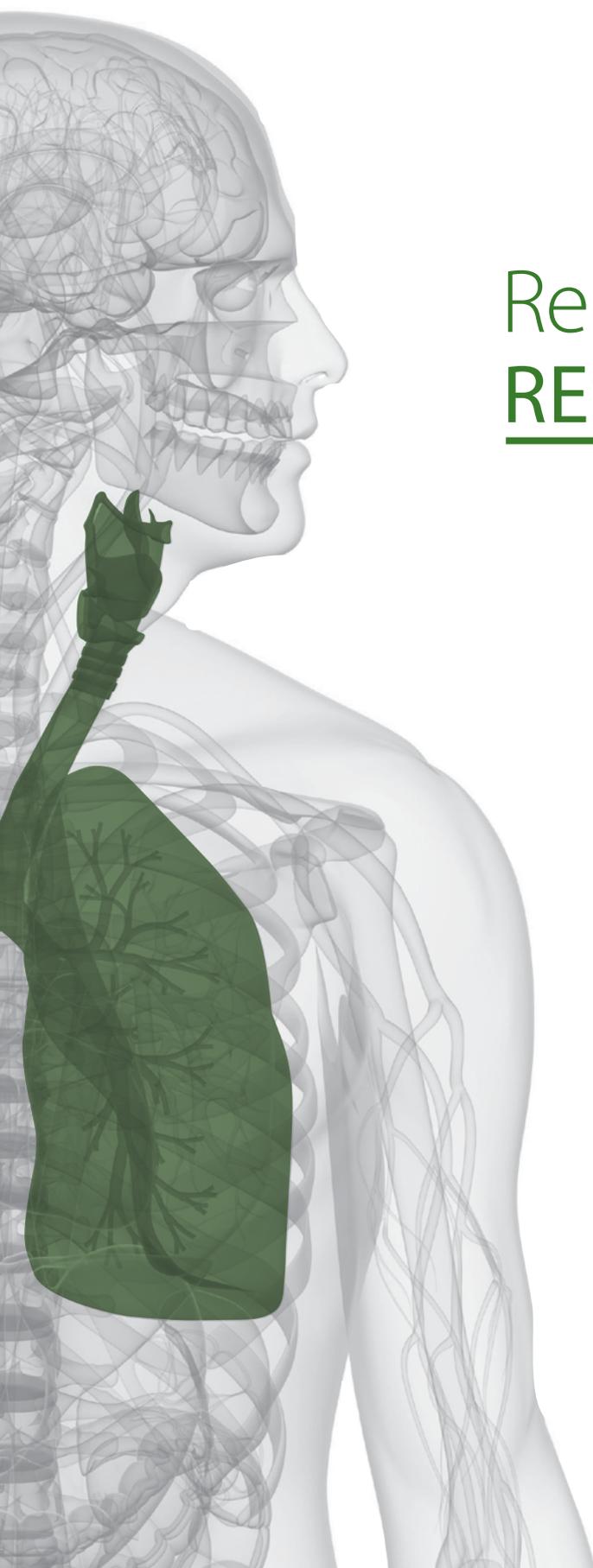




APPG on **Respiratory Health**



Report on inquiry into RESPIRATORY DEATHS

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FOREWORD BY STEPHEN McPARTLAND MP

Respiratory disease is the third biggest cause of death in the UK, killing around 80,000 people a year. It's deeply shocking that the death rate for respiratory disease in the UK is the worst amongst OECD nations.



A great many respiratory deaths are preventable with the right care. Positively, the Secretary of State for Health has recognised this and has made it a priority for NHS England to prevent people from dying prematurely from respiratory disease. His ambition is to make the country one of the best in Europe for survival rates for respiratory disease, by improving prevention, diagnosis and treatment.

The APPG on Respiratory Health shares this ambition. We must make a serious and sustained effort to tackle respiratory disease. Investment in clinical services and research for respiratory disease is disproportionate to the threat it poses to people's lives, and the consequential cost to our health service. There has been little progress made towards reducing respiratory deaths in recent years, despite the publication of a National Outcomes Strategy for COPD and Asthma and a plethora of clinical guidelines and standards.

In July 2013, the All Party Parliamentary Group on Respiratory Health agreed at its first meeting to carry out this inquiry to help the Government and the NHS understand why so many people are still dying from these conditions and what can be done to prevent this.

This report would not have been possible without the evidence provided – both in writing and at the sessions that the APPG held – by patients and the families of those who have died from respiratory conditions, healthcare professionals, charities and professional organisations. On behalf of the APPG I would like to thank each of them for their valuable contribution.

Their evidence revealed that a catastrophic combination of factors leads to thousands dying needlessly from respiratory disease. It points to low levels of investment in clinical services and research, care that fails to meet standards and guidelines, and a lack of infrastructure, data and clinical incentives to support improvements. All this is compounded by low public awareness of respiratory disease.

The time has come for the Government and the NHS to give respiratory disease the priority it deserves. This report makes recommendations that will achieve this by comprehensively addressing the issues highlighted by the evidence we received. We look forward to seeing them implemented.

Stephen McPartland MP
Chair of the APPG on Respiratory Health

June 2014

EXECUTIVE SUMMARY

Respiratory disease affects one in five people in the UK. It is responsible for around a million hospital admissions and is the third biggest cause of death in the UK.¹ UK death rates for respiratory disease compare very poorly with those in other developed countries; in 2010, the UK had a higher rate of respiratory deaths than any other country in the OECD.

There is an almost universal recognition that respiratory disease has been under-prioritised and neglected for many years, with a lack of leadership at both a national and local level failing too many people with respiratory disease. Evidence submissions made to this inquiry suggest that treatment, services and outcomes are well below those for other big killer diseases like cancer, heart disease and stroke. Although respiratory disease has featured alongside these other conditions as a national priority for reducing premature mortality since March 2013, the long-term under-prioritisation of respiratory health means that outcomes improvements are not keeping pace with those in other conditions. If we are to see comparable progress for respiratory conditions, we will need to have comparable sustained and focused investment and attention.

Awareness

In order to both prevent and manage respiratory disease, it is critical to improve understanding and awareness of respiratory disease. Too often, both patients and clinicians underestimate the risks of respiratory conditions such as COPD and asthma.

Reducing the impact of smoking on respiratory health is key. Patients need to be supported by clearer links being made between smoking and the onset and deterioration of respiratory disease; access to effective smoking cessation services and the implementation of appropriate tobacco control measures.

There is also a clear need for a national awareness-raising campaign about respiratory symptoms and more effective education for non-respiratory specialist healthcare professionals in primary, secondary and emergency care. Greater awareness and understanding would also help to stop people from dying prematurely from COPD because of late or inaccurate diagnosis.

Treatment

A great deal is known about what works in respiratory care; there is a wealth of evidence underpinning clinical guidelines and quality standards.

Good respiratory care reduces hospital admissions, is cost-effective and is already outlined in existing documents. However, the investment that has already been made in developing these standards, guidelines and incentives – and even an Outcomes Strategy – will not bear fruit without a concerted system-wide effort to implement them. In spite of irrefutable evidence in favour of interventions like asthma action plans, support to quit smoking and pulmonary rehabilitation, implementation is inconsistent at best. Meanwhile, poor prescribing for COPD and asthma is putting patients' lives at risk and wasting millions of pounds every year for the NHS.

Until excellent respiratory care is stimulated and rewarded through the commissioning system, and supported by national leadership and infrastructure, pockets of poor care will continue to put lives at risk. We need an implementation programme for the Outcomes Strategy; comprehensive national audit and data programmes for respiratory diseases; a strategic clinical network; and levers and incentives with real teeth to ensure that best practice is implemented.

Investment

Treating respiratory disease costs the NHS an estimated £4.7 billion a year and the cost is rising. Medical research is the best hope for improving future treatments, yet the amount of resource committed to researching respiratory disease does not match the burden it imposes on patients' quality of life, or its cost to society and the NHS. Research and healthcare resources must be better deployed to prevent respiratory disease from developing and to ensure effective treatment

is available.

Improving practice in the management and effectiveness of treatment for COPD is likely to result in around £15.5 million savings each year,² while savings of between £40,100 and £46,900 per 100,000 population can be achieved if good practice is delivered in asthma care.³ Strategic and effective investment has the power to bring not only significant savings to the NHS, but improvements in patients' quality of life and a significant reduction in deaths from respiratory disease.

We need to ensure investment and attention are given to building awareness, improving respiratory research and services, implementing the COPD and Asthma Outcomes Strategy and putting effective infrastructure in place for respiratory conditions. Only then will we be able to reduce respiratory death rates in line with the rest of the developed world.

SUMMARY OF RECOMMENDATIONS

1

The National Institute for Health Research (NIHR) and Medical Research Council (MRC) should increase investment in basic and applied research into respiratory disease so it is proportionate to the burden it poses.

2

NHS England should work with NHS Improving Quality to develop an implementation programme for the COPD and Asthma Outcomes Strategy. This should include the development of contractual incentives and levers, which are focussed on achieving outcomes in care, through the commissioning system.

3

NHS England and the Department of Health should prioritise respiratory conditions at a national level by investing in the following infrastructure:

- a respiratory Strategic Clinical Network (SCN) to ensure effective co-ordination and integration of care across primary, community, secondary and tertiary care; and
- an Intelligence Network for respiratory disease to ensure the right data is available to improve the quality of care and outcomes.

4

Following a positive evaluation of the breathlessness pilot, the Department of Health, NHS England and Public Health England (PHE) should run a national awareness-raising campaign on breathlessness which includes patient, healthcare professional and commissioner education.

5

Health Education England (HEE) should work with professional bodies such as the Primary Care Respiratory Society UK (PCRS) and British Thoracic Society (BTS) to ensure high, consistent standards of training and competency assessment for all healthcare professionals treating people with respiratory conditions. This should include working with NHS England to establish a system to assess and certify the competence of all healthcare professionals undertaking and interpreting quality-assured diagnostic spirometry.

6

The Government must implement all of the tobacco control measures in the Children and Families Act 2014 without further delay, including standardised packaging for cigarettes.

7

NHS England and PHE should provide support to Clinical Commissioning Groups (CCGs) and local authorities on capacity planning for smoking cessation services, including, in particular, the implementation of National Institute for Health and Care Excellence (NICE) guidance on cessation in secondary care settings.

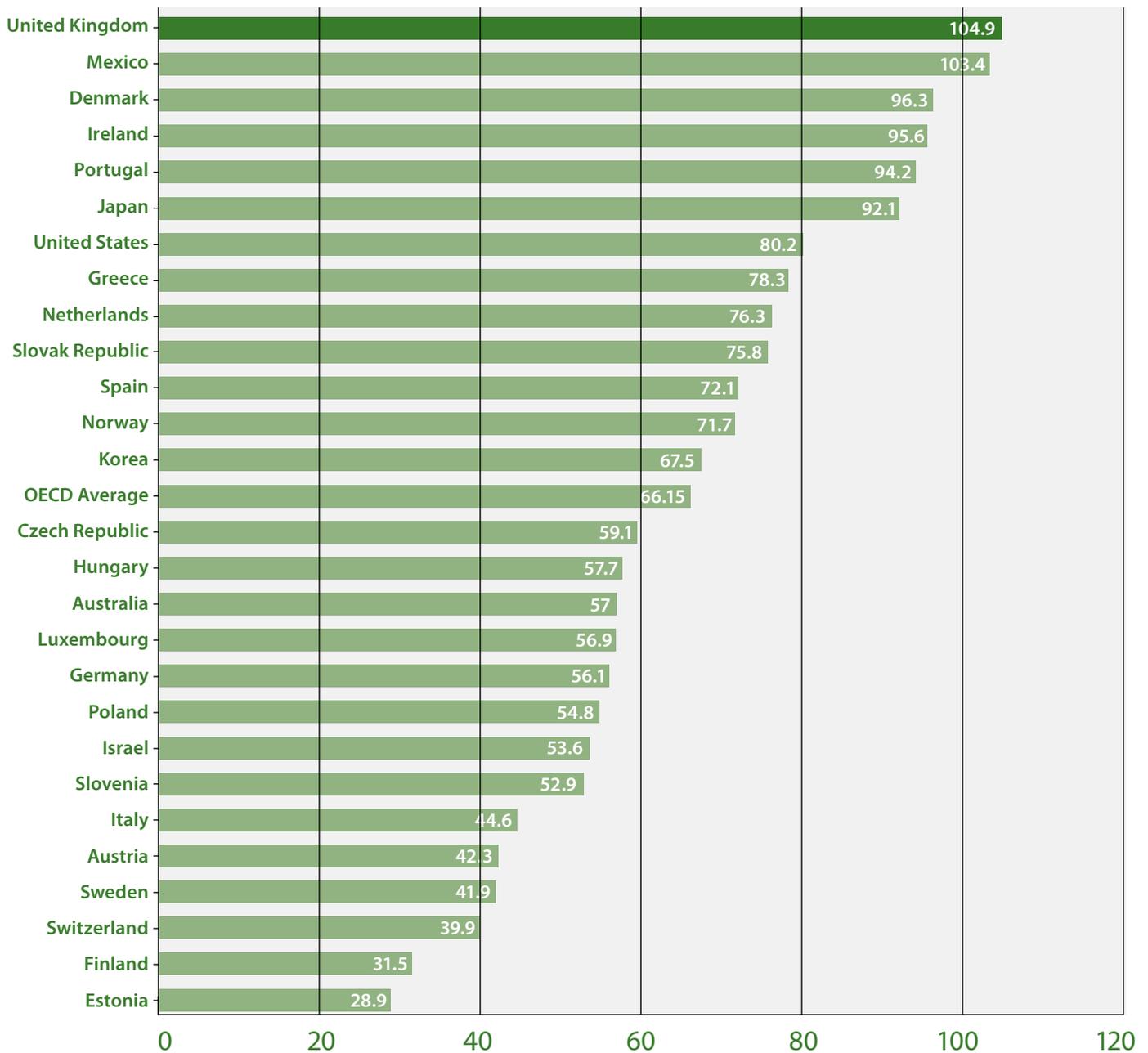
8	The Department of Health should introduce free prescriptions for people with respiratory and other long-term conditions.
9	NHS England should commission an ongoing national asthma audit to assess the extent that asthma care meets standards and to create a baseline against which it can ensure improvements are continually made. This should include auditing the uptake of the NICE quality standard for asthma in primary and secondary care.
10	NHS England should undertake a national improvement project on children's asthma care as an exemplar for long-term conditions management in children, focusing on improving prescribing, risk assessment and self-management support.
11	<p>NHS England should use its role as the system leader for commissioning to incentivise improvements in asthma care. This could include:</p> <ul style="list-style-type: none">• developing a national enhanced service for routine management of asthma in primary care that includes provision of an asthma action plan and a good quality annual asthma review;• developing a national asthma Commissioning for Quality and Innovation (CQUIN) for discharge from hospital that includes provision or review of an action plan and follow-up;• working with NICE to ensure asthma action plans are included in the CCG Outcomes Indicator Set; and• supporting the development of structured templates and alerts in primary care computer systems to ensure good practice is in place and ensure healthcare professionals are aware of which patients are at risk.
12	The Care Quality Commission (CQC) should conduct a themed inspection of prescribing and medicines use in asthma in primary care.
13	NHS England and CCGs should work together to develop a networked care model for delivery of services for people with severe asthma being treated in secondary care or designated specialist centres, with clear pathways in place to cover the journey through primary, secondary and tertiary care.
14	The BTS and NICE should include the use of risk assessment in primary care in clinical guidelines on asthma, so that an appropriate proactive approach to care can be planned and provided.
15	Department of Health and NHS England should continue to fund a regular national audit of COPD services.

16	Public Health England should introduce a case-finding spirometry test component as part of the NHS Health Check for people aged 40-74.
17	Department of Health and NHS Improving Quality should design and prioritise for use targeted case-finding tools, which CCGs and practices could use to identify those who may have COPD within their local population.
18	NHS England should prioritise the promotion of smoking cessation as an essential treatment for all people with COPD who smoke.
19	CCGs should invest in pulmonary rehabilitation services so that: all patients with limiting breathlessness can access services within a month of referral; rapid access to pulmonary rehabilitation is available for COPD patients following discharge from hospital; and an NHS-funded long-term exercise programme is available following completion of pulmonary rehabilitation.
20	CCGs should undertake a regular review of all COPD patients regarding their need for oxygen and refer on to an appropriate assessment centre to ensure that a personalised plan is put together for those requiring long-term oxygen use, as per NICE guidance.
21	CCGs should develop specific plans to ensure that all patients with COPD are appropriately supported to manage their condition; and all high-risk patients with COPD are identified and have appropriate access to expert care.

INTRODUCTION

Respiratory disease affects one in five people in the UK. It is responsible for around a million hospital admissions and costs the NHS an estimated £4.7 billion⁴ a year. Respiratory disease is also the third biggest cause of death in the UK: in 2012 it killed 80,000 people not including lung cancer, which killed an additional 35,500 people.⁵

Respiratory deaths per 100,000 population, 2010 (standardised rates)



However, the death rate for respiratory disease compares very poorly with other OECD countries. In 2010, the UK had the worst death rate amongst these countries for respiratory disease: it was almost double the rate of Germany, and more than three times that of Finland. In comparison, the death rate for circulatory diseases in the UK was below the OECD average, and the rate for cancer was just above the average.⁶

The Government has set out a clear ambition to reduce premature mortality – it is one of five key areas against which the NHS will be judged – and respiratory disease, along with the other big killer diseases, is rightly highlighted as an area where improvements need to be made. In March 2013, the ‘call to action’ set out the Secretary of State for Health’s ambition for England to be among the best in Europe at preventing premature mortality⁷ and the Mandate to the NHS for 2014/15 set the objective of avoiding an extra 30,000 premature deaths a year by 2020.⁸

The figures above set out the scale of the challenge in reducing premature deaths from respiratory disease and suggest that there is a need for urgency in facing that challenge. A concerted effort across the whole healthcare system, led by NHS England and other national bodies will be needed if outcomes for respiratory disease are going to be significantly improved. The NHS has a track record in achieving substantial improvements in outcomes for cardiovascular disease and cancer as a result of sustained campaigns to make system-wide changes to the organisation of care. Respiratory disease needs to have this same level of attention and priority now.

An Outcomes Strategy for COPD and Asthma, which sets out what needs to happen to improve outcomes for these conditions, was published by the Department of Health in 2011.⁹ A number of clinical guidelines and quality standards have also been issued. However, these have yet to make a positive impact on key outcomes such as admissions and – in the long-term – on preventing premature deaths. All levels of the NHS and national bodies need to take action to put its recommendations into practice, or outcomes will not change, and people will continue to die prematurely from respiratory disease.

This inquiry set out to explore why so many people are still dying from respiratory disease, and makes a clear set of recommendations about the actions required to reduce premature deaths. It also considered what the factors contributing to respiratory deaths might be, and what the barriers and challenges might be for the Government and the NHS to address these factors. As well as looking at the overall picture for respiratory disease, it focussed specifically on chronic obstructive pulmonary disease (COPD) and asthma, two of the most common respiratory conditions which are responsible for a large number of hospital admissions.

The APPG received oral or written evidence from over 50 individuals and organisations with an interest in respiratory disease. Written submissions are included in annex 1 to this report. This was supplemented by testimony at two evidence sessions hosted by the APPG. The evidence submitted forms the basis of this report.

What is respiratory disease?

Respiratory disease covers a diverse range of conditions including chronic obstructive pulmonary disease (COPD), asthma, bronchiectasis, interstitial lung disease (including idiopathic pulmonary fibrosis and sarcoidosis), and lung cancer, as well as many others. Respiratory doctors also manage pneumonia, which is a severe infection of the lungs that kills large numbers of people, including those with existing lung conditions. Respiratory infections and lung cancer are often excluded from statistics on respiratory disease.

Asthma and COPD

This report focuses on the two most common long-term respiratory conditions, asthma and COPD. They affect around six million people right across the

age spectrum. Several thousand deaths from these two conditions alone are thought to be avoidable every year.^{10, 11}

- Asthma affects people of all ages; 20% of those with asthma are children and young people; the goal of asthma care is to control symptoms; it is not a progressive condition though can worsen; most asthma deaths are considered to be avoidable.
- In COPD, the population is older; 13% of people over 35 are estimated to have COPD; many people with COPD are or have been smokers; it is a deteriorating and terminal condition; the number of deaths is much higher in COPD than in asthma.

RESPIRATORY DISEASE

“Respiratory diseases are the poor relation to the big killers.”

Professor Graham Devereux, University of Aberdeen

The overwhelming majority of those submitting evidence were clear in their view that treatments, care and services for respiratory disease were not on a par with the other ‘big killer’ diseases of cancer, heart disease and stroke.

This was reflected in poor outcomes for respiratory disease at a national level: although it is the third biggest killer in the UK, progress has been relatively poor in reducing the number of deaths in recent years. For comparison, the UK mortality rate for circulatory diseases has fallen more than twice as quickly as that for respiratory diseases from 2001–2010.¹²

Respiratory conditions are also responsible for a large number of hospital admissions, and there is significant variation across the country: in 2010/11 in England there was a six-fold variation in the rate of emergency admissions for asthma in adults, and a 19-fold variation in children. There was a five-fold variation in the rate

of emergency admissions for COPD, and a three-fold variation in the rate of readmissions.¹³ Respondents highlighted a large and varied number of reasons for these poor outcomes.

Respondents pointed to the fact that investment by the NHS in respiratory disease did not match the burden that it imposed on society in terms of premature mortality and ill health. In 2012/13 the NHS spent £4.7 billion on respiratory disease, which was 4.9% of its budget.¹⁴ However, respiratory disease was responsible for 7.07% of the burden imposed by disease in the UK in 2010.^{15, 16} This disparity is concerning when respiratory conditions accounted for three out of the top ten leading causes of death in 2012.¹⁷

United Kingdom mortality rate – 2001–2010		
Year	Diseases of the circulatory system per 100,000	Diseases of the respiratory system per 100,000
2001	257.38	78.10
2002	250.96	80.01
2003	243.38	85.44
2004	223.96	78.02
2005	211.28	79.33
2006	196.95	74.27
2007	188.09	73.39
2008	181.56	74.69
2009	169.15	69.58
2010	164.19	67.50

Research investment

Many respondents also highlighted the need for more investment in research into respiratory disease. The Medical Research Council (MRC), which funds basic research (to improve knowledge and understanding of a disease) spent 3.1% of its budget on respiratory disease in 2012/13.¹⁸ The National Institute for Health Research (NIHR), which funds applied research (using the knowledge and understanding gained through basic research to improve care and outcomes for patients, for example by developing treatments) spent 3.4% of its budget on research into respiratory disease in 2011/12.¹⁹ Investment and resource should be proportionate to the burden of disease if we are to make progress in understanding respiratory disease better and reducing deaths.

Investment should also be better directed. In particular, a large proportion of the medicines budget in England, around 13% of the primary care prescribing budget (2012),²⁰ is spent on respiratory medicines.

Implementation of the medicines optimisation principles²² could ensure that the investment made in these medicines is not wasted.

Recommendation

NIHR and MRC should increase investment in basic and applied research into respiratory disease so it is proportionate to the burden it poses.

Increased investment in research will also fast track the development and testing of new treatments ensuring a direct impact on the lives of those affected by respiratory disease.

Making respiratory disease a real priority

Many respondents commented on the fact that they did not feel that the Government and NHS attached the same priority to tackling respiratory disease as it did to the other big killers. Although an Outcomes Strategy for COPD and Asthma, which set out what needed to happen to improve outcomes for people with these conditions, was published by the Department of Health in 2011, respondents felt that the strategy had lost momentum since its publication as there was no plan for ensuring it was implemented.

“Recent NHS changes have slowed the implementation and uptake of recommendations within the Strategy and in many areas implementation programmes have now stalled.”

Boehringer Ingelheim Ltd

Respiratory disease does feature as a priority improvement area for reducing premature mortality in the NHS outcomes framework, the public health outcomes framework, and the CCG Outcomes indicator set, alongside reducing mortality in the other major disease areas. However, it is not clear what plans are in place to develop specific initiatives to achieve this, and lack of implementation of the Outcomes Strategy for COPD and Asthma is seen as a significant issue which may threaten a reduction in mortality in this disease area.

NHS Improving Quality, the organisation which seeks to drive improvement across the NHS by providing improvement and change expertise, had an improvement programme for 2013/14 to support delivery of the Cardiovascular Disease Outcomes Strategy. Given that, of the five ‘big killer’ diseases, England performs worst compared to our European peers on premature mortality for respiratory disease, similar support should be provided for delivery of the Outcomes Strategy for COPD and Asthma.

National infrastructure for respiratory

“As a speciality we were disappointed not to be one of the priority areas identified...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.”

British Thoracic Society

Respondents pointed to the lack of infrastructure for respiratory disease as a particular problem. Specifically, they highlighted the lack of formal, funded clinical networks which bring together clinicians, commissioners, and patients in a particular geographical area to improve care for respiratory disease. Networks established for other conditions have achieved outstanding improvements in care for patients. For example, the stroke networks in London developed a strategy which enabled people to access specialist care quickly. Since implementation in 2010, this has saved 400 lives; reducing deaths by 12% and increasing the proportion of people still alive after 90 days from 81.5% to 88.7%.²² These are significant and impressive improvements in outcomes and illustrate the benefits that a concerted approach by networks can bring.

Under the new health and care system Strategic Clinical Networks (SCNs) have been established and funded by NHS England for cancer, cardiovascular disease (including stroke, diabetes and kidney diseases), mental health (including dementia and neurology), and maternity and children, but not for respiratory disease.

Although ten respiratory networks were established and supported by the Department of Health in 2010 and were starting to make an impact at a regional level, their funding has now run out, and most ceased operation in 2013 as a result. Three of the networks have continued through different arrangements: in London their work continues through a Clinical Leadership Group; and in the East of England and the South East Coast region the networks are being hosted and funded by the regional Academic Health and Science Networks. Several of the maternity and children SCNs are planning work on asthma, but such patchy arrangements will not provide the national focus necessary to significantly improve mortality for respiratory disease.

When the structures of SCNs was announced in 2012, NHS England said it expected the conditions and patient groups for which they were prescribed to change over time and that it anticipated reconsidering priorities for them within three to five years. A review to consider whether there is scope to include respiratory conditions would be timely.

“Better data capture is key. There is no point trying to change what you don’t/can’t measure.”

Dr Dominick Shaw, Associate Professor and Honorary Consultant, University of Nottingham

Some respondents also raised the issue of the lack of available data for respiratory disease and how this can impact on improving outcomes. Again, respiratory disease is lagging behind other conditions in this respect. The National Cancer Intelligence Network – a network of organisations including the Department of Health and NHS, charities and research organisations – was formed in 2007. It collects anonymised data about everyone diagnosed with cancer which is used to provide a range of information and has expanded what is known about cancer. It has developed a range of electronic information tools, for example to help commissioners make decisions about services and is helping to improve quality of care. Similarly, data collection through the Myocardial Infarction National Audit Project (MINAP) has been providing comprehensive data on cardiovascular disease since 1999. The lack of comprehensive data for respiratory disease was highlighted when a submission to the Department of Health in 2012/13 to create a national

CQUIN on COPD to incentivise excellent secondary care, was turned down due to lack of baseline data.

Public Health England (PHE) has now set up Intelligence Networks for the other conditions with SCNs to deliver information, data and evidence to support their decisions on improving care. Establishing which data on respiratory outcomes should be collected and how, would help establish the baseline necessary to develop incentives and measure improvements. It would also help the Government and NHS to understand where the system is working and where changes need to be made, so that outcomes can be improved.

Implementation of guidelines and standards through better incentives

Respondents also pointed to the fact that, although various high quality, well established guidelines and standards are in place for respiratory diseases, they are often not implemented or enforced.

NICE has published clinical guidelines on COPD, tuberculosis and idiopathic pulmonary fibrosis (IPF) and guidelines on diagnosis and monitoring of asthma and bronchiolitis in children are currently being developed. Quality standards have been published on COPD, asthma and smoking cessation, and the Department of Health has asked NICE to develop standards for sleep disordered breathing and IPF. However, given the range of respiratory conditions and the poor outcomes, respiratory conditions seem to be under-represented in the NICE work programme. Instead, the British Thoracic Society publishes the majority of respiratory guidelines, including a particularly well-respected guideline on the management of asthma. Whilst these set out what good care should look like, there is no formal obligation on the NHS to implement them, and they are not enforceable. There is evidence that they are often ignored in routine practice, and some repeated audits of respiratory care show little or no adherence to the guidelines year after year.

“Diminished prioritisation of respiratory care at a central level translates into downgrading of respiratory care as a priority at a local level.”

Royal College of General Practitioners

There is a range of incentives that can be used to improve the care provided by different parts of the NHS in line with guidelines and standards. However, respondents felt that these were not being used sufficiently to incentivise good quality respiratory care, and that where they were being used they were often not that effective. In particular respondents pointed to the fact that the Quality and Outcomes Framework (QOF) was focussed on processes of care rather than quality and is therefore considered to be largely a 'tick box' exercise for GPs. For example, although the QOF indicator on offering smoking cessation to patients with a range of long-term conditions saw 95.8% of patients offered support to quit smoking in 2012/13, a large percentage of those with COPD continue to smoke.

Questions (set out in more detail in the asthma section of the report) have also been raised about whether the inclusion of annual asthma reviews in QOF has had the

intended effect of ensuring that high quality asthma reviews are delivered. NHS England is currently seeking to simplify the QOF: proposals for improvement should redress the balance between incentivising improved outcomes and processes of care.

Recommendation

NHS England should work with NHS Improving Quality to develop an implementation programme for the COPD and Asthma Outcomes Strategy. This should include the development of contractual incentives and levers, which are focussed on achieving outcomes in care, through the commissioning system.

Incentives in primary care

The GP contract includes two mechanisms for incentivising practices to improve the quality of particular services.

The *Quality and Outcomes Framework (QOF)* is a set of clinical and public health indicators against which GP practices score points. They are paid according to how many points they score. There are six indicators for COPD and four for asthma, as well as four smoking indicators in 2014/15.²³

Enhanced Services are additional services that GP practices can choose to provide, and for which they will be paid extra. Some are specified nationally and are an optional part of the GP contract. There are currently six national enhanced services, including services for patients with complex health needs at high risk of unplanned hospital admission, alcohol reduction, learning disabilities, dementia, patient participation and extended hours.

Clinical Commissioning Groups (CCGs) can also commission enhanced services locally over and above those specified in the national GP contract.

Incentives in secondary care

Commissioning for Quality and Innovation (CQUIN) makes part of the value of a service contract dependent on improvements in the quality of the service. Similar to Enhanced Services, some are agreed nationally, and some locally.

The *Quality Premium* rewards CCGs for making improvements in service and associated improvements in outcomes. There are four national measures on reducing premature mortality, reducing avoidable hospital admissions, rolling out the Friends and Family Test and improving patient experience of hospital services, and preventing healthcare associated infections. There are also three measures based on priorities agreed locally.

Although no reward is involved, the *CCG Outcomes Indicator Set* benchmarks CCG performance against a number of indicators including on reducing premature mortality from respiratory disease, and enhancing quality of life for people with long-term conditions, some of which specifically cover COPD and asthma.

Recommendation

NHS England and the Department of Health should prioritise respiratory conditions at a national level by investing in the following infrastructure:

- **a respiratory Strategic Clinical Network to ensure effective co-ordination and integration of care across primary, community, secondary and tertiary care; and**
- **an Intelligence Network for respiratory disease to ensure the right data is available to improve the quality of care and outcomes.**

Raising awareness

Respondents considered that public awareness and profile of respiratory diseases was much lower than that for the other 'big killers.' Much of this was attributed to the fact that some respiratory diseases – and specifically COPD – are considered by many, including patients and healthcare professionals, to be self-inflicted as a result of smoking. Despite the fact that smoking also contributes to other conditions such as heart disease and cancer, respondents felt that people with other conditions were not stigmatised in the same way. This lack of public awareness was thought to be compounded by the fact that lung health does not feature in the NHS Health Check – which those between the ages of 40 and 74 are offered every five years – alongside heart disease, stroke, diabetes, kidney disease, and some kinds of dementia.

However, the Be Clear on Cancer television advert, which encourages people with a persistent cough – a possible sign of lung cancer – to visit their GP, has demonstrated that it is possible to raise awareness of a lung condition successfully to achieve impressive results in earlier diagnosis. An extra 700 people were diagnosed with lung cancer between May and July 2013, when the advert was first run, with 300 of these people receiving potentially curative treatment.²⁴ Awareness of early signs of lung disease, such as shortness of breath, or persistent cough, is important if patients are to present earlier.

The NHS business plan 2014/15 – 2016/17 includes a deliverable to support two symptom awareness campaigns by March 2015. It would be very appropriate for breathlessness to be one of these.

The Department of Health, NHS England and Public Health England piloted a campaign in the press and on the radio earlier this year in Oldham and Rochdale, to raise awareness of breathlessness as a symptom of respiratory diseases. This campaign focuses on the symptom rather than a specific disease area, which means that it can also be used to identify potential heart disease and hypertension in some people. This simple approach should be effective at raising awareness of lung health as it encourages those getting out of breath during everyday activities to go to their GP. Healthcare professionals and commissioners were also educated to refer promptly to lung function testing, where appropriate, as part of the campaign.

Recommendation

Following a positive evaluation of the breathlessness pilot, the Department of Health, NHS England and Public Health England should run a national awareness-raising campaign on breathlessness which includes patient, healthcare professional and commissioner education.

Improving the knowledge of healthcare professionals

Respondents highlighted two main issues in relation to healthcare professionals: the lack of respiratory specialists; and the lack of education and knowledge on respiratory conditions amongst generalist healthcare professionals, particularly in – but not restricted to – primary care. One study mentioned in the evidence found that 20% of nurses in general practice with an advanced asthma role did not have accredited asthma training, and 52% of nurses with an advanced COPD role did not have accredited COPD training.²⁵ In a study of 150 healthcare professionals, only 7% were able to demonstrate the use of a metered dose inhaler accurately, though 75% said they were involved in teaching inhaler technique.²⁶

Diagnosis was noted by respondents as a particular area in which the knowledge and skills of healthcare professionals need to improve. It is estimated that around three million people have COPD, yet fewer than one million of them have actually been diagnosed. Spirometry measures the amount (volume) and/or speed (flow) of air that can be exhaled in one breath. It is the main tool for diagnosing COPD and can also help

diagnose other respiratory conditions, including asthma. Yet respondents pointed out that although there have been some improvements in the use of spirometry over the last ten years, it is still underused, and the quality of spirometry in primary care is often poor. This can lead to both delays in diagnosis, and people being misdiagnosed meaning that opportunities are missed to initiate treatment which could control symptoms and slow progression of disease.

“There is evidence that spirometry is still under-used, and that the quality of spirometry measurement in primary care is inconsistent.”

British Thoracic Society

Improving the quality of spirometry is highly relevant to the aim in the NHS business plan 2014/15–2016/17 to bring in robust quality assurance measures for diagnostic services in more than 70% of all scientific and diagnostic services.

Recommendation

Health Education England should work with professional bodies such as the Primary Care Respiratory Society UK and British Thoracic Society to ensure high, consistent standards of training and competency assessment for all healthcare professionals treating people with respiratory conditions. This should include working with NHS England to establish a system to assess and certify the competence of all healthcare professionals undertaking and interpreting quality-assured diagnostic spirometry.

Smoking

The impact of smoking on people’s lungs is well established: it is a contributory factor in over a third of all respiratory deaths.²⁷ It is the primary cause of COPD and lung cancer, and can trigger asthma attacks and reduce the efficacy of asthma medication. Pregnant women who smoke also increase their child’s risk of developing asthma and other lung problems in their early years.

An estimated 86% of deaths from COPD and 81% of lung cancer deaths are attributable to smoking.²⁸ As many as 20% of the population in England continue to smoke²⁹ and the figure is estimated to be even higher in people who are living with a lung condition.³⁰

“The fact that ten million people still smoke is testimony to the sustained inadequacy of the political and medical response to the tobacco epidemic.”

UK Centre for Tobacco and Alcohol Studies

The need to tackle smoking in order to tackle respiratory disease was mentioned by the vast majority of respondents: both helping smokers to give up, and discouraging others (particularly young people) from taking up the habit. Furthermore, healthcare professionals need to consider stopping smoking as a treatment intervention in people with lung disease, since it can slow the progression of disease.

Early evidence suggests that the ban on smoking in public places in England has led to improvements in lung health. Several studies have shown reductions in emergency admissions for asthma in both adults and children following the introduction of the ban.³¹

The Children and Families Act 2014 contains measures to help further reduce the harm caused to children by smoking. It enables the Government to introduce regulations for standardised packaging for tobacco products, ban smoking in cars when children are present and makes it an offence for a person over 18 to buy tobacco on behalf of someone under 18. The Act also bans the sale of electronic cigarettes to under-18s. The Chantler review investigating standardised packaging concluded that it would be likely to contribute to a modest but important reduction in smoking, including reducing the rate of children and young people taking up smoking.³²

Recommendation

The Government must implement all of the tobacco control measures in the Children and Families Act 2014 without further delay, including standardised packaging for cigarettes.

Other measures such as higher tax increases for tobacco, minimum pricing, and tackling tobacco smuggling were proposed by respondents. The current tobacco control plan for England ‘Healthy lives, healthy people’ seeks to achieve a decrease in smoking to 18.5% by 2016. Scotland and Ireland, which have adult smoking rates similar to that in England, have both recently adopted much more ambitious targets to reduce smoking to less than 5% by 2034 and 2025 respectively.

“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.”

Dr Colin Michie,

Consultant Paediatrician, Ealing Hospital

Respondents also highlighted the importance of smoking cessation services in helping people to quit – both to help prevent them developing respiratory diseases and to slow their progression. The need for more and better services was emphasised, including services in hospital, recognising that patients are often more susceptible to advice on stopping smoking immediately after a respiratory crisis. Respondents pointed out the importance of hospital services being well integrated with services in primary care. Healthcare settings should also have clear no smoking policies for both staff and patients on the premises.

In November 2013, NICE issued public health guidance on smoking cessation in acute, maternity and mental health services. This recommended a number of measures including all hospitals having an on-site stop smoking service, people who smoke being identified and offered support to stop, integrating stop smoking services across primary and secondary care, and ensuring hospital premises are smoke free.

It is unclear how much impact the NICE quality standard for smoking cessation is having in practice on the care of people with respiratory conditions, when there is no follow up to ensure the quality standard is delivering improved care in the NHS. Stopping smoking can make such a difference to the progression of respiratory disease so it is vital that implementation of this good practice advice is prioritised.

The NHS business plan 2014/15–2016/17 aims to maximise the value of preventive interventions by ‘making every contact count’ and smoking cessation would be an excellent area in which to implement this initiative.

Recommendation

NHS England and PHE should provide support to CCGs and local authorities on capacity planning for smoking cessation services, including, in particular, the implementation of NICE guidance on cessation in secondary care settings.

Prescription charges for medicines

Good compliance to medicines can help to keep symptoms under control and forms part of good management of a condition. Many respondents felt that poor compliance with medication may be a result of the cost of medication and called for the prescription charge to be scrapped for people with asthma. An Asthma UK survey in May 2014 found that among people who pay prescription charges, the costs of asthma medicines have directly prevented 59% of people from taking them as prescribed. Nine out of ten of those people (88%) think that this has affected their asthma for the worse, including people who believe that it led to asthma attacks (12%) and even hospital admissions (10%). The system of exemptions from prescription charges in England has not been properly reviewed since it was established in 1968; an exemption from prescription charges for people with asthma and other long-term conditions could help them to stay on top of their symptoms and prevent unnecessary asthma attacks.

People living with COPD also use a variety of inhalers to control everyday symptoms of breathlessness. 44% of those with COPD are below retirement age,³³ and therefore face many of the same problems due to the prohibitive costs of prescriptions.

Recommendation

The Department of Health should introduce free prescriptions for people with respiratory and other long-term conditions.

Environmental issues

Respondents also highlighted the need to address other issues that impact on respiratory diseases including air pollution and poor housing conditions.

Two thirds of people with asthma find that air pollution makes their asthma worse.³⁴ During the high air pollution alert across the UK in April 2014, a survey of people with asthma found that 84% reported using their reliever inhaler more than usual, and nearly a third had experienced an asthma attack as a result of the pollution.³⁵

Around a third (10,000) of excess winter deaths are due to respiratory conditions. Cold weather is a strong predictor of the numbers of COPD patients having extra exacerbations and admissions to hospital, and dying from the condition. Good quality housing, which is warm and free of damp, is important for respiratory health. Respondents made strong recommendations for housing to be improved and for COPD patients to be included as part of the Warm Homes Healthy People scheme.

The APPG certainly considers these to be important issues and welcomes the comments received. However, we have refrained from making recommendations on these issues as they are outside the remit of this inquiry, which is focussed on changes to health policy and clinical practice.

ASTHMA

“Medical professionals in the UK have generally developed an attitude of complacency when dealing with asthma.”

Parent of a child who died following an asthma attack

Asthma is one of the most common long-term conditions in the UK. It affects all age groups and often starts in childhood. It is a disease characterised by recurrent attacks of breathlessness and wheezing, which vary in severity and frequency from person to person. In an individual, they may occur from hour-to-hour and day-to-day as well as changing over the course of their lifetime. This condition is due to inflammation of the air passages in the lungs and affects the sensitivity of the nerve endings in the airways so they become easily irritated. In an asthma attack, the lining of the passages swell, causing the airways to narrow and reducing the flow of air in and out of the lungs.³⁶

An estimated 5.4 million people, including 1.1 million children, are estimated to have asthma, and it is responsible for over 65,000 hospital admissions a year. The cost of managing asthma in the NHS runs to over £1 billion each year.³⁷ Asthma deaths peaked in the mid-1960s and again in the late 1970s and early 1980s. Although they have declined since then and appeared to have plateaued in the mid-2000s, there has been an increase in asthma deaths over the last five years. Today, over 1,000 people a year in the UK – that’s three every day – are still dying as a result of asthma and the UK has one of the highest asthma mortality rates in Europe.

Studies into asthma deaths began in the 1960s in response to concerns about the increasing number of deaths from this condition, with some important regional studies conducted recently in the Eastern region of England.³⁸ Most recently, the National Review of Asthma Deaths,³⁹ which looked at asthma deaths across the UK between 1 February 2012 and 31 January 2013, was published in May 2014. These studies have consistently highlighted that large numbers of asthma deaths are avoidable and identified a number of contributing factors such as poor medical care and underestimation of the severity of asthma, as well as highlighting the role that behavioural or psychosocial factors play.

The lessons need to be learnt from these studies and the recommendations implemented in order to prevent life threatening asthma attacks and deaths from asthma. In particular, the National Review of Asthma Deaths – the largest study of its kind in the world – found widespread issues with the quality of asthma care, highlighting neglect of many of the basic elements of care across the health system. National, regional and local leadership in the NHS must challenge this system-wide complacency about asthma and develop proactive plans to improve the quality of care at all levels of the system.

Positively, asthma was one of the earlier disease areas to have a quality standard developed by NICE. This sets out the 11 key areas on which clinicians and commissioners alike should focus their attention to ensure that they are delivering high quality care in line with evidence based guidelines. However, there appears to be no impetus in the system to see the quality standard implemented in practice, and no systematic approach to check that NHS organisations are adopting the quality standard as the benchmark for high quality care.

This part of the report sets out the ongoing issues for people with asthma and makes recommendations to address them.

Poor quality care

The majority of the people who submitted evidence to this inquiry felt that despite the fact that the British Thoracic Society had been publishing a clinical guideline for the management of asthma for over ten years, and a NICE quality standard based on this guideline was published in 2013, neither had been well adopted due to lack of levers and incentives in the system to drive implementation in practice, and the quality of care for asthma remained poor. There is no systematic monitoring of whether such guidance is being adopted.

“There is a gap between guidelines and reality.”

Sian Williams,

NHS England Clinical Leadership Group – Respiratory

Data from studies into asthma deaths and patient surveys demonstrate this again and again. Last year, as part of its Compare Your Care campaign, Asthma UK asked people with asthma about ten aspects of their asthma care covered by the quality standard, and then rated their care based on the answers they gave. Of nearly 5,000 people who responded across England, only 14% received care that fully met standards.⁴⁰ Only 16% percent of children received care that fully met standards. Poor overall medical care has consistently been highlighted as a contributory factor in asthma deaths. The Eastern region enquiry found that overall medical care of patients who died from asthma was adequate in only a third (33%) of cases, while the National Review of Asthma Deaths found that the overall standard of asthma care received by patients represented good practice in only 16% of cases overall and only 4% of children. It concluded that alternative management in line with guidelines could have prevented asthma deaths in 46% of cases.

“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.”

British Thoracic Society

Recommendation

NHS England should commission an ongoing national asthma audit to assess the extent that asthma care meets standards and to create a baseline against which it can ensure improvements are continually made. This should include auditing the uptake of the NICE quality standard for asthma in primary and secondary care.

Recommendation

NHS England should undertake a national improvement project on children’s asthma care as an exemplar for long-term conditions management in children, focusing on improving prescribing, risk assessment and self-management support.

Supporting self-management an integral part of regular review

“After four years of asthma that has been quite difficult to treat, I still do not have a management plan. This SHOULD be my lifeline to reduce hospital admissions never mind death.”

Michaela Barnard, asthma patient

Respondents highlighted in particular that people’s self-management of their asthma was poor, and that support and education to improve this needed to be provided. Clinicians should regard self-management support as important a skill and part of routine care as a prescribing intervention. Written asthma action plans are a key part of self-management support: they help people to understand when their asthma is getting worse and what to do about it. They are recommended for people with all long-term conditions, but the evidence for their value in asthma is overwhelming. People who do not have a written personal asthma action plan are four times more likely to have an asthma attack requiring emergency hospital treatment.⁴¹

The evidence shows that they can improve outcomes for people with asthma, particularly for those with moderate to severe asthma who are managed in secondary care, and may also reduce readmissions for people admitted to hospital for an asthma attack. Yet Asthma UK's Compare Your Care campaign found that only 22% of people in England had a written asthma action plan, and only 34% of children. The National Review found that action plans were known to be provided to only 23% of patients that died. The Eastern region enquiry found that only 33% of children who died had a plan. Despite the evidence in their favour, NICE has yet to recommend that indicators on written asthma action plans be included in either the QOF or the CCG OIS.

Guidance also recommends that people should have a review of their asthma at least annually as a routine part of their asthma care. Provision of annual asthma reviews is currently included as an indicator in the QOF and this is reflected in the number of people that say they have had one: 74% of those who participated in Asthma UK's Compare Your Care research said they had had a review in the last year, although the National Review of Asthma Deaths found that a smaller number of patients who died had a review in primary care in the year before they died – only 57%. Evidence from the National Review also calls into question the quality of the reviews that are

performed. It found that of the last reviews recorded in primary care prior to the fatal attack, only 27% of people had an assessment of their asthma control, 42% had an assessment of their medication use, and only 71% had their inhaler technique checked – all of which are key components of a review, alongside provision or review of an asthma action plan.

“‘Please look up how to use your inhalers on YouTube’ has happened and is thought to be adequate advice by some GPs.”

Dr Richard Iles, Addenbrookes Hospital

Discharge from hospital also provides an opportunity to provide an action plan or review an existing one, as part of a review with a respiratory specialist. Again, such a review is recommended in guidance as it can help reduce readmissions, yet the Compare Your Care campaign found that less than half of the people who had been admitted to hospital had had such a review. There are a number of examples of outcomes improving where local incentives have been provided for the quality of hospital care for asthma.

Improving hospital care for asthma in Wakefield

The Public Health Respiratory Team in NHS Wakefield has worked with Mid Yorkshire Hospitals Trust to implement an asthma care bundle, aimed at improving care for asthma patients in A&E, on the ward and at discharge, after identifying poor asthma outcomes in 2010/11. The care bundle is supported by a CQUIN scheme and has acted as a catalyst for the wider development of the asthma service.

The project aimed to improve the quality and consistency of care for patients and reduce asthma readmissions within 28 days of discharge. The project included diagnostic work and process mapping to understand the current pathway and a programme of staff training. The care bundle includes:

- administration of appropriate medication;
- reviewing inhaler technique;

- agreeing a self-management plan; and
- recommending GP and/or specialist follow up.

The results have been excellent. By the end of 2012:

- 96% of patients had a self-management plan at discharge, compared to just 8% at the start of 2011;
- 100% had a GP letter despatched within 24 hours of discharge and 93% were recommended for specialist follow up within four weeks;
- asthma readmissions within 28 days fell from five per month to fewer than two, and total readmissions from 109 to 39 a year; and
- total admissions fell from 580 to 430, and bed days from 2160 to 1407.

Recommendation

NHS England should use its role as the system leader for commissioning to incentivise improvements in asthma care.

This could include:

- **developing a national enhanced service for routine management of asthma in primary care that includes provision of an asthma action plan and a good quality annual asthma review;**
- **developing a national asthma CQUIN for discharge from hospital that includes provision or review of an action plan and follow-up;**
- **working with NICE to ensure asthma action plans are included in the CCG Outcomes Indicator Set; and**
- **supporting the development of structured templates and alerts in primary care computer systems to ensure good practice is in place and ensure healthcare professionals are aware of which patients are at risk.**

Prescribing issues

A number of respondents raised the issue of poor prescribing in asthma care – in particular over-treatment with reliever medication and under-treatment with preventer medication.

In people with well-controlled asthma there should be little or no need for reliever medication. Using a reliever inhaler more than a few times a week is an indicator of poor control and that preventer medication may need to be initiated or stepped up. Of the people for whom the National Review had prescribing data, 56% had been prescribed more than six reliever inhalers in the year before they died, and shockingly 4% had been prescribed more than 50, which suggests extremely poor symptom control. Conversely, preventer inhalers should be taken daily; prescribing advice recommends that people would normally need twelve preventer inhalers a year. Of the people for whom the National Review had prescribing data, 80% were issued with fewer than twelve preventer inhalers in the year before they died, which is unlikely to be sufficient to maintain asthma control.

The scale of prescribing errors highlighted by the National Review of Asthma Deaths was particularly alarming, with prescribing issues identified in almost half (47%) of cases, including people being given the wrong medicines or the wrong doses of the right medicines. Of particular concern was that some patients are also still being prescribed long acting beta agonists (LABAs – another type of medication) without inhaled steroids: this was found to be the case for two children in the Eastern region inquiry and five patients in the National Review. There are considerable concerns about prescribing LABAs without inhaled steroids. Guidelines recommend that LABAs are only started in patients that are already on inhaled steroids and that inhaled steroids should be continued. Use of LABAs without inhaled steroids is associated in trials with higher death rates.

Even when given the correct medicines, many patients are not shown how to use their inhalers properly, so are not getting maximum benefit. Adherence to treatment regimes for preventer medication is poor, as it is in many long-term conditions. Patients need help understanding when to step treatment up and down according to how well controlled their asthma is. The active involvement of pharmacists through the medicines optimisation programme is to be encouraged in order that patients derive maximum benefit from their medication, since they can reinforce the advice of clinicians and monitor how well controlled a patient is.

“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. The consequence of this leads to high medicine acquisition costs as well as poor patient asthma outcomes and the potential for adverse side effects.”

Royal Pharmaceutical Society of Great Britain (RPSGB)

The Care Quality Commission (CQC), the independent regulator for health and social care services, has been undertaking inspections of GP practices since April 2013, and the results from the first 900 surgeries inspected was published in December 2013. The Commission also undertakes themed inspections, which look at specific standards, sectors or types of care.

Recommendation

The CQC should conduct a themed inspection of prescribing and medicines use in asthma in primary care.

Ensuring those with severe asthma are referred to specialist care

Respondents highlighted that people with severe asthma – those who continue to have symptoms and frequent asthma attacks despite being on very high levels of asthma medication⁴² – were at higher risk of a fatal asthma attack. However, there is often poor recognition of severity amongst both healthcare professionals, and patients and their carers or families. The Eastern region enquiry judged that around half of all patients, and half of all children that died had severe asthma. Yet, despite the recommendations in national guidelines that people with severe asthma should be offered a multidisciplinary assessment by a severe asthma service, a quarter of the adults, and half of the children, had not been referred to a specialist. The National Review judged that nearly a fifth (19%) of the people who died had not been referred to a specialist when they should have been, or there had been a delay in referral.

The under-provision of specialist care was also raised as a concern. In the past, the services provided by hospitals for people with severe asthma have varied across the country. Services for severe asthma are now commissioned as a specialised service directly by NHS England, which sets out centrally which assessments and treatments need to be provided in order for hospitals to be designated as a specialist centre, and for consistency of service. Between only six and eight services are expected to be designated as specialist centres for severe asthma. This could lead to difficulties for people accessing these services: some will have to travel long distances to be seen, often when they are very unwell, and this could potentially lead to people deciding not to take up referrals.

Furthermore, these services will only be provided for a very small subset of people with the most severe asthma: around 1,000 referrals a year are expected,⁴³ although many clinicians in the field feel this is likely to be an underestimate. Asthma UK estimates that around 5% of people with asthma – or 250,000 people – may have severe asthma. If the anticipated patient numbers are inaccurate, CCGs will need to commission services for others with severe asthma outside of the subset in the specialised centres, which could lead to inequities.

There needs to be an accurate estimate of the number of people that need different types of assessments and treatments. This will ensure that the right services are available to the right people. A networked care model will enable specialist centres to work with other hospitals in their region so that people with severe asthma can be seen closer to home, where possible. Designated specialist centres will be required to play a wider role in educating primary and secondary care clinicians, which will also help to improve healthcare professionals' knowledge of severe asthma, and in particular help them to understand when people should be referred to a specialist.

Recommendation

NHS England and CCGs should work together to develop a networked care model for delivery of services for people with severe asthma being treated in secondary care or designated specialist centres, with clear pathways in place to cover the journey through primary, secondary and tertiary care.

Other factors

Although having severe asthma puts someone at higher risk of having a fatal asthma attack, around half of those who died from asthma in the Eastern region enquiry and nearly 60% of those considered by the National Review were judged to have mild to moderate asthma.

Respondents also highlighted a number of other factors that put people with asthma at higher risk of a fatal attack. These included behavioural or psychosocial characteristics such as poor compliance with medication, failure to attend medical appointments, being in denial about their asthma, depression, problems with alcohol, smoking and family problems. The Eastern region

enquiry identified such characteristics in 81% of patients, and in 60% of children, which may have contributed to their death. The National Review found that there was one or more avoidable factors related to the patient, their family or the environment (which as well as the behavioural and psychosocial factors listed above also included allergy – see below) in 65% of the overall cases they reviewed and in 93% of the cases where the patient was 19 and under.

Allergy to a range of trigger factors – such as pollen, animal hair and house-dust mite – was also highlighted as a risk factor in the evidence provided. The Eastern region enquiry found that where patients died following a sudden severe asthma attack, the vast majority of

these deaths had occurred between April and August, suggesting that a seasonal allergen could be responsible. Although only three of these patients had a recorded history of allergy, it was considered possible that half of the patients suffering a sudden severe attack could have been prone to allergy. The Eastern region enquiry into children’s death found that five were likely to have been exposed to known allergens, including pets and food, shortly before they died and a further two died suddenly between June and August, suggesting an acute allergic trigger. However, although the panel considered that 13 of the children were likely to have had allergy, only three had received a formal assessment in an allergy clinic.

Claire’s story

Claire O’Beirne’s son, Malcolm, died following an asthma attack a few days after his tenth birthday. Malcolm was diagnosed with asthma when he was four. His asthma was considered to be mild: he took his medicines regularly and he saw his GP when necessary which wasn’t very often. When he was little he had eczema, which had improved but never disappeared completely. Although Claire had asked about allergy testing at this time she was told that this was not necessary. Malcolm also began to develop hay fever when he was eight.

The asthma attack which led to Malcolm’s death was his first serious attack. At about 11.30pm on the night of 31 May 2003, Malcolm complained of feeling unwell and seemed agitated. Claire rang the out of hours GP but as Malcolm lost consciousness she then called 999. Unfortunately there was a delay with the ambulance response so Malcolm did not arrive at hospital until 40 minutes after Claire called for help, by which time it was too late.

A report from a respiratory specialist for the Coroner’s Office concluded that Malcolm had suffered a sudden onset, catastrophic asthma attack, most probably caused by exposure to an allergen to which he had become acutely sensitive.

“We were naturally devastated to lose our son to a condition which had appeared to us to be relatively mild and under control and about which our GP practice had not seemed unduly concerned. Malcolm had never been referred for any type of more specialised investigation into either his eczema or asthma so naturally in retrospect we wondered whether this was a gap in his care. We also became aware of other missing elements, such as never being given a personal asthma action plan and no real attention being paid to the hay fever.”

Although the death rate for asthma is relatively low, many of these deaths are preventable, which can be very hard for families to hear after such a tragedy.

The value of risk-assessing people with asthma to enable those at increased risk of an attack to be identified and managed effectively has been recognised by both the Department of Health's Outcomes Strategy for COPD and Asthma, and its good practice guides to designing and commissioning services for asthma for adults and children.⁴⁴ The Eastern region enquiry recommended the use of at-risk registers of asthma patients in primary care, while the National Review of Asthma Deaths said that triggers should be recorded.

Risk factors for asthma attacks have already been identified by systematic review and include smoking, poor adherence to preventative treatment, overuse of reliever treatment, allergies, past emergency visits or hospital admissions, obesity, low educational attainment and lack of self-management education.⁴⁵ There is also some evidence that use of risk-registers in asthma care improves outcomes.⁴⁶ These risk factors must be routinely recognised in clinical practice to make sure people with asthma are given the right preventative care.

Recommendation

The BTS and NICE should include the use of risk assessment in primary care in clinical guidelines on asthma, so that an appropriate proactive approach to care can be planned and provided.

CHRONIC OBSTRUCTIVE PULMONARY DISEASE

Around three million people in the UK are estimated to be living with chronic obstructive pulmonary disease (COPD), 2.2 million of whom are undiagnosed.⁴⁷ Seven years after the publication of the British Lung Foundation's *Invisible Lives* report, which highlighted this serious issue, many people with COPD continue to go undiagnosed.

COPD is a progressive disease, encompassing bronchitis and emphysema, where patients find themselves increasingly breathless. A COPD patient's journey is often punctuated with multiple exacerbations – a sudden worsening of symptoms triggered by an infection or exposure to pollution – which contribute to the high rate of hospitalisation for this group.

COPD exacerbations are the second most common cause of emergency hospital admissions in the UK after ischaemic heart disease, with an estimated 94,000 admissions per year.^{48,49} It is also one of the most costly inpatient conditions treated by the NHS, making up over £800 million in direct healthcare costs and equating to £1.3 million for every 100,000 people.⁵⁰

Patients admitted to hospital with this condition have a very high risk of mortality: 50% of people with a severe COPD exacerbation will die within four years of an admission.⁵¹ Around 5% of all deaths in England and Wales are due to COPD – over 25,000 deaths a year⁵² – yet it has a low public profile and early symptoms are little-known to the public.

Quality and benchmarking of COPD services

Respiratory conditions, including COPD, have historically been under-prioritised in the NHS, both at the centre by policy makers and at a local level. Despite being the fifth biggest killer disease,⁵³ COPD did not have its own Outcomes Strategy until 2011. Evidence to the inquiry voiced concerns that the Outcomes Strategy has not been adopted consistently and huge variations in care still exist across the country. The National COPD Audit brings together data on primary care, secondary care, pulmonary rehabilitation and patient experience in order to highlight areas for improvement. The availability of a rich source of data and information from the audit is therefore an invaluable resource which can be used to drive up the quality of care

and services provided to COPD patients and to remove any unwarranted variations.

The first COPD audit was conducted in 1997 and care for COPD patients has since improved enormously. For example, between the 2003 and 2008 audits, provision of early discharge programmes for COPD rose from 44% to 59% and the availability of non-invasive ventilation (NIV), which is an effective treatment for acute and chronic respiratory failure, went up from 89% to 97%.⁵⁴ The latest audits also introduced new patient-reported measures of services, which could be developed to be a useful benchmark indicator of the quality of COPD care.

NICE developed a quality standard for COPD very early in its extensive programme of quality standards in 2011. This highlights many of the areas we raise here – quality diagnosis, smoking cessation, pulmonary rehabilitation, oxygen treatment and management planning. It is therefore perplexing that there are no levers in the system to drive implementation of the quality standard and to ensure that the investment in such a comprehensive piece of work by NICE actually delivers improved care. There appears to be no specific monitoring of the uptake of such core guidance and no incentives for CCGs, practices, and community and acute trusts to deliver care in line with it.

Recommendation

Department of Health and NHS England should continue to fund a regular national audit of COPD services.

Detection and early diagnosis

One of the biggest factors affecting COPD mortality rates is the speed and accuracy of diagnosis. All too often, COPD is missed or misdiagnosed until the disease becomes so severe that everyday tasks become difficult as patients are restricted by their breathlessness. Moreover, a late diagnosis means that the effectiveness of life-extending treatments and interventions is limited. Wider awareness of the early signs of COPD could lead to earlier diagnosis, which may slow the progression of disease and reduce premature mortality.

Evidence submitted to this inquiry unanimously called for earlier and accurate diagnosis. A staggering 13% of people over 35 have COPD,⁵⁵ but many are diagnosed late. Up to a third of people admitted to hospital with a COPD exacerbation have not been previously diagnosed.⁵⁶ A recent study of over 39,000 COPD patients also showed that more than half had symptoms for six to ten years before the diagnosis was made, and 42% had shown signs that might have been COPD between eleven and 15 years prior to finally being diagnosed.⁵⁷ Patients showing early symptoms of COPD and those at risk of developing the disease need to be screened using quality assured spirometry. This could also help to raise awareness of the early symptoms of lung disease.

“There is poor public health awareness about respiratory disease – it does not feature in health checks, for example. There are major TV campaigns for other diseases but not for respiratory.”

Association of Respiratory Nurse Specialists and the Royal College of Nursing

The NHS Health Check had been developed specifically to detect early symptoms of cardiovascular disease but it has since included other tests to cover stroke, dementia, diabetes and kidney disease. The test misses out checking lung health, despite large numbers of older people being long-term smokers. For example, 19% of 50-59 year olds and 13% of over 60s are current smokers⁵⁸ and therefore at a higher risk of lung disease. Furthermore, several studies have found that lung function testing is a good indicator of a person’s likelihood to die from a number of conditions other than respiratory.^{59,60} Introducing a spirometry element to the Health Check therefore not only has the potential to identify people with early onset lung disease, but also to strengthen the Health Check to make it much more effective at evaluating overall health.

Using spirometry for accurate diagnosis

In 2011, Hinchingsbrooke Health Care NHS Trust introduced a spirometry testing service to support primary care practices in the local area to make accurate respiratory diagnoses of their patients.⁶¹

An audit of services found that up to 30% of COPD patients referred on for a consultation into secondary care, could have been accurately diagnosed and managed in primary care. A spirometry service was set up to support GP practices which lacked the expertise to diagnose and manage respiratory patients.

The new service produced cost and efficiency savings: there was a reduction of 78% in unnecessary consultant appointments and a reduction in waiting times from eight weeks to one week.

Patients’ diagnosis accuracy also improved enormously, affecting their access to appropriate

treatments, such as referral to pulmonary rehabilitation (PR) programmes. COPD severity is categorised into five stages and access to PR is normally recommended for those with stage three and above.

As a result of introducing the spirometry testing service:

- 32% of patients had their diagnosis changed;
- 54% of patients were added to the COPD disease register;
- 20% had the severity of their COPD reclassified by one stage; and
- 38% had the severity of their COPD reclassified by two stages.

Case-finding spirometry using a hand-held device can be done by any healthcare professional to see whether lung function may be impaired. The Health Check should also feature questions to assess people for breathlessness. Together with case-finding spirometry, questions on breathlessness can assess the likelihood of COPD as well as a range of other respiratory conditions.

Recommendation

Public Health England should introduce a case-finding spirometry test component as part of the NHS Health Check for people aged 40-74.

The evidence submitted calls for a more targeted approach to the case-finding of COPD in primary care, so that the resources used in COPD management can be deployed much earlier in the COPD pathway, where interventions are less expensive and when they are more likely to prolong life. This was a major recommendation in the Outcomes Strategy for COPD and Asthma, but it needs sustained promotion and implementation to become embedded in routine practice. Although CCGs have overall responsibility for case-finding within their local populations, the tools to aid healthcare professionals to identify those at risk of COPD in their communities need to be developed so that they can be prioritised for use at a national level. Computer programmes such as GRASP COPD, have already been designed to help to identify those who may have COPD on the GP register, but these programmes have not been prioritised and incentivised for use nationally, so uptake is low.

Individuals at high risk of lung disease include current and past smokers, those over 35, those with a history of respiratory infection or a chronic cough, and those working in at-risk occupations. The success of local case-finding initiatives in London suggests that a sustained improvement in COPD diagnosis is possible in primary care and that such policies need to be implemented systematically.⁶²

Recommendation

Department of Health and NHS Improving Quality should design and prioritise for use targeted case-finding tools, which CCGs and practices could use to identify those who may have COPD within their local population.

Evidence-based treatments: smoking cessation

Evidence submitted to the inquiry re-affirmed the importance of quitting smoking as early as possible to improve survival rates of COPD patients. Quitting smoking in the early stages of the disease has been shown to halve the rate of decline in lung function.⁶³ Supporting a COPD patient to quit smoking can literally prolong their life. Supporting COPD patients to quit smoking should be regarded as a core intervention in the management of COPD. It is also considered an extremely effective intervention in terms of value for money, coming second only to flu vaccinations.⁶⁴

The harm caused by tobacco use is well-documented, but for COPD patients it is even more important that smoking is discontinued as part of the effective treatment of their condition. The smoking rate for those with a COPD diagnosis is much higher than the smoking rate of the general population. Over a third of patients with COPD continue to smoke,^{65,66} compared with 20% of the general population. However, studies also show that patients with a diagnosis of COPD are far more motivated to quit smoking than those people with normal lung function. Annual spirometry, smoking cessation advice and a letter from a physician have been shown to significantly increase quit rates at three years among smokers who have been diagnosed with COPD (25%) compared to smokers with normal lung function (7%).⁶⁷

This suggests that although interventions to support a patient with COPD to quit smoking are likely to be more successful, offers of smoking cessation are not being translated into referrals. Incentives should be used to encourage outcomes rather than processes for the referral of COPD patients to attend smoking cessation appointments. Giving up smoking can be incredibly difficult and this is why most people who successfully quit do so with help and support. For example, just over half (52%) of those setting a quit date in 2012/13 using NHS stop smoking services were able to quit successfully.⁶⁸

Recommendation

NHS England should prioritise the promotion of smoking cessation as an essential treatment for all people with COPD who smoke.

Evidence-based treatments: pulmonary rehabilitation

“Exercise programmes should be provided in the community to follow on for those who completed PR rather like those provided for heart patients. Instead, respiratory exercise sessions are often run and funded by the patient support groups.”

Malcolm Ginever,

Chair of Breathe Easy Nottingham

Patient groups responding to this inquiry have championed the transformative effect that pulmonary rehabilitation (PR) services have had on their daily well-being. PR is an eight-week programme designed to increase exercise tolerance and equip patients with a good understanding of their disease, through a combination of exercise classes and educational workshops. It is also an indispensable aspect of treatment for those with moderate and severe COPD, having been shown to be a cost-effective intervention in reducing hospital re-admission rates and improving quality of life for patients.⁶⁹ NHS England estimates that 260 lives could be saved per year from better access to this important service.⁷⁰

Despite published guidance from the Department of Health on when COPD patients should be given access to PR, availability and quality of these services remains patchy across the UK, with the Department of Health estimating full provision at only 58%.⁷¹ Furthermore, the National COPD Audit in 2008 found that only 15% of patients had participated in a PR programme in the previous twelve months.⁷² Access to timely PR services, which are easily accessible to patients, is essential to help patients maintain an active life and should be seen as a cost-saving and indispensable treatment by healthcare professionals and commissioners alike.

There is a specific improvement area in the CCG Outcomes Indicator Set to ensure that patients with COPD and a specified level of breathlessness should be referred to PR services. It is unclear how this can be achieved when there is such a variation in availability of services across the country and this presents a significant equity issue.

Only four patients need to take part in a course of PR to prevent one re-admission to hospital and the positive effects and increased exercise tolerance generally lasts for about a year.⁷³ There may even be a case for patients to gain access earlier to a PR programme. As the case study from Hinchingsbrooke demonstrates, many patients have the stage of their disease inaccurately assessed and therefore the level of breathlessness should be used to assess the need for PR, rather than just the recorded stage of disease. Patients who have already completed PR should be referred and supported to undertake long-term exercise classes to maintain the benefits achieved by attending a course of PR.

Recommendation

CCGs should invest in pulmonary rehabilitation services so that:

- **all patients with limiting breathlessness can access services within a month of referral;**
- **rapid access to pulmonary rehabilitation is available for COPD patients following discharge from hospital; and**
- **an NHS-funded long-term exercise programme is available following completion of pulmonary rehabilitation.**

Neil's story

Neil, 50 from Norwich, was continuously misdiagnosed by doctors despite being at high risk of lung disease and showing signs of the condition throughout his thirties. By the time he was finally diagnosed, he had lost most of his lung capacity.

Neil was a long-term smoker who for many years worked in cold and dusty conditions. When he was younger, Neil visited doctors regularly and had breathless attacks that sometimes required emergency treatment in hospital. However, he was never offered a lung function test by his doctor and felt that his smoking habit was used as a reason to dismiss his symptoms and not to investigate them any further.

At the age of 39, Neil finally managed to see a specialist in the hospital – however, his symptoms led doctors to think that he had asthma, and he was misdiagnosed. After a doctor told him the extent of scarring and damage already done to his lungs, Neil quit smoking completely on the same day. He also cut out some of the work, like welding and painting, which contributed to his poor lung health.

Five years ago, Neil developed two bouts of pneumonia. His health deteriorated – he felt constantly breathless and could barely walk 50 feet. Even at this stage, Neil was not given a lung function test or information about how to manage his condition; instead he was told that he could expect to recover. Soon, he was forced to give up work completely, and was increasingly cared for by his partner, Wendy. He was largely inactive for the next year and his condition deteriorated after a series of chest infections.

Eventually, a doctor told Neil that he had COPD. He had lost a staggering 70% of his lung function before it was even tested. Neil was able to speak about his condition with a specialist nurse at his local surgery, who seemed to be the first person to care and want to help him personally.

“The benefits of exercise cannot be understated and when I talk to people about my illness no one has heard of COPD – it seems that even the GPs don't understand the importance of early diagnosis and intervention.”

The doctor sent Neil to attend pulmonary rehabilitation sessions, which was run by a team of dedicated people. It was the first time in many years he really felt that he was getting better. The eight week programme was life changing, having a positive effect on Neil's ability to get around and do everyday tasks.

He also joined his local Breathe Easy support group, which brought patients together with healthcare professionals. Here, Neil was given information about his condition and ways to alleviate his symptoms.

Neil feels much better now than he did five years ago, and continues to help out at his local Breathe Easy group as much as he can. The social aspect of the group keeps everybody going but really the information is the treatment – everyone that joins the group can become a respiratory expert, he says.

Evidence-based treatments: oxygen therapy

“The Government and the NHS in England need to ensure that severely affected patients are adequately supported. For example, long-term oxygen therapy can double survival in hypoxemic COPD patients.”

Dr Gary Ruiz, Consultant Respiratory Paediatrician at King's College Hospital

Oxygen therapy has been highlighted as another important intervention with the potential to extend life in of those with COPD. This treatment involves the administration of oxygen at concentrations greater than that in ambient air with the intent of treating or preventing the symptoms and manifestations of hypoxia – low levels of oxygen in the blood. In hypoxic COPD patients, long-term oxygen therapy can improve survival rates by around 40%.⁷⁴ Whilst oxygen therapy can significantly prolong life for hypoxic COPD patients, it can also cause damage for others if overused.

Official figures suggest that home oxygen therapy is provided to around 85,000 people in England at a cost of approximately £110 million each year.⁷⁵ Yet between 24% and 43% of the oxygen that is prescribed to these patients is not used or confers no clinical benefit.⁷⁶ Conversely, a fifth of people with COPD would benefit from home oxygen therapy but do not currently receive it.⁷⁷

A formal assessment for oxygen therapy needs to be made by a respiratory specialist, who will not only base the prescription on individual clinical need for oxygen but also take into account the patient's lifestyle and personal circumstances.

A third of COPD patients report using oxygen at home,⁷⁸ yet many clinical commissioners do not commission quality-assured clinical assessment and review of their patients' need for long-term home oxygen, increasing the potential for poor quality and waste.⁷⁹ There have been some recent examples of good practice with regards to home oxygen prescribing,⁸⁰ however no recent national data has been published to assess how this has been adopted in all areas. The introduction of a

Home Oxygen Assessment and Review Service across all CCGs would reduce costs and ensure consistency, as well as improving quality of life for patients.

Recommendation

CCGs should undertake a regular review of all COPD patients regarding their need for oxygen and refer on to an appropriate assessment centre to ensure that a personalised plan is put together for those requiring long-term oxygen use, as per NICE guidance.

Self-management and access to expert care

Supporting self-management in patients with COPD involves equipping a patient with safe and accurate information and guidance. This may reduce the rate of disease progression; improve recovery time following an exacerbation; and promote independence and quality of life. An individualised self-management plan, together with evidence-based treatments, can also improve mortality rates.

Time with healthcare professionals is important to ensure patients are equipped with the knowledge to manage their condition. For example, prompt treatment at the onset of exacerbated symptoms can result in less lung damage, faster recovery and fewer admissions and readmissions to hospital.⁸¹ A patient with better knowledge of how to recognise early symptoms of an exacerbation, and with a plan on what to do early on, can therefore maintain better overall health. Community-based respiratory teams may be best placed to intervene in cases of poor management and provide support following discharge from hospital. Unfortunately, no national assessment of access to community-based teams has been done and it is unknown whether similar levels of support exist for very sick patients in different areas. PR programmes are also a key component for delivering self-management support, due to the educational aspects of the eight-week course and the length of time spent with a healthcare professional.

A regular review and assessment of the progression of COPD and regular testing of lung function is just as important as the initial diagnosis in determining appropriate management to improve the patient's quality and length of life. Breathlessness is a chronic

symptom of COPD but primary care professionals need to be vigilant so that, for any worsening in breathlessness, other possible causes are also investigated.

“There is a lack of a whole systems approach to COPD management. COPD is not just a disease of the lungs but has multiple medical and psychological co-morbidities.”

Royal College of General Practitioners

Four out of five people with COPD are reported to have at least one other long-term condition, which includes cardiovascular disease, depression and anxiety disorder.⁸² Effective management of co-morbidities is important in managing overall health and wellbeing for COPD patients.

The NHS business plan 2014/15–2016/17 includes a commitment to developing a self-management guide for people with complex care needs. This is highly appropriate for people with COPD, many of whom have several co-morbidities.

As part of the plan to improve supported self-management, the following should be considered by CCGs: longer appointment times, training of primary care staff in motivational techniques and management of multiple co-morbidities, production of high quality written plans, and a regular review process.

“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.”

British Thoracic Society

Although most COPD patients are managed exclusively in primary care, very sick patients at high risk of premature death need to be referred onto specialist care. Regular monitoring of the progression of COPD needs to include consideration of referral onto specialist care if the patient is experiencing frequent exacerbations, rapid progression, or early onset disease which may have a genetic component. Sleep disordered breathing and evaluation for possible lung volume reduction surgery also need assessment by a respiratory specialist.

Recommendation

CCGs should develop specific plans to ensure that:

- **all patients with COPD are appropriately supported to manage their condition; and**
- **all high-risk patients with COPD are identified and have appropriate access to expert care.**

ACKNOWLEDGMENTS

46 pieces of written evidence were received and eight witnesses gave oral evidence.

Witnesses providing oral evidence to the inquiry:

Kay Boycott, Chief Executive, Asthma UK

Mike Heaphy lost his wife to COPD and provided a patient and carer perspective

Dr Mark Levy, Clinical Lead on the National Review of Asthma Deaths

Prof Mike Morgan, National Clinical Director for Respiratory, NHS England

Claire O'Beirne lost her son to asthma and provided a patient and carer perspective

Prof Mike Roberts, Clinical Lead for the COPD Audit programme

Prof David Strachan, Professor of Epidemiology at St George's, University of London

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Organisations providing written evidence to this inquiry:

Association of Respiratory Nurse Specialists

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British Thoracic Society

Education for Health

GlaxoSmithKline

London Respiratory Clinical Leadership Group

NHS England

Royal College of General Practitioners

Royal College of Nursing

Royal College of Paediatrics and Child Health

Royal College of Pathologists

Royal College of Physicians

Royal Pharmaceutical Society

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Susan Spence, Community COPD Specialist Nurse, South Tees NHS Trust

Prof Mike Thomas, Professor of Primary Care Research, University of Southampton

Prof John Warner, Professor of Paediatrics, Imperial College London

Dr Robert Wilson, Consultant Physician and Head of Lung Division, Royal Brompton

Stephanie Wolfe, Respiratory Nurse Specialist

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Malcolm Ginever (Breathe Easy Nottingham)

Doug Hardy

Tessa Jelen (Breathe Easy Paddington)

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GLOSSARY

The Audit	The National COPD Audit
BE	Breathe Easy support group, run by British Lung Foundation
BTS	British Thoracic Society
CCGs	Clinical Commissioning Groups
CCG OIS	CCG outcomes indicator set
COPD	Chronic obstructive pulmonary disease
CQC	Care Quality Commission
CQUIN	Commissioning for Quality and Innovation
Eastern region enquiry	Eastern region confidential enquiry into asthma deaths
HEE	Health Education England
IPF	Idiopathic pulmonary fibrosis
LABAs	Long acting beta agonists
MINAP	Myocardial Infarction National Audit Project
MRC	Medical Research Council
The National Review	The National Review of Asthma Deaths May 2014, Royal College of Physicians
NHS IQ	NHS Improving Quality
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
PHE	Public Health England
PR	Pulmonary rehabilitation
QOF	Quality and Outcomes Framework
SCN	Strategic clinical network
The Strategy	The Outcomes Strategy for COPD and Asthma 2011, Department of Health

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