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.[1] The UK's mortality rates for respiratory conditions are among the highest in Europe. [2]

Respiratory diseases such as asthma and COPD also create a huge drain on NHS resources, costing the NHS over £4 billion in 2010/11.[3] Deaths from COPD could be reduced by nearly a third if the NHS delivered services in line with the best,[4] and up to 90% of asthma deaths have avoidable factors.[5]

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'[6] and COPD, which affects an estimated 3 million people in England (over 2 million of whom are undiagnosed)[7].
- 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 **5pm 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.

APPG on Respiratory Health - Questions

Personal Information:

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: • 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.
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.

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 for 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: 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 asthma[8] 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?

Asthma is the commonest chronic disease in childhood with one in 11 children in the UK currently receiving treatment for asthma[1]. 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 group[2].

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 years[3].

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.

[1]Asthma 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

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. 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 costs[4]. 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

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

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.

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.

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?

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?

[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.