottery.
Guarantee that [patient will be seen by consultant in a given time. Set standards.
Pneumonia / flu jabs for all? Review efficacy or pilot.
Raise awareness amongst health professionals e.g. at a recent event at our City hospital held on the same day as a chest clinic, neither of the 2 nurses running the clinic were aware of Breathe Easy and support groups.

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

Very evident that much respiratory illness is a consequence of life style and deprivation. Concentrate on those areas and groups. i.e smokers, obese people, lack of exercise, etc
Those with a genetic pre-disposition
Harder to reach groups especially from ethnic minorities.

5. What can the Government and the NHS in England do to reduce respiratory deaths?

Address some of the issues cited above, especially raising its priority.

Look at air quality and pollution levels. Add information about poor air quality especially particulates to local weather forecasts or display in the streets as they do in Thailand for example.

Tighten up on engines, especially diesels to further reduce particulates. Look at both domestic and commercial vehicles. Integrate with eco thinking for overall car design, so mandatory stop start technology. Make sure cars carry more people etc.

Foster support groups but give them a mission, and perhaps measurable objectives too. Build into health professional contracts sometime for them to actively support or be involved with support groups and patient groups. Foster patient involvement and interest.

Cooperate better with drug companies for the development of new antibiotics and therapies.

Ensure there is access to information at the point of diagnosis.

Develop post pulmonary community based exercise programmes perhaps available on prescription

Ensure that each surgery has a basic set of appropriate diagnostic equipment with people trained to use it

The advice around keeping warm in the winter and cool in the summer needs to be more consistent. Exacerbations / unplanned hospital admissions are linked to both yet it is not clear what patients should do. When should the public be informed through perhaps the weather forecast. What is a realistic temperature at which a bedroom should be maintained in the weather and what cost?

A proper patient voice in commissioning so that the patient experience is reflected

More joined up thinking from say causes such as air quality to engine design or particulate traps, to self management in the community, to all the medical aspects.

Chronic Obstructive Pulmonary Disease (COPD) Questions: Please give your answers in no more than 300 words per question, including references where appropriate.

Background

COPD kills about 25,000 people a year in England and Wales. Recent figures showed that COPD accounted for 4.8% of all deaths in England between 2007 and 2009. It is the fifth biggest killer disease in the UK after cancer, heart, stroke, and liver disease. Premature mortality from COPD in the UK was almost twice as high as the European (EU-15) average in 2008 and 1 in 8 people over 35 has COPD that has not

been properly identified or diagnosed.¹

Questions

1. What are the most important factors contributing to the current high level of premature mortality from COPD?

[See comments on respiratory section](#)

2. What are the barriers to achieving improvements to the high mortality rate from COPD both locally and nationally?

[See comments on respiratory section](#)

3. What could the NHS in England do to prevent or delay the onset of the advanced stages of COPD?

[See comments on respiratory section](#)

4. What could the Government in England do to reduce premature mortality from COPD?

[See comments on respiratory section](#)

1. Are you aware of any examples of successful projects or programmes - from the UK or internationally - that have reduced the number of people dying from COPD?

The In Force project in Nottingham (a partnership with Pharma, Nottingha PCT and Breathe Easy) attempted to find the missing undiagnosed COPD patients. Sorry but do not have the results

Various Post Pulmonary Rehab exercise programmes almost all run by voluntary groups who fund them themselves. The idea is ongoing maintenance but with people from your local area. No personal statistics to support this, but try the BLF.

Specialist clinics for a particular condition such as Bronchiectasis or IPF

5. How can better diagnosis rates be achieved in practice and what barriers exist to making these improvements?

Health professional interest. If your doctor is interested in the disease you get better attention. So many initiatives have come from this. Can we not reinforce, tempt, pressure through say QOFs, to make it a proportionate requirement. There will always be arguments for the disease burden of a particular CCG, but respiratory numbers are so great

Better training

Process improvement to reflect a gold standard pathway applied consistently.

The right equipment. E.g. as a group we have bought at least 12 nebulisers

(and other items such as pulse oximeters) in the last 2 years to plug gaps in local surgeries

6. Do you have any comments about services, provision or investment in your local area, which affect COPD patients? Please also feel free to give examples of best practice in your area.

We have had tremendous support from 3 respiratory nurses, and at least one GP, and a Professor of Epidemiology, who have given their time freely to talk to our group. The nurses particularly have been on hand to give advice, comfort and generally support us. These sessions are ‘worth their weight in gold’ for patients.

2. Do you have any other comments relevant to this inquiry?

¹ All references in this paragraph: An Outcomes Strategy for COPD and Asthma, Department of Health, July 2011.

Name:	Mr Doug Hardy
Job Title:	Senior Project Manager - retired
Organisation:	N/A
Region/location:	East Midlands
Capacity in which you are replying to the inquiry	As a long term asthma sufferer and supporter of Asthma UK

Asthma Questions

- What are the problems within the NHS that prevent a lot of people from receiving care that fully meets clinical standards? You can build on the experiences you shared at the Compare Your Care event.

In my personal experience the referenced problems may be summarised as follows:

- A lack of training of some NHS practitioners in the developed practises for the management of asthma
- The need for documented annual asthma reviews for all asthma patients
- The need to ensure patients understand their inhalers and associated usage techniques
- The fundamental requirement, where this is possible, for patients to maintain their general heath, including weight and fitness, to support the management of their asthma
- The need to create an better understanding of asthma and its associated risks within society.

- What can the Government and NHS in England do to improve asthma care and ultimately reduce asthma deaths?

To address the identified problems, the following steps need to be undertaken by the Government/NHS to improve asthma care in the community:

- Ensure all practitioners within the NHS involved in the management of asthma are given appropriate training in the management of asthma conditions
- Ensure that all practitioners conduct their work in accordance with developed guidelines and standards
- Conduct audits to confirm that practise is in line with guidelines and standards
- Ensure that all asthma sufferers are given documented annual reviews in accordance with developed standards, to review all aspects of the management of their asthma
- Ensure that practitioners stress to their asthma sufferers the need to

maintain their general health, including weight and fitness, to facilitate the management of their asthma

- To generally enhance the profile of asthma as a respiratory disease that, if not appropriately managed, can lead to premature death

3. Do you have any other comments relevant to this inquiry?

Name:	Tessa Jelen
Job Title:	Chair
Organisation:	Breathe Easy Paddington
Region/location:	Westminster
Capacity in which you are replying to the inquiry	Knowledge of services and patients with respiratory conditions
List of any supplementary information attached (if any)	Breathe Easy Paddington last newsletter CLAHRC poster submission for exercise

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

When I was diagnosed with emphysema and fibrosis there was no support mechanism's in Westminster. I attended a Breathe Easy Group in Stockwell, but was unable to attend their exercise group as being in a different ward. This made me firstly join the PPI committee for the Royal Brompton, where I lobbied for them to initiate a Breathe Easy support group and exercise sessions. Westminster's Imperial has since progressed with supplying local support, but CLCH has still to firm up the new commissioning for the NHS COPD Rehabilitation Team in the community, who also run an 8 week exercise and information course. Our Breathe Easy (BE) has been unable to find another years funding for our weekly exercise class to provide continuation to the latter.

Breathe Easy are local geographic groups, independent and patient led, previously supported by the British Lung Foundation and using their charity number. Our Westminster Group now has 150 members

I have since joined the Stakeholder Committee for CLCH, conducted PLACE assessments, User panel for CLCCG and WCN Advisory Board. Even attending courses by CLAHRC to help with the difficulty with patient involvement and negotiation with the NHS has only slightly improved the outcomes.

It is known (see Final report from the London Respiratory Team three-year programme July 2010-June 2013) that diagnosis is weak and the over prescribing of inhalers is one of the most costly prescribed drugs. Often respiratory problems is automatically called asthma.

It is hoped that much more community accurate lung function testing is

carried out to identify those undiagnosed for this third biggest killer

I have spoken at 12 different community events regarding (eg library and Health Fairs), but have difficulty in getting a COPD lung function testing to attend, but WHEN they have done - have had astounding turnout and some surprise diagnosis results. The new Tr-Borough team has now agreed to support our group by attending 2 events a year

2. What changes can be made to improve outcomes for all or most respiratory conditions?

Exercise is a major part of increased life expectancy for respiratory disease (weak muscles need more oxygen. The NHS COPD Rehabilitation team is still struggling in its new formation and their important 8 week exercise class is under utilised at present. GP's are lapsing in referring patients to them and our Breathe Easy (BE) has been unable to find another years funding for our weekly exercise class which provided community continuation to the 8 week course. We have a DVD showing how successful this was, especially as our group also offered alternative therapies such as massage, manicure and talks on local community support services.

Isolation is also a problem and we are able to help this with the support of two church mini-bus to transport members to meetings and outings

Pollution is another problem which has major impact on respiratory health.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

The need for integrated care and the continued support of patients between primary and secondary care.

To think outside the box - more inhalers, continued steroid medicating, use of oxygen are all being used as the basic support - but there are other mechanisms, such as osteopathy for asthma lung expansion, Buteyko techniques for postural advantages. An example is a recent member on continual steroids, weakened immune system, bang on swollen legs, uncontrolled infection in wound - no home help, hospital outpatient visiting, eventual admittance to ward, where she picked up another lung infection and died.

If one of my members is struggling, I can formally refer them to the Falls Team, but not to the COPD team.

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

Smokers

Building site workers (these do not admit to problems)

Miners

5. What can the Government and the NHS in England do to reduce respiratory deaths?

Help Community support groups, more GP referrals and accurate diagnosis



Breathe Easy Paddington

for Westminster Residents affected by lung disease



breatheeasypaddington
@talktalk.net

Charity number: 326730

LAST OF SEASON'S OUTINGS

Funded by NatWest, arranged by L&Q & Breathe Easy

We have successfully had multiple spring visits to Richmond, Kew and Chiswick House this year, during which we must give our thanks to Pret A Manger for donating sandwiches for some of the events.



We now have on a few visits left. One is to see the Autumn colors on 17th & 24th October at Isabella Plantation in Richmond and then to lovely Pembroke Lodge for cream tea.

We also plan a visit HQS Wellington on the Thames on the 28th October, a trip promoted by our stalwart member, John Parry, who was in the Merchant Navy during the Battle of the Atlantic.

This tour will tell us about the amazing struggle that enabled us to win the war.

If interested Contact Tessa
0207 834 0894



Silver Sunday October 6th

Counsellor Christabel Flight promotes a yearly celebration day for the aged. Check it out on silversunday.org.uk/

We are supporting this on **4th October**, to hear the Royal Philharmonic Orchestra playing "The Very Best of John Barry" at a Friendship Matinee at The Royal Albert Hall.

The **Tate Britain** is also having a free tour and tea & cake from 2.30 – 3.30 on 6th Silver Sunday. Call Rebecca on 0207 821 2970

**Issue 12
Sept 2013**



Our special metal bear badges are now available at our meetings, plus handmade cards

All only £1 each which will go to our Breathe Easy

Recycle 4 Charity.co.uk

HAVE YOU A PRINTER??

If not then give the enclosed freepost recycle bag to someone who has.

£8 raised this quarter.

Contact the Editor or 01273 400185 info@recycle4charity.co.uk and quote

C15950 for more freepost bags

TRANSPORT



Felix is still driving us to, and showing us around the beautiful Isabella Plantation

Mickey (pictured left) has also been a mainstay in volunteering to drive the Crypt bus for our members, if Daniel, our regular volunteer driver, is tied up with his work.

Once again we must ask you to either use or pass on the free envelope enclosed for sending back ink cartridges and raising us funds through Recycle4Charity.

Why not ask a local business to join for their laser cartridge collection?



BLF Helpline
03000 030 555

British Lung Foundation

73-75 Goswell Road,
London, EC1V 7ER
londonandsouth@blf.org.uk
0207 688 5594

BLF group support
Jo.Newton@blf.org.uk

breatheasypaddington
@talktalk.net

www.blf.org.uk/paddington

Chair & Editor:

Tess 0207 834 0894

Members Secretary:

Samuel 07810 281349

Dates & Talks

Next Paddington
Breathe Easy
Meetings
11.00 to 13.00, at
Ada Court, 10-16
Maida Vale, London
W9 1TD

Mon Oct 21st
Dial a Ride

Mon Nov 4th
Air Liquide

Mon Dec 16th
Party

Mon Jan 20th
what your library offers

Monday Feb 17th
tba

EVENTS

On the day for the picnic at Eccleston gardens rain was forecast, so we set up at lovely St Gabriel's Church vestry, thanks to the kindness of Philip Griffin, their Treasurer and our Emily with catering.



We have also represented our group at a few library and community events.

Soapbox at the Tate Gallery. Free events for people near or beyond the age of 60. Book a place to have your say on 0207 887 8888 for 16th October or 6th November event.

FUNDING

Sainsbury's in Pimlico have donated a £25 gift token and have promised this twice yearly.

Clover Campbell died this last quarter, her family has donated £100 to us through Local Giving. There is also a £300 payment from Maria Johnston's annual birthday fete. Sadly Maria has since passed away.

Don't loose your chance to input ideas for commissioning of community services. Visit www.centrallondonccg.nhs.uk/news/help-us-to-shape-local-health-services-for-201415.aspx and give them your ideas to improve your service.

Just heard THIS newsletter is a winner!!! BLF have awarded us the National Breathe of Fresh Air Award for the most outstanding group newsletter

British Lung Foundation

The British Lung Foundation (BLF) invites you to "Carols by Candlelight on Monday 2nd December at 7pm at St Pancras Church, Euston Road, NW1 2BA. Tickets cost a suggested donation of £25 for adults and £10 for children and will include a free prize draw. It will be a magical event. Contact BLF 0207 078 7912

We welcome a new BLF CEO, Penny Woods who is making a lot of positive changes. Breathe Easy Group Development will now be handled by Jo Newton. More focus will now be on research.

Do visit the BLF website which is becoming slicker—you can also link to our last newsletter through our page.

COMMITTEE

Tess Jelen	Chair and Events
Margery Arthur	Secretary
Samuel Cassidy	Membership Secretary & Treasurer
Carol Walsh	Vice Chair
Cecilia Worthington	Hospitality
Rita Datta	Meet & Greet & Membership attendance

VOLUNTEERS

John Parry	Raffle draw
Josie McIntosh	Raffle ticket, cake & card sales

COMMITTEE NEWS

Carol Walsh

has been nominated to the role of a Carer Ambassador.

Tess Jelen

Sits on L&Q City Central Neighbourhood Committee, Central London CCG User Group and Commissioning Subgroup. Westminster Health Watch Committee, CLCH Quality Stakeholder Committee, WCN Advisory Board.



THURSDAY pm EXERCISE CLASS

Funding applications have been submitted hoping to continue our Exercise class at Ada Court, which has been going so well the past year. Hopefully there will be a result to enable us to start up again in the New Year.



We have had such enthusiasm from the participants, our edge being that we work at the right pace, have a multitude of alternative therapies and time for sharing information on local support services. Our sincere thanks to the Peoples Health Trust for this initial start up.



We have made a DVD of the class with comments by the participants which you can purchase for £1.50.



Phone Tess on 0207 834 0894 if you wish one to be posted to you

Referral to NHS COPD Rehabilitation Exercise Classes

I am sure we all know how important exercise is for those with lung conditions. If you feel now is the time to join the Pulmonary Rehabilitation classes ask your healthcare professional (HCP) or GP to refer you at, why not mention it at your next check-up? Joining will help considerably in your health's maintenance and you will feel good!

If you have previously attended a rehabilitation course, you will already know how beneficial these sessions are. Those who have attended in the last 12 to 18 months may be able to attend again, if you are still in contact with the team you can ask them about this, or you can ask to be referred again.

If you have been unwell, for example with a chest flare-up (exacerbation) you may need extra exercise support and can possibly access this sooner, again your GP, hospital doctor or HCP will usually need to refer you to ensure that the classes are currently suitable for you.

Westminster COPD Team,

Central London Community Healthcare NHS Trust
contact 07506 609 186

Or leave a message through 020 8962 4499 (central booking office)

Matters of Interest

Measuring experience in people living with COPD

Hello, My name is Matthew Hodson and I am a COPD nurse working in East London.

I am currently undertaking some research into the development of a patient reported experience questionnaire. Designed to look at the experience of people living with COPD and healthcare.

I have been in contact with Tessa your BE Chair who has kindly invited me to your **Breathe Easy meeting on 21st October 2013** to see if there would be any members who would be interested to participant in the study.

Included with this newsletter is a Patient Information Sheet which tells you lots more about the study and my contact details.

Thank-you for your time & look forward to meeting with as many of you as possible.

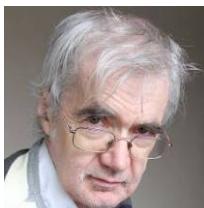
ON-LINE

This is YOUR group. If you have any ideas or want to get involved, please do phone me on 0207 834 0894, or t.jelen@btinternet.com

www.lunguk.org/paddington

<http://www.crowdfundsw1.com/>

<https://Localgiving.com/breatheeasywestminster>



MEMBERSHIP

Samuel Cassidy (left) is your Members Secretary.

Karolina is back and will be contacting you to conduct a membership survey by phone. Please help in answering the questions.

We now have 127 members on our list, and an average 25 attending our meetings. Hopefully our telephone survey will find out how to increase our numbers and guide us to know what you want from the group.

Could anyone enjoying email please contact me on scass4be@gmail.com if you would like to receive your quarterly newsletter by email attachment and save us the stamp cost. Or how about donating some stamps to help cover post costs?

PS. We keep receiving great feedback for our "birthdays cards to members"

Westminster Respiratory Health

Author: Tessa Jelen

Aim of Project: To increase quality of life for people with respiratory disease through exercise, information and support

Exercise is proven to increase life expectancy for those with lung disease as muscles need less oxygen if healthy. NHS COPD rehabilitation lasts for only 8 weeks – this group was run for a year to help patients keep up their **fitness**

All participants completed a Par-Q and most needed Doctors permission to attend. The group did a **walking** test. Some members were very elderly. Membership was enthusiastic and constantly expanding.



The Falls Team helped with some problems. Breathing and **stamina** tests showed improvement. An added advantage was the massage and other therapies offered for **free** along with **information** and networking



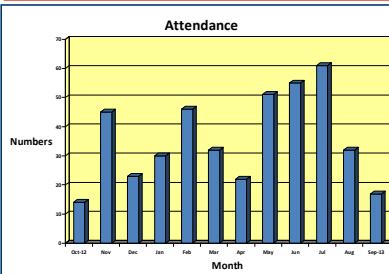
Funding was achieved from the Health Lottery through the Peoples Health Fund.

~

Multiple local service providers became involved and gave talks. The Falls team supplied great support

~

Thanks to Ada Court who provided the venue



Without the help of CLAHRC and their encouragement and advice to liaise with the NHS team and find out about Level 4 trainer requirements, this group would not have existed

Contact us to receive our DVD showing the success of the group, the alternative therapy's and comments of the participants

breatheeasypaddington@talktalk.net

We are proud to have achieved a membership of 30 with an average attendance of 38 a month, with a maximum of 60 in July

A poster to mark the first five years of the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care (NIHR CLAHRC) for Northwest London – a partnership between Imperial College London and Chelsea and Westminster Hospital NHS Foundation Trust

This article/paper/report presents independent research funded by the National Institute for Health Research (NIHR). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.



All Party Parliamentary Group on Respiratory Health
Inquiry into respiratory deaths

APPG Inquiry Questions

Personal Information

Name:	Rowena Jeremy
Region/location:	West Midlands - Stourbridge
Capacity in which you are replying to the inquiry	Parent of child (aged 8) who died following an asthma attack in May 2012 Also an asthmatic myself

Asthma Questions

1. What are the problems within the NHS which prevent people with asthma from receiving care that fully meets clinical standards?

Medical professionals in the UK have generally developed an attitude of complacency when dealing with asthma. There appears to be a lack of familiarity with the British Guidelines on the Management of Acute Asthma.

2. What can the Government and the NHS in England do to improve asthma care and ultimately reduce asthma deaths?

1. Ensure all medical professionals are both familiar with and follow the British Guidelines on the Management of Acute Asthma.

This is the most important thing that can be done. Delivering training and then expecting this to be implemented is not enough. Regular inspections need to be carried out and action needs to be taken immediately if the guidelines are not being followed.

An independent investigation into my son's death, completed by a paediatric respiratory expert, found that the guidelines were not properly followed. The medical team failed to recognise the severity of his exacerbation, he was not adequately monitored or reviewed, and he did not receive adequate medication. He had been in hospital for 11 hours before he died, 5 hours before his death he walked down 2 flights of stairs and across a hospital to attend the X-ray department, the treating doctor advised my husband to go home (only 1 parent allowed to stay on the ward overnight) as he would be discharged in the morning and was being kept in for observation. Had the treating medical professionals followed the guidelines (and acknowledged his past medical history which I provided throughout his time at the hospital and could have been accessed by the treated medical staff) they would have realised the severity of his condition and treated it appropriately, and in all likelihood he would not have gone into

respiratory arrest. These failings contributed to my son's death.

2. Ensure hospital wards are adequately staffed and equipped.

At the inquest it was stated that there was only 1 nurse and 1 student nurse looking after 11 children (including 4 in the High Dependency Unit) on the ward on the night he died. This is inadequate and would explain the hospitals failing to adequately monitor his condition.

From his medical notes and statements delivered at the inquest we discovered that it took over an hour and a half for a registrar to assess his condition once the nurse observed a severe deterioration. It then took a further hour to move him to HDU. He was not reviewed again for another hour and 45 minutes. It was only at this point was more intensive therapy realised.

A consultant was not called to examine him (even though he had been admitted more than 8 times in the previous year suffering with a severe exacerbation of asthma) until he went into respiratory arrest. He should have been called sooner (a FOI request from the hospital involved confirmed that there was not a single consultant physically in the hospital on the night of his death).

This lack of staff across all medical grades contributed to a general lack of care. It was inadequate and would explain the hospitals failing to adequately monitor and therefore fail to appreciate the severity of his condition.

The hospitals own Root Cause Analysis Report (RCA) admitted that the staff failed to use the Paediatric Early Warning System.

The same RCA acknowledged that the paediatric resuscitation trolley had missing equipment and this caused delays when resuscitation was required. The hospital involved was investigated as part of the Keough Review into 14 failing hospitals 12 months after my son's death, and on the 2 unannounced visits the review team made to the Paediatric ward they found the resuscitation trolley had missing equipment.

To me these failings show that staff at all level failed to appreciate the severity of asthma and in this case caused my child's death.

Outside of the emergency situation we found ourselves in on the night he died, accessing well trained and knowledgeable staff was never easy. Although scheduled to see a named consultant a minimum of twice a year, more than often a lower graded medical professional was sent in his place who had no knowledge of the medical history. I found these appointments a complete waste of time. The named consultant never saw my son during a period of ill health (even though he was admitted more than 20 times to the hospital he worked at).

3. Provide more funding for Asthma research - ensure new asthma medication is funded through NICE

4. Provide better information to patients on triggers and symptoms to look out for to ensure they attend primary care early to avoid hospital admission/death
5. Allow Salbutamol inhalers to be included in first aid kits at shopping centre, sports centre, pubs/clubs, theatres etc.
6. Provide free prescriptions for asthma medication

3. Do you have any other comments relevant to this inquiry?

Personal Information

Name:	Karenjeet Kaur
Region/location:	Wolverhampton, West Midlands
Capacity in which you are replying to the inquiry	Relative of an asthma sufferer

Asthma Questions

1. What are the problems within the NHS which prevent people with asthma from receiving care that fully meets clinical standards?

Asthma is deemed to be a very mild illness across society. Very little emphasis is placed around the possible dangers of this illness, as the general enigma is that a simple puff on an inhaler resolves all symptoms. This primarily stems from the fact that very little information if any at all is circulated highlighting the potential dangers asthma can cause and how severe an illness it can be if not treated properly. It wasn't until a personal experience when I embarked on campaigning for Asthma UK that I realised how alarming these figures were.

Speaking from a personal experience, I feel asthma is not treated extensively and investigated thoroughly until it gets to a stage where it can no longer be ignored. If simple steps were to be taken at an earlier stage the asthma sufferer could have avoided in personal experience, near death or death itself. It is alarming as to how many young people are suffering with asthma today, but the real question is do these people know the real dangers of asthma? Have they been shown how to take an inhaler properly? What information is also given as to how lifestyle changes can help them?

I would like to know the figures of how many asthma sufferers, regardless of the severity are referred to asthma clinics for not only more extensive treatment but for more information and guidance.

2. What can the Government and the NHS in England do to improve asthma care and ultimately reduce asthma deaths?

There has been for years unquantifiable amounts of government led campaigns to encourage people to help quit smoking. You can't go 2 miles or flick a radio station without hearing or seeing some sort of anti smoking advertisement. There are advertisement campaigns highlighting the symptoms of a stroke and what actions need to be taken as soon as these symptoms become evident. But do people know what to do when a loved one is having an asthma attack and an inhaler isn't available or working? What actions should they taking to help? This information needs to be widely circulated and promoted via advertisement campaigns, as I'm sure there are far more asthma suffers in the UK than those who die from smoking

related illnesses.

All first aid kits should have a battery-powered nebuliser contained within them, so regardless of where the asthma sufferer is they have some sort of treatment readily available. All asthma sufferers should be told about nebulisers and given the option to purchase one if needed. Its only until the asthma really deteriorates that this option is currently heard of.

All asthma sufferers should be given free prescriptions, regardless of age, background or profession. Given the current financial climate a proportion of the UK population may be unable to afford the cost of an annual prescription or regular medications. So if such a privilege is given to those with diabetes, I feel it should be given to the asthmatics too.

3. Do you have any other comments relevant to this inquiry?

APPG on Respiratory Health - Questions

Personal Information:

Name:	Ian Kenworthy
Job Title:	Chairman
Organisation:	Breathe Easy Tameside & Glossop
Region/location:	North West
Capacity in which you are replying to the inquiry	Group representative
List of any supplementary information attached (if any)	

Respiratory Disease Questions: Please provide as much or as little information as you wish, up to a max of 300 words per question.

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

Respiratory disease receives much lower financial investment in research, funding and care generally than all the other diseases mentioned. Huge disparity in service between GP's despite QOF

2. What changes can be made to improve outcomes for all or most respiratory conditions?

Improve education at primary care level. Spend more on research.
Ensure quality Pulmonary Rehabilitation available with early access in all areas. Ensure GP's provide more information to patients including emergency drugs at home for self medication after education i.e. steroids and antibiotics.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

Lack of knowledge both health professionals and patients. Lack of access to facilities and services. Poor communication between services both primary and secondary levels. Lack of funding compared to other diseases.

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

Groups who have worked in polluted industrial environments
People who smoke
Those with hereditary lung illnesses

5. What can the Government and the NHS in England do to reduce respiratory deaths?

Improve education, treatment optimisation. Increase smoking awareness. Make the NHS Outcomes Strategy for COPD and Asthma published in 2011 followed by the NICE CG101 COPD Guidelines published in 2004 and updated in 2012 mandatory for all geographical areas

Name:	Barbara Preston
Job Title:	Retired from paid employment. Secretary of Breathe Easy Nottingham
Organisation:	BE Nottingham
Region/location:	Nottinghamshire
Capacity in which you are replying to the inquiry	As secretary of BE Nottingham and a patient involved in a number of activities e.g. CCG Patient Cabinet, PPG, Service User & Carers Advisory group (for Nottingham University nursing course). More importantly as someone who's had bronchiectasis most of my life (I'm now 70).
List of any supplementary information attached (if any)	Although I don't have COPD I worked on Nottingham City's INFORCE project for about 3 years and in all sorts of other ways shared experiences of patients with respiratory conditions, working towards better COPD treatment pathways . There are approximately 200 members in BE Nottingham with attendance at monthly meetings around 60. The largest proportion of our members have COPD. A handful have asthma.

Respiratory Disease Questions:

1. In your opinion, are respiratory disease treatments, care and services on a par with those for other big killer diseases, such as heart disease, stroke, liver and cancer? Please give reasons. You may wish to comment on investment, or variations in care or outcomes.

No - pathways less clear cut, standards more variable, GP's knowledge often patchy, sometimes to the point of being ill informed e.g. misdiagnosis of asthma was found to be common when nurses reviewed all patients in the INFORCE project; misunderstanding of use of certain antibiotics e.g. offering ciprofloxacin which should be reserved for treating pseudomonas; use of spirometry variable, some GP practices not even having trained staff.

Research - investment in respiratory diseases much less, particularly compared to heart disease & cancer.

Culture - Cardiac diseases in particular are dramatic and cancer is emotive (particularly breast cancer) whereas lung diseases generally develop slowly, often not till middle age and are hardly sexy. Public know little about lung diseases. Often dismissed as smokers cough etc. Patient may even be blamed e.g. because smoked. The umbrella term COPD is not widely understood/known though people have often heard of emphysema and usually of chronic bronchitis. Little understanding of need to get diagnosis and treatment as soon as possible as there is no cure but the disease can be slowed. Link with smoking & lung disease generally focuses on lung cancer rather than COPD etc. Public information e.g. re

flu jabs tends to refer to diabetes & asthma but rarely other lung diseases.

2. What changes can be made to improve outcomes for all or most respiratory conditions?

Education, education, education - for both public and GPs.

Improve & standardise treatment pathways.

Most treatment can be focussed in primary care if there are informed GPs, specialist health practitioners & funding transfer from secondary care. Of course respiratory consultants will still be necessary but hospitalisation should be a last resort + consultants should if possible come out to the community e.g. health centres. The emphasis must be on self care but this depends on considerable time being spent with the patient when first diagnosed, good literature to support and regular reviews e.g. with a specialist nurse. Breathe Easy is a great support but we can't take on everyone and self-help groups aren't for everyone. We need to find other alternatives too e.g. mentors, GP clinics, buddyng.

Better communications between different sections of the NHS e.g. ambulance staff need to know that certain patients must be taken straight to a respiratory ward, not to A & E.

Give bigger proportion of money to relevant research.

Encourage exercise programmes. It has been noted by some specialists that exercise can benefit patients as much as medication. Pulmonary Rehabilitation courses are important, including both exercise and life style education. Motivation to exercise is difficult subsequently but group psychology can aid regular exercise in a group format.

3. What are the main barriers to better respiratory care, where it impacts on premature mortality?

As far as I can see treatment is patchy, some areas having clear pathways for treating respiratory disease, others less so.

GPs vary tremendously, some reluctant to spend their time on diagnosis & support in the vital early stages. Specialist diagnosis may be necessary e.g. to identify IPF. Some GPs still uncertain about self-management, though most patients are capable given time and resources. For example, some won't give patients rescue medication, some won't prioritise appointments for these patients, failing to ensure their reception staff book them appropriately. AS a result a patient may become severely ill, perhaps fatally,

because of delays.
Poor follow-up of patients e.g. checking use of inhalers, nebulisers.
Don't always have annual spirometry tests. Not all practices have trained staff for tests anyway.
CCGs need to have clear plans of pathway. Patient Involvement vital on whatever form of committee is established to oversee them.
Lack of protected education time for GPs e.g. I've found some ignorance re bronchiectasis and have had to tactfully inform new GPs. My CCG is now making sure that all their GPs have the BTS's pathway for the disease.
Patients don't always know where to go and when, particularly at weekends and public holidays.
Lack of research about treatments & causes.
Education of public in significant roles needs improving e.g. teachers re asthma attacks.

4. Are there any particular groups at higher risk of respiratory disease? Why is this the case?

Low income groups appear to be. I presume this because of some or all of the following: poor housing; greater tendency to smoke; possible difficulties in paying for prescriptions; long working hours e.g. if have more than one low paid job; poorer diets; lack of exercise. I presume there is research evidence on such issues.

Those in severe difficulties e.g. homeless, addicts etc, are bound to be vulnerable.

Those, who may overlap with the above, who live chaotic lives.

Those at risk because of occupational risks e.g. certain chemicals.

Smokers of course and those exposed to smoke e.g. children.

Those who have a defeatist attitude to life e.g. thinking 'you have to die of something' & can't see the point of working on one's health & getting the best quality of life possible for as long as possible. I know of no research on this but anecdotally have found some evidence of this. I suspect it ties in with the factors I identified earlier e.g. people for whom life is a struggle.

5. What can the Government and the NHS in England do to reduce respiratory deaths?

Ensure all CCGs have clear, gold standard, pathways for treatments of ALL respiratory diseases. Guidelines need to include the education of health practitioners, particularly GPs. Exercise groups need to be part

of the plans. Self-management & an emphasis on primary care is essential. Ensure appropriate specialists are trained and available e.g. spirometry technicians, physios who can teach chest clearance exercises.

Allocate money for research. This needs to be, not only re treatments & causes of lung disease, but re social aspects e.g. social background to lung disease, attitudes to self-care, ways of buddying with newly diagnosed patients and so on.

Educate the public e.g. through TV adverts & leaflets. If the name COPD is to continue then it needs to be used e.g. on flu adverts etc. G

Increase taxes - or allocate public money differently - so that there doesn't need to be cuts of nursing staff, especially specialist respiratory staff.