

# Consultation on a Strategy for Services for Chronic Obstructive Pulmonary Disease (COPD) in England

## DH INFORMATION READER BOX

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<b>For recipient's use</b>	

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# Foreword by Secretary of State for Health

The journey of care is often complex, and services must be tailored at a local level. Sometimes, however, it is right for the NHS to take stock, to consider whether more could be done to make a positive impact on the lives of people who have a long-term condition such as chronic obstructive pulmonary disease (COPD) or asthma. This is done by drawing together evidence at a national level, mapping existing services to understand where improvements can be made and identifying interventions that produce enhanced models of service provision and care.

Since 2005 the Department of Health, the NHS and other key stakeholders have been working together to identify the best ways to improve care and outcomes for those with COPD and to reduce the overall prevalence of the disease.

We estimate that over 3 million people in England live with this condition. Most of us will know someone who has it. The harsh reality is that one person dies in England and Wales from COPD every 20 minutes – a loss of about 25,000 lives every year. COPD is also the second most common cause of emergency admission to hospital and the fifth largest cause of readmission to hospital. It is also one of the most costly diseases, in terms of acute hospital care.

It has therefore become clear that we need to change our approach to prevention, diagnosis and treatment. As we developed the strategy outlined in this consultation document, we had extensive engagement



with people with COPD and their carers working in our External Reference Group. They have told us that, among other things, they want an accurate diagnosis. They want to understand how they can best manage their condition and would like to see services and treatment available closer to home. In addition, clinicians have made it clear that there is scope to improve the efficiency of services as well as the quality. We also want to make sure that the general public understand the benefits of good lung health, know how to prevent damage to the lung that can lead to chronic disability, and maintain an ability to work and to enjoy everyday activities that most of us take for granted.

This strategy proposes how best we think those objectives can be achieved. It offers a real opportunity to make a difference, although we recognise that significant challenges lie ahead. Successful implementation will require ongoing commitment and ambition and the engagement and involvement of all stakeholders.

The strategy does not define how each aspect of care should be delivered. We think services need to be sensitively planned and appropriately delivered in response to the needs of each local community. However, it is designed to support local service plans within the NHS, and to complement other related national and local initiatives. These include the clinical guidelines developed by the National Institute for Health and Clinical Excellence (NICE) and other broader health promotion initiatives such as the national tobacco control programme. With better-co-ordinated and integrated services, we can provide care that better meets the complex needs of people with COPD and meets their expectations.

Because of the magnitude of the burden of asthma, we have given separate attention to that condition within this strategy, highlighting where there are synergies in the approach to the care of these conditions and where there are differences. The chapter on asthma also highlights some aspects of good asthma services.

The next step is for you to add your views to the debate.

A handwritten signature in black ink that reads "Andy Bannan". The signature is written in a cursive, slightly slanted style.

# Preface by Professor Sue Hill and Dr Robert Winter

Joint National Clinical Directors for the respiratory programme

**This consultative document marks an important milestone in lung disease and for people living with COPD. It signals a commitment to improving lung health and reducing the burden of lung disease as well as to providing high-quality care that is safe, effective and responsive to the needs of individuals in streamlined services that are delivered closer to home.**

We would like to express a huge thank you to all those people who have worked on developing the national strategy for COPD. There has

been a significant and constructive engagement with a wide range of stakeholders. In particular, we would like to thank all those people with COPD and their carers and relatives. Without their insight and support, we would not have been able to develop this strategy to meet their needs. We would specifically like to thank the External Reference Group for their time and expert input, and Professor Peter Calverley, who jointly chaired the External Reference Group.

We would also like to thank those people with asthma who have engaged in the programme, and Professor Martyn Partridge, and Asthma UK, for supporting the development of the chapter on asthma.





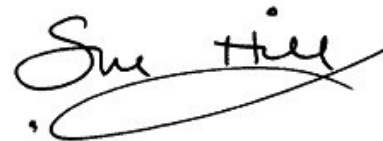
This strategy is intended to help:

- reduce the risk of developing COPD by improving prevention and health promotion initiatives;
- identify those people with COPD or at risk of developing COPD as early as possible;
- ensure accurate diagnosis, evidence-based treatment, proactive management and regular review through an integrated care pathway that provides the right care in the right place for the right person and that includes comprehensive community-based services, where most people are cared for;
- ensure better support for people with COPD and their carers, so that they become active partners in their care;
- provide the best support and treatment in periods when the condition worsens, through the integration of services and care across the primary, secondary and tertiary sectors, in the NHS and social care;
- provide access to the best available support for those who are at the end of life and for those who are bereaved.

This strategy requires all those working in health and social care to

break down existing barriers and be true partners in the prevention of COPD and in the identification and care of people with the disease.

Success will require joint planning and working between commissioners and providers, professional groups, the third sector and people with COPD and their carers. Its success will also depend on clinical leadership and engagement to develop local ownership and a shared sense of purpose. This strategy will then become a reality for people with COPD.



**Professor Sue Hill**  
**Chief Scientific Officer**  
**Department of Health**  
**National Clinical Director**



**Dr Robert Winter**  
**Medical Director**  
**East of England SHA**  
**National Clinical Director**



# Guidance on consultation and consultation questions

## The consultation document

1. This document has seven chapters. Each chapter has a similar structure: setting out the case for change, and giving recommendations and supporting rationale.
2. The consultation document is accompanied by a Consultation Impact Assessment and a draft Equality Impact Assessment as separate documents. Full impact assessments will accompany the finalised strategy. These will be available at: [www.dh.gov.uk/en/Consultations/index.htm](http://www.dh.gov.uk/en/Consultations/index.htm)
3. The Department is inviting all interested stakeholders to comment on the contents of this document before it is published in final form.

## The consultation process

### Criteria for consultation

4. This consultation follows the Government's Code of Practice. In particular, we aim to:

- formally consult at a stage where there is scope to influence the policy outcome;
- consult for at least 12 weeks<sup>†</sup> where possible and with consideration give longer timescales where feasible and sensible;
- be clear in the consultation documents about the consultation process, what is being proposed, the scope to influence and the expected costs and benefits of the proposals;
- ensure that the consultation exercise is designed to be accessible to, and clearly targeted at, those people it is intended to reach;
- keep the burden of consultation to a minimum to ensure that consultations are effective and to obtain consultees' 'buy-in' to the process;
- analyse responses carefully and give clear feedback to participants following the consultation; and
- ensure that officials running consultations are guided in how to run an effective consultation exercise and share what they learn from the experience.

5. The full text of the code of practice is on the Better Regulation website at: [www.berr.gov.uk/files/file47158.pdf](http://www.berr.gov.uk/files/file47158.pdf)

#### **Comments on the consultation process itself**

6. If you have concerns or comments that you would like to make relating specifically to the consultation process itself, please contact:

Consultations Co-ordinator

Department of Health

3E48 Quarry House

Leeds LS2 7UE

email: [consultations.co-ordinator@dh.gsi.gov.uk](mailto:consultations.co-ordinator@dh.gsi.gov.uk)

**Please do not send consultation responses to this address.**

#### **Freedom of information**

7. We manage the information you provide in response to this consultation in accordance with the Department of Health's **Information Charter**.
8. Information provided in response to this consultation, including personal information, may be published or disclosed in accordance with the access to information regimes. The relevant legislation in this context is the Freedom of Information Act 2000 (FOIA) and the Data Protection Act 1998 (DPA).
9. If you want the information that you provide to be treated as confidential, please be aware that, under the FOIA, there is a statutory Code of Practice with which public authorities must

comply and which deals, among other things, with obligations of confidence. In view of this, it would be helpful if you could explain to us why you regard the information you have provided as confidential. If we receive a request for disclosure of the information we will take full account of your explanation, but we cannot give an assurance that confidentiality can be maintained in all circumstances. An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department of Health.

10. The Department of Health will process your personal data in accordance with the DPA and in most circumstances this will mean that your personal data will not be disclosed to third parties. However, the information you send us may need to be passed on to colleagues within the UK Health Departments and/or published in a summary of responses to this consultation.

#### **Summary of the consultation**

11. A summary of the response to this consultation will be made available before or alongside any further action, such as laying legislation before Parliament, and will be placed on the Consultations website at: [www.dh.gov.uk/en/Consultations/Responsestoconsultations/index.htm](http://www.dh.gov.uk/en/Consultations/Responsestoconsultations/index.htm)

#### **Timetable**

12. The consultation runs from the 24 February 2010 to 6 April 2010. Details of how to respond are at Appendix 8. We will use

responses to inform the final development of the strategy for COPD. This document can also be obtained from the Department of Health's website: [www.dh.gov.uk/en/Consultations/index.htm](http://www.dh.gov.uk/en/Consultations/index.htm)

### List of consultation questions

1. Do you believe this strategy will improve the lives of people with COPD?
2. Do you feel the specific recommendations are the best way to make this positive difference?
3. What one thing would you most want **to change** about the current provision of **health and social care services** for people with COPD?
4. What one thing would you most want **to keep** about the current provision of **health and social care services** for people with COPD?
5. Do you have confidence that this strategy will make a positive difference for people with asthma?
6. What one thing would you most want **to change** about the current provision of **health and social care services** for people with asthma?
7. What one thing would you most want **to keep** about the current provision of **health and social care services** for people with asthma?
8. Do you feel this strategy will help everyone with COPD or asthma to get the best care regardless of their age, sex, ethnicity, religion and beliefs, disability or sexual orientation?
9. Is there anything more that should be done to improve the strategy's effect on the equality and diversity issues of age, sex, ethnicity, religion and beliefs, disability and sexual orientation?
10. What more could be done to increase the benefits and/or decrease the costs of the recommendations in the strategy?
11. Do you feel we have identified the main similarities and differences between COPD and adult asthma?
12. Is there anything you, or your organisation, could do to help us implement the strategy?
13. Are there gaps in the knowledge about how to diagnose and manage COPD and asthma that could be filled by research in order to deliver better services?
14. Is there anything else you think would improve the quality and productivity of services for people with COPD and asthma?
15. Do you have any other comments?



# Executive summary

## Aim of the strategy

13. The aim of the strategy is to advise how local communities can prevent people getting COPD, understand the risks of having poor lung health, secure improvements to the diagnosis of, and care of people with, the disease, and reduce health inequalities. We want to support people with COPD and their carers by offering practical advice and education on managing their disease. Our aim is to ensure that everyone diagnosed with COPD receives equitable, responsive, high-quality and effective health and social care services from the right person, at the right time, in the right place, that are effective and provide good value for money for taxpayers.

## The issue

14. As outlined later in this strategy, recent reports and research have highlighted the issues in relation to the current provision of COPD services in England. COPD presents a huge challenge to society, both now and in the future. Approximately 835,000 people in England have been diagnosed with COPD;<sup>1</sup> however, we estimate that over 3 million people have the disease. The harsh reality is that one person dies every 20 minutes from

COPD in England and Wales, about 25,000 people a year.<sup>2</sup> Many live with the condition, which contributes to the economic burden of COPD associated with long-term medical management and disability-related costs. The direct cost of COPD to the UK healthcare system is estimated to be between £810 million and £930 million a year;<sup>3</sup> and without change, this impact is set to grow.

15. This strategy seeks to help prevent people getting COPD. In particular, it seeks to help the NHS to:
  - identify people with COPD earlier in the course of the disease – an estimated 2 million people have COPD that remains undiagnosed, and those cases that are diagnosed are mainly moderate to severe disease;
  - improve diagnosis for COPD – there are also significant numbers of misdiagnosis;
  - develop structured care appropriate to people's needs, focusing on accurate and earlier diagnosis and the provision of structured care;
  - help people manage their condition themselves by way of structured exercise and education, which have been shown to have a direct impact on people's lives;

- reduce the number of people admitted to hospital. Between 1991 and 2001, age-adjusted rates of admission for COPD rose by 50%, and rates of readmission vary by up to five times in different parts of England;
  - address the poor prognosis for people with COPD, as on average 15% of those admitted to hospital die within three months, and around 25% die within a year of admission; and
  - improve access to end-of-life care for people with COPD.
16. Because of the magnitude of the burden of asthma, we have given separate attention to that condition within this strategy, highlighting where there are synergies in the approach to the care of these conditions and where there are differences. We also highlight some aspects of good asthma services.

## The strategy's objectives

17. The key objectives of the strategy, addressed in more detail in this document, are as follows:
- **Objective 1:** The two over-arching objectives for the first part of the strategy are:
  - **Prevention** – so that people make healthy choices about their life and thus reduce their chances of getting lung disease. Our work in this part of the strategy will focus on behaviours that

support or lead to smoking cessation and other forms of risk-reducing behaviour.

- **Supporting early identification** – so that people recognise the symptoms of lung disease and seek assessment and advice from healthcare professionals. Early identification is identified in more detail in Chapter 3 and, as outlined in the Consultation Impact Assessment, it can bring significant longer-term health and economic benefits.
- **Objective 2: Good-quality early diagnosis** – so that people get an accurate, quality assured, diagnosis and there is clear differentiation of COPD from asthma and other diseases. When diagnosed, people get good-quality information on the illness and on the services available, both at diagnosis and throughout the course of their care.
- **Objective 3: High-quality care and support following diagnosis** – by developing an organised, proactive, multidisciplinary approach to the management of COPD, including both chronic and acute care. Where admitted to hospital, specialist respiratory assessment on referral will ensure that people with COPD are dealt with in a pathway that is most appropriate to meet their clinical needs.
- **Objective 4: Improving access to end-of-life care services** – improving access to high-quality end-of-life care services and ensuring equity in care provision for people with severe COPD, regardless of setting.

## Implementation

18. In accordance with the drive to devolve responsibility for NHS services to local organisations, this strategy lays great emphasis on local health and social care communities and the third sector taking responsibility for contributing to service change and improvement. The public expects appropriate, integrated services planned and delivered around individual needs, from diagnosis to end of life. This strategy reviews the case for change and describes the good practice that is already taking place in the NHS to deliver good COPD services.
19. It does not set national targets or milestones, but points out where we can expect the NHS to realise efficiency savings in their efforts to improve services. While some elements of the strategy could ultimately require primary care trusts (PCTs) to re-prioritise resources in order to make funding available, this will be clarified once the impact assessment is finalised after the consultation. The final impact assessment will contain a much more robust indication of any additional costs or further savings for the NHS.
20. The Department of Health also has a role to play by developing tools, harnessing expertise and giving advice where appropriate on wider policy contexts. For this reason the strategy also describes how (subject to available funding) the Department of Health will take action to support the improvement of services for people with COPD. Given that Sir David Nicholson

challenged the NHS to prepare for a range of scenarios, including generating £15–£20 billion in efficiency savings from existing NHS resources over the three-year period from April 2011, it is imperative that the NHS makes better provision of services for people with COPD now. This includes taking forward a programme of work looking to support quality and productivity in certain long-term conditions, which is being led by Sir John Oldham.

21. Any guidance from outside agencies or bodies set out in the strategy is endorsed on the basis that it is considered best practice.

## What will the strategy mean for people with COPD and their carers?

22. Full implementation of the strategy will mean that all people with COPD and those who care for them would have the best possible healthcare and support. We know that early diagnosis, effective intervention and support from diagnosis through the course of the illness can enable people to live well with COPD. We also know that improving health and social care outcomes in COPD in the short and medium term can have significant benefits for society, both now and in the future.



# Introduction

A large dandelion seed head is the central focus in the lower-left foreground, standing tall in a lush green field. Several dandelion seeds are captured in mid-air, blowing away from the seed head towards the upper right. The background is a vibrant blue sky filled with soft, white, wispy clouds. The overall scene is bright and airy, suggesting a clear, sunny day.

## Overview

23. Chronic obstructive pulmonary disease (COPD) is an umbrella term adopted across the world since the early 1960s to describe a group of conditions that may be better known by the public as chronic bronchitis or emphysema. Because of the similarities in the symptoms and magnitude of the burden of asthma, we have also included a chapter on the condition within this document.
24. The main symptoms of COPD are shortness of breath and reduced exercise ability, together with a cough and production of phlegm that may get worse at certain times over the course of a year.
25. There is no doubt about the current and future challenges posed by COPD, and the need for concerted action.<sup>4</sup> Many live with the condition, which contributes to the economic burden of COPD associated with long-term medical management and disability-related costs.
26. Links have been established between deprivation and behavioural factors known to affect health, which have important relationships with COPD. Smoking is the single most important and preventable cause of avoidable ill health and premature death in England. In 2008, over 80,000 deaths in those aged over 35 (18%) were attributable to smoking.<sup>5</sup> Smoking is far and away the most important cause of COPD and stopping smoking plays a key part in reducing risk. However, simply increasing the numbers of people who avoid tobacco or quit smoking is not enough to address the problem of COPD.
27. COPD describes lung damage that is gradual in onset and results in progressive airflow limitation. When fully established, this lung damage is irreversible, leading to disability and eventually death, if it is not identified and treated early.
28. Even if everyone diagnosed with COPD who smokes gave up immediately, their lungs could not be repaired and, in some, lung damage would continue with the progression of the disease.
29. There is clear evidence that early identification of COPD, and effective treatment and intervention, benefits people and lightens the burden of their care. An improved understanding of the risks of COPD and early management of its symptoms will, over time, enable the natural history of the disease in a population to be changed and a preventive and more holistic approach to care to be taken.

## Purpose and scope of this document

30. The NHS, the Department of Health and key stakeholders have worked together since 2005 to develop a strategy for services for COPD in England. The range of stakeholders has included people with COPD and their carers, health and social care professionals, health managers, commissioners, and the private and third sectors.

31. This strategy reviews the case for change and describes current good practice based on published evidence, whenever available. In accordance with the drive to devolve responsibility for the NHS to local organisations based on local needs, we are laying great emphasis on local health and social care communities, and voluntary and professional organisations, taking responsibility for leading and contributing to service change and improvement.
  32. Success in delivery is dependent on the use of appropriate preventive strategies, and on integrated services planned and delivered around individual needs from maintaining health and well-being to diagnosis and eventually to end of life. It is largely up to the NHS and the public to ensure that change occurs, although the Government has a role to play in supporting the development of tools, encouraging and spreading good practice and scientific and technological advances, and harnessing expertise.
- ### Quality and productivity challenge
33. Alongside the commitment to increase frontline NHS funding in line with inflation, we have also set out the quality and productivity challenge the NHS needs to meet. Demand for services is increasing and there are areas where we could increase the quality, efficiency and value for money of services, as well as improve outcomes for people with the disease. *High Quality Care for All* (the Next Stage Review of the NHS, published in 2008) and the local visions developed by strategic health authorities (SHAs) that accompanied it set an ambitious goal of putting quality at the heart of the NHS by making it its organising principle.
  34. As the NHS Chief Executive has set out, we are required to deliver £15–£20 billion in efficiency savings over the three-year period from 2011. We therefore need to use our growth in 2010/11 to put into effect the changes that we know will deliver the most benefits to patients in the future. This will be tough, but it is possible. We need a relentless focus on three things to make this possible: first, improving quality while improving productivity, using innovation and prevention to drive and connect them; second, having local clinicians and managers working together across boundaries to spot the opportunities and manage the change; and third, to act now for the benefit of the long term.
  35. The challenge is therefore to ensure that we continue to provide high-quality services during a period in which growth in expenditure on the NHS will be restricted despite increased demand.
  36. Many of the measures recommended in the strategy are designed to support the NHS to meet the quality and productivity challenge, either by identifying where resources might be released or by improving understanding of the key interventions that have greatest effect.

37. A phased approach to implementation of the recommendations in the strategy, and ensuring appropriate management of those with moderate and severe COPD, will mean ensuring that those people whose COPD has already been diagnosed have a correct diagnosis, and are managed according to the most cost-effective and evidence-based interventions. More specifically, this will be ensured by taking action to:
- review those people who are on both the COPD and asthma registers;
  - review home oxygen registers; and
  - work with NHS Improvement, as part of their Lung Programme, to:
    - reduce the number of hospital admissions for COPD;
    - reduce length of stay for people with COPD, where appropriate;
    - develop cost-effective models of chronic disease management by the introduction of regular review, use of care plans and secondary prevention for those with COPD; and
    - reduce admission rates for asthma to at least the current national average.
38. In future years, implementation will include reviewing all those on the GP-held registers with COPD and asthma, developing wider programmes of prevention and identification to ensure the long-term sustainability of services by stopping people getting COPD, and finding those people who have the milder stage of COPD to stop them progressing in severity.
39. In five years' time, the NHS will need to have more services closer to home. There will need to be much less variation, with defined National Institute for Health and Clinical Excellence (NICE) quality standards and patient pathways. Some of this will require new ways of organising services to deliver care. Convenience for the system too often takes precedence over convenience for people with COPD and asthma. There is still too much variation in the quality and safety of care. Too much care is organised in hospitals, which best practice shows could be better organised in community settings. Care provided by different professionals and organisations also needs to be better integrated around people with COPD and asthma.
40. Because of the magnitude of the burden of asthma we have also included a chapter on the condition within the national strategy for COPD. This chapter highlights where there are synergies in the approach to the diagnosis and care of these two conditions and where there are differences. We will also undertake further work to determine where, out of the estimated £1 billion of expenditure on asthma, further efficiencies could be made.
- Our aim**
41. We want to advise how local communities can prevent people getting COPD, understand the risks of having poor lung health,



secure improvements to the diagnosis of, and care of people with, the disease, and reduce health inequalities. We want to support people with COPD and their carers by offering practical advice and education on managing their disease. Our aim is to ensure that everyone diagnosed with COPD receives equitable, responsive, high-quality and effective provision of health and social care services from the right person, at the right time, in the right place, that are effective and provide good value for money for taxpayers.

42. We also want to provide advice and support for commissioners, hospitals, general practice, PCTs and SHAs. All these constituent parts of the NHS must deliver services for COPD while planning, developing and monitoring services against the backdrop of *High Quality Care for All* and the associated work of the SHA clinical pathway groups.
43. The finalised strategy needs to be:
  - consistent with latest evidence, where it exists, or with consensus by national and international experts;
  - consistent with other clinical strategies and existing national service frameworks;
  - integrated across health sectors and with social care;
  - based around individual needs of people with COPD and their families and carers;

- addressing health inequalities and improving outcomes for people with COPD and their carers;
- utilised to support and promote the importance of good lung health and well-being; and
- cost effective.

## The case for a strategy in England

44. In England there has been a growing recognition of respiratory disease as a challenge to public services. In 2001, the British Thoracic Society report *The burden of lung disease*<sup>6</sup> was one of the first documents to point out the high levels of respiratory disease in this country and its potential impact.
45. The British Lung Foundation, which has long been campaigning for people with COPD, recently launched a campaign to help find the 'missing millions' with COPD and called on government to make COPD a national priority.
46. The Chief Medical Officer focused on smoking in his annual reports for 2002 and 2003. In his annual report for 2004, *It takes your breath away*,<sup>7</sup> he made a number of recommendations, including the need for a more accurate diagnosis (through an improvement in the standards of spirometry) and more structured care for people with COPD. At the same time he also commissioned a strategic scoping review of lung and respiratory

disease. This then led to the decision to take national action on these conditions.

47. The NHS already has some guidance available through the National Service Framework for long-term conditions (2005).<sup>8</sup> This sets out a range of quality requirements and key priorities that can be applied to people with COPD and other respiratory conditions. However, as the report by the Healthcare Commission, *Clearing the air*,<sup>9</sup> highlighted, there remained a need for PCTs and the NHS in general to:

- improve diagnosis for COPD – an estimated 2 million people have COPD that remains undiagnosed and there are also significant numbers of misdiagnosis;
- develop structured care appropriate to people's needs, focusing on accurate and earlier diagnosis and the provision of structured care;
- help people manage their condition themselves by way of structured exercise and education, which have been shown to have a direct impact on people's lives;
- reduce the number of people admitted to hospital. Between 1991 and 2001 age-adjusted rates of admission for COPD rose by 50%, and rates of readmission vary by up to five times in different parts of England;
- address the poor prognosis for people with COPD, as on average 15% of those admitted to hospital with COPD die within three months, and around 25% die within a year of admission; and

- improve access to end-of-life care for people with COPD.

48. This strategy seeks to help the NHS address all of these concerns.

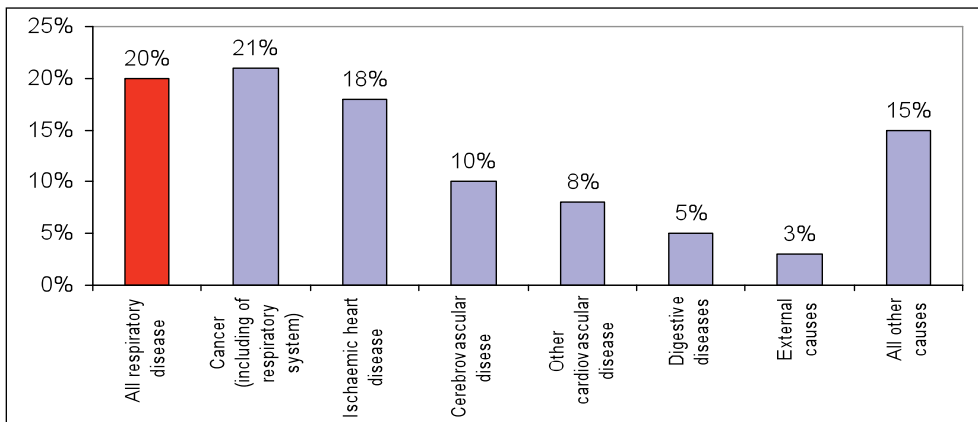
## The social and economic cost of COPD

49. COPD is a progressive illness, and the number of people dying as a result of COPD increases with age. Above all COPD is disabling. Although it affects people in different ways, those with COPD often have breathlessness, reduced exercise tolerance, a cough and repeated chest infections.

50. Approximately 835,000 people in England have been diagnosed with COPD;<sup>10</sup> however, we estimate that over 3 million people have the disease. Of the estimated 2 million who have undiagnosed COPD, it is estimated that 5.5% will have it at the mild end of the spectrum.<sup>11</sup>

51. COPD causes more than 25,000 deaths a year in England and Wales. Data from the World Health Organization (WHO) shows that death rates from diseases of the respiratory system in the UK are higher than both the European average and the European Union (EU) average. This difference is particularly marked for females: death rates from respiratory disease for females in the UK are about three times higher than those for females in France and Italy.<sup>12</sup> COPD is expected to be the third leading cause of death worldwide by 2030.<sup>13</sup>

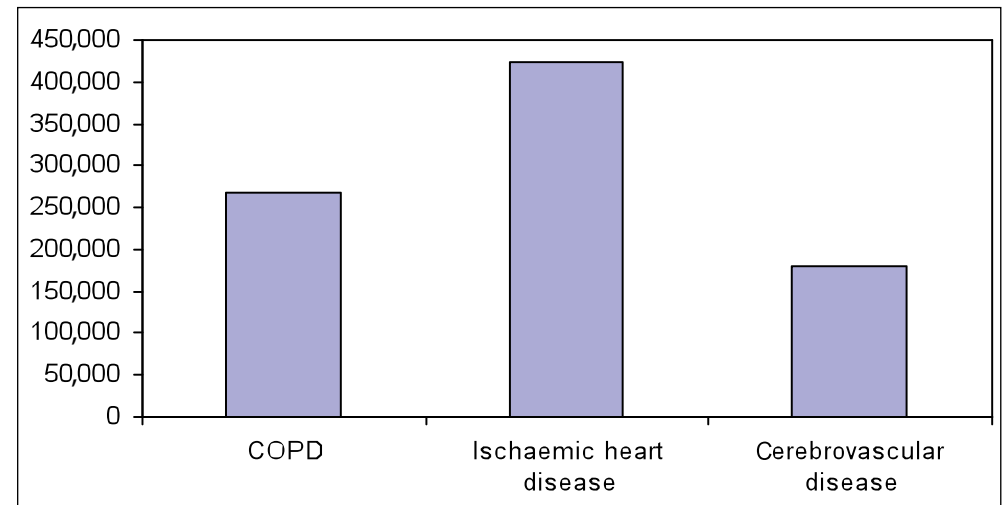
**Figure 1: Percentage of deaths attributable to respiratory disease**



Source: Hospital Episode Statistics

- 52. At present there is a lot of treatment taking place in secondary care. Hospital admissions make up a significant part of the direct costs, as does the drugs bill and the number of consultations in primary care.
- 53. The median length of stay in 2008 was five days, compared with six days in 2003. There has been an increase from 26% to 34% in the proportion of people having a stay of three days at most since 2003. Although the length of stay in hospital is generally decreasing, the percentage of people with a main diagnosis of COPD readmitted to hospital within 28 days of being discharged is increasing. The readmission rate in 2008 was 33%, up from 31% in 2003. The median time to readmission was 38 days.<sup>14</sup>

**Figure 2: Admissions to hospital by condition, 2007/08**



Source: Hospital Episode Statistics

- 54. The profile of COPD means that it is an expensive disease for the NHS when it is not identified and treated early. The direct cost of COPD to the UK healthcare system is estimated to be between £810 million and £930 million a year;<sup>15</sup> and without change this impact is set to grow.
- 55. There is a broader economic cost. The annual cost of COPD-related lost productivity to employers and the economy has been put at £3.8 billion. Some 25% of people with COPD are prevented from working due to the disease. COPD causes at least 20.4 million lost working days among men and 3.5 million days among women every year – more than any other respiratory condition.<sup>16</sup>



56. In addition there is a social cost. Quality of life is undermined. Problems with restricted mobility may be compounded by social isolation and the psychological conditions that go with it. A survey by the British Lung Foundation found that 90% of people with severe COPD were unable to participate in socially important activities such as gardening, 66% were unable to take a holiday because of their disease and 33% had disabling breathlessness.
59. Membership of the sub-groups are attached at Appendix 2. Other groups have met to support the development of the strategy, including those looking at pulmonary rehabilitation and non-invasive ventilation.
60. A wide range of stakeholders was represented on these groups, including those from health and social care, voluntary organisations, people with COPD and their carers, industry and other professional groups. The emerging recommendations from the ERG and the sub-groups have been tested in stakeholder workshops and regional listening events.

## How the strategy has been developed

57. This strategy has been developed by the NHS and its stakeholders over a three-year period, working collaboratively under the auspices of the Department of Health and an External Reference Group (ERG) (see Appendix 1 for membership).
58. The ERG formed six sub-groups, which looked at:
- patient-focused outcomes;
  - prevention and awareness raising;
  - screening, detection and diagnosis;
  - chronic care and end-of-life care;
  - acute care; and
  - management of medicines.
61. There has been involvement of pharmaceutical and medical device companies in the development of the strategy through two forums run by the British Lung Foundation and funded by GlaxoSmithKline. The pharmaceutical companies with an interest in COPD have all taken part, including those with new treatments in the pipeline. The Association of the British Pharmaceutical Industry has also participated in this forum, as has the medical device companies' trade association BAREMA. Issues around training and testing have been foremost in these discussions and all the members have been encouraged to provide information and research findings to the Department of Health over the past three years.
62. The two groups joined together to discuss communications issues and work with the Department of Health in providing advice and information.

63. Throughout the last three years all the companies have received regular briefings on the strategy, and have provided input on their individual areas of research and expertise both direct to the Department of Health and via the forums. It has been an inclusive process and we understand that the companies are now looking to the future and how they can contribute to the work ahead of ensuring that the strategy is successfully implemented.

## Implementation

64. In accordance with the drive to devolve responsibility for NHS services to local organisations, this strategy lays great emphasis on local health and social care communities and the third sector taking responsibility for contributing to service change and improvement.

65. The public expects appropriate, integrated services planned and delivered around individual needs, from diagnosis to end of life. This strategy reviews the case for change and describes the good practice that is already taking place in the NHS to deliver good COPD services.

66. It does not set national targets or milestones, but points out where we can expect the NHS to realise efficiency savings in their efforts to improve services. While some elements of the strategy could ultimately require PCTs to re-prioritise resources in order to make funding available, this will be clarified once the impact assessment is finalised after the consultation. The final

impact assessment will contain a much more robust indication of any additional costs or further savings for the NHS.

67. Nevertheless, the Department of Health also has a role to play by developing tools, harnessing expertise and giving advice where appropriate on wider policy contexts. For this reason the strategy also describes how the Department of Health will take action to support the improvement of services for people with COPD. This includes taking forward a programme of work looking to support quality and productivity in certain long-term conditions that is being led by Sir John Oldham.

68. One action is the development of clinical networks. A great deal of effort has been, and continues to be, invested in these to support improvement in a wide range of conditions in different parts of the country. Such networks have been particularly effective in providing services for cancer, diabetes, heart disease and now stroke and renal disease.

69. To support the development and implementation of the strategy, we are therefore planning to facilitate the establishment of respiratory networks at a regional level (subject to available funding).

70. We will also support pilot projects (subject to available funding) to gather further information on innovation and improvement where there are gaps in the evidence, as well as to test and evaluate different models of care and provision in terms of measurable outcomes. We have asked NHS Improvement

([www.improvement.nhs.uk](http://www.improvement.nhs.uk)) to undertake this work. They will also explore the important clinical and network links between respiratory disease and cardiovascular disease given the coexistence of these conditions, and the opportunity for delivery of integrated care and optimised therapeutic interventions.

71. COPD has also featured in many of the SHA clinical visions developed in response to the NHS Next Stage Review, under the long-term conditions clinical pathway grouping. The strategy will support these work streams, and those being developed as part of the quality and productivity work streams currently being developed by each SHA. The strategy will ensure that there is a continuous focus on finding those people with mild to moderate COPD, and that these people are included in structured programmes of assessment and follow-up.
72. The Department of Health will draft its own detailed implementation plan to accompany the final document, and PCTs may do likewise. As stated earlier, it is important that PCTs identify areas that increase the quality, efficiency and value for money of local services, as well as improving outcomes for people with the disease.



# 1. Setting the scene



## What is COPD?

73. COPD is now the term used most widely by the clinical community for the conditions characterised by generally irreversible airflow limitation. The airflow obstruction is usually progressive and not fully reversible and does not change markedly over several months. It is treatable, but not curable; however, early diagnosis and treatment can markedly slow the decline in lung function and hence lengthen the period in which a person can enjoy an active life.
74. In the past, many people described as having COPD were diagnosed as having chronic bronchitis, emphysema or chronic unremitting asthma. Chronic bronchitis is characterised by recurrent cough and production of sputum. By contrast, emphysema is progressive destruction of the alveoli, the gas-exchanging air sacs in the lungs. In some people, chronic bronchitis and emphysema affect different parts of the same lung, and so the two conditions can quite often occur together.
75. Significant lung damage may be present before airflow obstruction or small airway collapse can be detected, for example in young adults and in some people who have substantial emphysema without airflow obstruction. Symptoms such as breathlessness and cough may only be reported late in the disease, when detectable airflow obstruction is present.

## Who is at risk?

76. Current and ex-smokers are most at risk of developing COPD, due to the dominant role that smoking plays in causing the disease. To this group we can add people who have been exposed to inhaled dusts and gases in the workplace; those who have an inherited genetic predisposition that leads to the early onset of emphysema; and those who have previously been diagnosed with asthma. COPD is occasionally the result of inadequate lung development in childhood or damage caused by infections in childhood which affect lung growth and development.
77. Maternal smoking during pregnancy is associated with reduced lung function in school-aged children, and also affects foetal development of the respiratory system. There is strong evidence that exposure in pregnancy may predict the development of asthma and reduced lung function later in life.<sup>17</sup>
78. Young people who are likely to take up smoking in their teen years – either due to pressure from their peers or the smoking role model presented by their families – are in a different, but no less important risk category. The General Household Survey (GHS) for 2006 found that two-fifths of smokers had started smoking regularly before they were 16 years old.<sup>18</sup>
79. Smoking is more highly represented in lower socioeconomic groups: 26% of routine and manual workers smoke, compared with 15% of those in managerial and professional occupations.<sup>19</sup>

Department of Health estimates suggest that the routine and manual occupational group represents almost half of the people with (diagnosed or undiagnosed) COPD in England. Men aged between 20 and 64 who are employed in unskilled manual occupations in England and Wales are around 14 times more likely to die from COPD than men employed in professional roles, and are around seven times more likely than those in managerial and technical occupations.<sup>20</sup>

80. The picture is even worse for smokers from the most disadvantaged sectors of society, where in some cases (e.g. for people with schizophrenia) smoking prevalence can reach 74%.<sup>21</sup> COPD represents an enormous challenge – and opportunity – for the Government’s strategic objectives of reducing health inequalities among these groups.
81. A new smoking danger is the respiratory risk caused by smoking cannabis. This was highlighted by the British Lung Foundation’s report *Cannabis: A smoking gun*, which was published in 2002.<sup>22</sup> For the first time, a research review showed that people who smoked pure cannabis were putting their lungs at risk of developing COPD.

## Symptoms

82. Chronic cough is often the first symptom of a respiratory condition to develop. People often ignore it, or treat it as a normal consequence of smoking or other exposures, for example to dust at work.

83. Persistent and progressive breathlessness is also a characteristic of a respiratory illness. People with COPD experience breathlessness at lower levels of exercise than unaffected people of the same age. At first, the breathlessness may only be noticed when doing strenuous exercise. This often leads to a change in behaviour so that strenuous exercise is avoided. As the condition deteriorates, breathlessness can become present during everyday activities (e.g. dressing or washing) or while at rest.
84. People with a respiratory illness often produce small amounts of sputum or phlegm associated with a cough, which can increase in volume or change colour during flare-ups or episodes of worsening symptoms (exacerbations of the disease).
85. Other closely related obstructive lung problems such as asthma and bronchiectasis may also contribute to the development of COPD, or may coexist with COPD in some people. As COPD progresses and becomes more advanced other complications may arise, such as respiratory failure and heart failure.
86. Because of the magnitude of the burden of asthma, we have included a chapter on the condition within the strategy (see Chapter 6). This chapter highlights where there are similarities in the approach to the care of these two conditions, and where there are important differences.



## Two people's stories

### Case study 1

I am an ex-policewoman and I was so well known for my smoking habit that my nickname was Rizla!

I first started to see my health deteriorating in the year 2000 but even so it was some time before I went to discuss this with my GP. By the time I did, I was so weak that I could hardly walk, and found myself having to hang on to my shopping trolley when I was in the supermarket.

After having a spirometry test, I was told by my specialist that I had chronic obstructive pulmonary disease and that my condition was so bad that I would have to be admitted to hospital the next day. I then spent five days in hospital, but as I started to feel better I didn't take my diagnosis too seriously and continued to smoke.

Two years later I was back in hospital. I had become so breathless that I could barely move. My friend's daughter came to help me get dressed, put me in a wheelchair and took me to my local surgery. There they took one look at me and called an ambulance to take me to hospital.

I was in hospital for 11 days that time. I was so helpless and weak that I didn't even have the strength to clean my teeth. This really shocked me and I finally took the decision to stop smoking. I was relieved to be able to breathe in air that I no longer wanted to breathe in smoke.

I have now been a non-smoker for four years and I am so glad that I was able to give up. I lost my father to COPD and I only wish I had known more about the disease and the damage that smoking can cause.

My life is now severely restricted and I have to use oxygen to keep my oxygen levels up while getting around and doing small tasks. However, I have been very lucky to have the support of a local Breathe Easy group, part of the British Lung Foundation's support network. I have found the support and advice I have received from my friends there invaluable.



### **Case study 2**

I have COPD at an advanced stage and require oxygen therapy 24 hours a day. Over the last 21 years I have had to learn how it changes my everyday style of living. This has been especially hard, as I am only 47 years of age, a wife, and a mother of two.

I am determined to live my life to the full. I do meet prejudices along the way, as many people assume I must have been a heavy smoker, which is not the case. I was just unlucky. I have never smoked.

My condition has robbed me of many things: there is no spontaneity in my life because of the need for forward planning; I also receive funny looks from passers by when I go out with my oxygen; and I find people don't invite me to parties or functions, even family gatherings have stopped.

I have tried to turn the negativity of my illness into a positive by campaigning to improve services for service users with COPD, and also other people using oxygen, by enlightening the Government to the situation and needs of the service users. I have also tried to help people with COPD have more understanding about their way of life and the way it will affect them.



## 2. Prevention and identification



87. In the longer term, changes to the quality and cost of healthcare for those with COPD depends on fewer people developing the disease and, if they do develop it, being diagnosed much earlier. Many of the measures recommended in this strategy are designed to support this shift, either by identifying where resources might be released (and redeployed for this purpose), or by improving understanding of the key interventions that have greatest effect.
88. We believe that COPD can be prevented in many cases through behaviour change: those who do not have the disease can take action to minimise their risk of contracting it by either stopping or not starting smoking, and by avoiding risks in the workplace; and those with the disease, particularly in its early stages, can take action to improve their long-term outcomes.
89. We need to change the perception of the NHS from one of a treatment service to one where more effective prevention and better support for lifestyle choices can result in healthier outcomes for all, and where people are identified earlier if they do have lung disease, so they can be managed more effectively. Addressing lifestyle factors, such as smoking, can both reduce the incidence of chronic disease like COPD and prevent premature deaths.
90. The two over-arching objectives for the first part of the strategy are as follows:
- **Prevention:** So that people make choices about their life that are healthy, and therefore reduce their chances of getting lung disease. Our work in this part of the strategy will focus on behaviours that support or lead to smoking cessation and other forms of risk-reducing behaviour.
  - **Supporting early identification:** So that people recognise the symptoms of lung disease and seek assessment and advice from healthcare professionals. This is identified in more detail in Chapter 3, and, as outlined in the impact assessment, early identification can bring significant longer-term health and economic benefits.

## Summary of recommendations

**Recommendation 1:** Work should be undertaken locally to identify where prevalence is high, and planned interventions should be developed to encourage behaviour change and help to minimise inequalities.

**Recommendation 2:** The importance of lung health should be understood and people should take appropriate action to maintain good lung health.

**Recommendation 3:** The consequences of exposure to the main risk factors of COPD should be understood and people with early symptoms of lung disease need to be able to recognise their symptoms and seek further investigation.

**Recommendation 4:** Further evaluation work should be undertaken on the impact of the use of lung age tests on individuals' motivation for smoking cessation and testing for lung disease as a case-finding approach.

**Recommendation 5:** Employers should look to minimise the risks of workforce exposure to known risk factors and work with partners from health and social care to support people with COPD to manage their condition and remain in work.

**To support implementation, the Department of Health will take the following actions (subject to available funding).**

Action 1: Develop a toolkit that will:

- identify priority audiences at risk of COPD;
- assist with mapping local prevalence of lung disease;
- provide advice on where to find – and how to reach – these audiences at a local level;
- provide insight into the lifestyles, motivations and emotional 'drivers' of those we need to reach, in order to design approaches that have real 'resonance' for them;
- develop 'style guidelines' and 'messaging' to support local interventions; and
- help stakeholders to understand who to build partnerships with in order to deliver effective interventions.

Action 2: Support pilot programmes to investigate the costs and benefits of simple testing for impaired lung function and lung age measurement in order to support the motivation to stop smoking.

Action 3: Identify how spirometry can become an integral part of occupational health services in at-risk workplaces in order to improve prevention and early identification.

91. While 835,000 people have already been diagnosed with COPD in England, many of them were not diagnosed until they had moderate to severe disease. It is estimated that there are a further 2 million people with COPD who have not yet been identified, and many of these have the earlier stages of the disease. These are referred to as the 'missing millions'.
92. COPD is potentially preventable in the overwhelming majority of cases. The key to the successful prevention, identification and treatment of the disease in its early stages is to improve understanding of the disease and encourage behaviour changes among those affected, or those likely to be affected. To succeed, we will need those people at risk of COPD to respond to messages and interventions by:
- reducing their risk-taking and adopting more positive, health-enhancing behaviours; and
  - recognising and responding to the early symptoms of COPD by seeking advice and, where appropriate, a confirmed and accurate diagnosis.
93. COPD is not curable but treatable, and can be managed in order to minimise the burden it imposes. This burden falls not only upon the individual but also on their families, and on society as a whole through the demands placed on public resources. The earlier COPD is identified, the better the outcome for all.

## Our approach

94. The key to the successful prevention and treatment of the condition in its early stages is **behaviour change** among those affected, or those likely to be affected. The burden of the disease can be reduced by behaviour change in two ways. Firstly, people can take action to avoid the causes and exacerbating factors of COPD, such as cigarette smoke, workplace dusts and gases. Secondly, people can promptly recognise the symptoms of the disease and seek help.
95. However, changing people's behaviour is a huge and complex challenge. Some of the behaviours that individuals may need to change are either deeply ingrained, or deeply cherished, with the added complication of addiction for those who smoke. Simply raising awareness of COPD will therefore not be enough. The development of the strategy has included the trial and evaluation of a range of approaches to finding the specific triggers for behaviour change across a diverse range of audiences.
96. In order for the objectives of early identification and prevention to be met successfully, the contributions of a wide range of participants in health and social care need to be delivered in a co-ordinated way.



### Case study: South Tyneside PCT

The British Lung Foundation's *Invisible Lives* report reported that South Tyneside has the highest proportion of people at risk of future hospital admission with COPD in the UK (62%).

The British Lung Foundation therefore ran a fully integrated COPD awareness and telemarketing campaign in South Tyneside in January and February 2009, comprising:

- a telemarketing campaign to 5,000 'at-risk' households;
- pre-campaign communication with healthcare outlets in order to engage support;
- a COPD poster and leaflet campaign aimed at GP surgeries, pharmacies, health centres, libraries and other venues;
- a local media campaign targeted at newspaper, radio and TV outlets highlighted by marketing data; and
- four awareness stands with free lung testing in targeted community settings.

The lung testing events alone identified 153 people potentially living with undiagnosed COPD. The overwhelming popularity of the free lung function tests demonstrated that when given the opportunity to find out more about lungs within a healthcare setting, the public will respond positively.

Further information can be obtained from the British Lung Foundation.

97. Those working in healthcare delivery, from commissioners to providers, private companies to third sector organisations, need to **work together** to deliver these overall objectives in an appropriate way which fits local circumstances. We also want to **enable these organisations** to deliver the objectives in a consistent way by giving them a framework within which they can all work, share effort and understand each other's contributions.
98. The resulting approach is designed to ensure that activities delivered in a particular area or among specific groups of people are tailored to local needs, but can easily be recognised as part of a national approach.
99. We know that complex clinical terms like COPD are not universally understood by the general public. For this reason we will help the NHS to identify people at risk of developing COPD, and also those who already have the disease, by adopting messages built around the concepts of **lung health, lung disease and lung age** (lung age is the biological age predicted from estimating a person's lung function, after taking into account their sex and height – someone with damaged lungs will have a lung age older than their actual age). We believe that these concepts have resonance and meaning for the public.
100. Only limited behaviour change can be achieved through mass communication campaigns alone. In addition, lung disease affects some communities disproportionately, so generic, nationwide campaigns can be ineffective in delivering lasting behaviour



change. The strategy is therefore to support local and regional approaches which:

- encourage the targeted identification of those audiences who are putting themselves at risk through their behaviour;
- enlist and support local healthcare resources to deliver personalised and appropriate interventions that provide compelling reasons for people to change their behaviour; and
- enable appropriate co-operation or collaboration with third sector and commercial organisations in order to help find people and engage them with appropriate messages.

101. Activity typically starts with a local needs assessment, but we want this to progress to the development of interventions or activities that are pre-tested for efficacy and effect, with continual evaluation to create 'total-learning processes'. Many of the groups that we are trying to reach with this strategy have been difficult to engage with in the past, so the collaboration of local communities in the design, evaluation and continual improvement of interventions, measured against outcomes, will be key to those interventions' success.

102. Some of those working in the healthcare system may already be in a position to deliver these objectives, without needing much in the way of support. However, for those who do need support, we have commissioned the development of a toolkit.

103. This toolkit will:

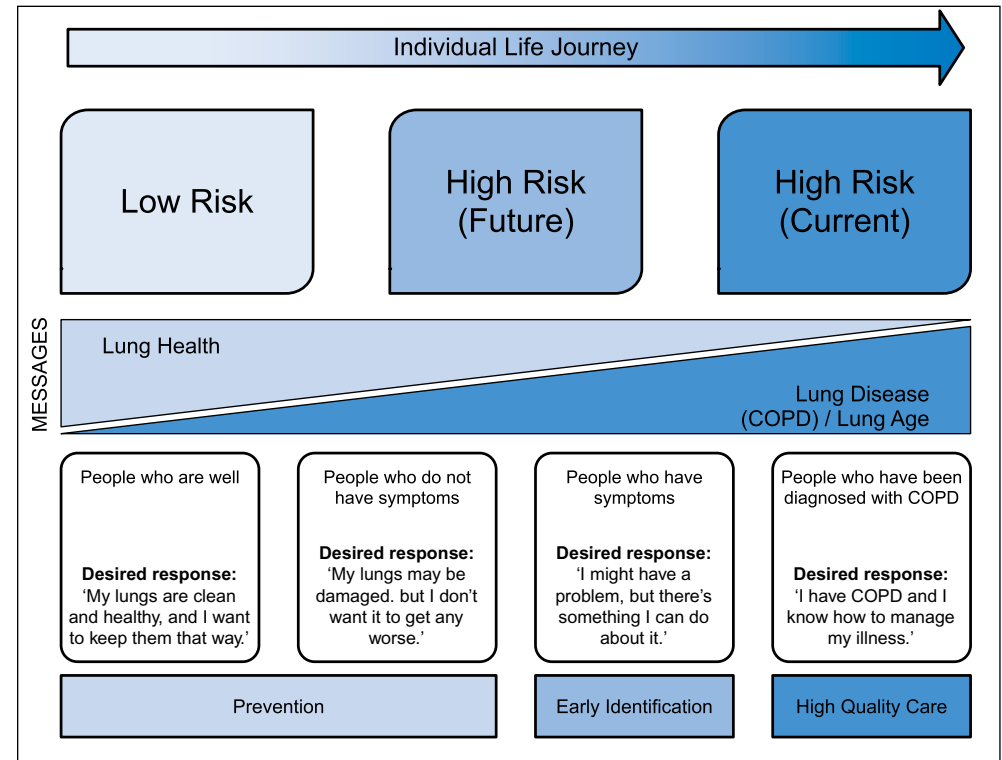
- identify priority audiences at risk of COPD;
- assist with mapping local prevalence of lung disease;
- provide advice on where to find – and how to reach – these audiences at a local level;
- provide audience insight into the lifestyles, motivations and emotional 'drivers' of those we need to reach, in order to design approaches that have real 'resonance' for them;
- develop 'style guidelines' and 'messaging' to support local interventions; and
- help stakeholders to understand who to build partnerships with in order to deliver effective interventions.

104. The toolkit will be published alongside the finalised strategy, with a more comprehensive and interactive toolkit developed for use via the internet. In the meantime, the initial work to identify the priority audiences for behaviour change has been completed as part of the development phase of the strategy, and is outlined below.

## Matching the strategy to the risk of lung disease

105. People who are at risk of developing lung disease fall within a broad range. At one end of the spectrum are those who are well and are not currently exposed to the triggers or do not have the underlying genetic and other factors known to cause lung disease. Then there are those who are exposed to the agents that cause lung disease or have the other underlying factors that can cause lung disease, but who are not experiencing any symptoms. At greatest risk are people who are exposed to the agents or have the underlying inherent factors that cause lung disease, who are experiencing symptoms but have not yet been seen by a healthcare professional and who are not diagnosed.
106. Our strategy is to design different interventions – using different messages – depending upon where an individual falls on this risk spectrum.

Figure 3: Individual Life Journey



107. Lung disease is a major contributor to health inequalities: those in the lowest social groups are up to 14 times more likely to have the disease than those from the highest.
108. It is recommended that lung health/lung disease interventions appropriate to key audiences are delivered to those assessed as having the greatest need in local communities. Our approach and choice of priority audiences reflects this, but the identification

of people in those audiences in specific local communities will require the joint effort of health and social care professionals, supported by local prevalence data provided by the Department of Health and regional public health observatories.

**Recommendation 1: Work should be undertaken locally to identify where prevalence is high, and planned interventions should be developed to encourage behaviour change and help to minimise inequalities.**

## Targeted interventions to reduce risk

109. We believe that behaviour change that promotes better lung health among these priority audiences could be delivered through targeted health interventions delivered in partnership with voluntary and/or private sector organisations. Targeted interventions will promote good lung health by talking not about COPD, but about the more easily understood concepts of **lung health, lung disease** and **lung age**. Interventions also need to provide people with compelling motivations to change their behaviour – as appropriate to each of the audience groups.
110. The use of more easily understood concepts of this kind, and not their clinical terms, is a much more effective approach when promoting healthy behaviours. For example, the National Service Framework for coronary heart disease succeeded in helping to deliver improvements across the entire patient pathway by

highlighting the importance of ‘heart health’.<sup>23</sup> The national programme for improving heart health contributed to a reduction in mortality and significant improvements in care for people with heart disease.

## Priority audiences

111. While COPD is the fifth largest killer disease in England, 89% of people (and 85% of smokers) in the UK have never heard of it.<sup>24</sup> Although terms such as chronic bronchitis and emphysema may be better understood by the public, the relationship between maintaining good lung health and developing lung disease is not well understood, and those most at risk of contracting lung disease persist with behaviour that puts them at risk.
112. Certain sections of the population are more likely to develop COPD than others.
113. We have identified eight audiences for initial prevention and early identification. These priority audiences include the vast majority of those people who are most at risk of lung disease, although they do not cover everyone in that category. We believe that with the limited resources available for conducting health campaigns, targeting these audiences will be the most efficient way of tackling the current and future prevalence of lung disease.

114. The chosen audiences have been prioritised because:

- there is a strong clinical case (such as a particular susceptibility to the disease);
- they represent relatively consistent populations in terms of culture and outlook;
- there is evidence to suggest that their behaviour can be changed or moderated through targeted intervention;
- there is evidence that they can be reached relatively easily, whether through the media or through their local communities; and
- there is evidence that there are some underlying motivations that we can draw on to encourage changes in behaviour.

**Recommendation 2: The importance of lung health should be understood and people should take appropriate action to maintain good lung health.**

115. Smoking and exposure to dusts and gases at work constitute the biggest risk factors for lung disease, so our effort is initially focused on the following groups:

- **Routine and manual – men:** Men working in routine and manual occupations make up a large proportion of the at-risk audience, due to the prevalence of smoking in this group, the fact that they start smoking at an earlier age, and their higher risk of exposure to occupational environmental hazards

affecting respiratory conditions.<sup>25</sup> We estimate that half of those with current lung disease will come from the routine and manual group of both men and women.

- **Routine and manual – women:** In the UK, the rate of lung disease has been increasing nearly three times faster among women than men.<sup>26</sup> Women are more susceptible to developing lung disease than men, because their lung function worsens with lesser duration of smoking or intensity of smoking than that of men.<sup>27</sup>
- **Employers in industries that potentially affect lung health:** 15% of the burden of lung disease is estimated to come from occupational exposure to dusts and gases.<sup>28</sup> Actions taken or not taken by employers in these workplaces have an impact on the lung health of their employees.
- **Pregnant women:** Because maternal smoking increases the risk and severity of lung disease among children.<sup>29</sup>
- **Parents who smoke:** Because children who have parents who smoke are much more likely to smoke themselves,<sup>30</sup> and are more susceptible to peer influence to start smoking.<sup>31</sup>
- **'Tweens' (7–12-year-olds):** Because smokers who start at this age are more likely to find it hard to give up smoking and are more likely to have damaged their lungs before they have fully matured. In addition, their likelihood of developing early-onset lung disease and more severe lung disease is significantly increased.<sup>32</sup>

- **Older smokers (age 55+):** Because older smokers and ex-smokers with 20 or more 'pack years' (a person has one pack year if they have smoked 20 cigarettes a day for a year) may have damaged their lungs sufficiently to feel the effects of lung disease as their lung capacity declines.<sup>33</sup> This group will also contain the vast majority of those with the most severe and therefore costliest-to-treat cases of lung disease.
- **Black and minority ethnic groups, with specific emphasis on Bangladeshi men:** Bangladeshi men have one of the highest rates of admissions to accident and emergency departments for lung disease<sup>34</sup> and a very high smoking prevalence (44%).<sup>35</sup>

116. Where possible, local needs assessment and intervention design should be used to identify and reach the specific at-risk populations within a local area. In some cases this may identify audiences that are not among the priority audiences outlined above; in these cases, the local needs assessment should take precedence.

## Understanding the risks

**Recommendation 3: The consequences of exposure to the main risk factors of COPD should be understood and people with early symptoms of lung disease need to be able to recognise their symptoms and seek further investigation.**

117. This strategy relies on the notion that interventions should seek to establish a connection between inhalational exposure and poor lung health.
118. The greatest risk to lung health is posed by smoking. Other factors include workplace exposure and general environmental pollution. Specific interventions need to be tailored to the circumstances of the individual in order to bring about the desired behaviour change.

## Understanding environmental factors

119. The two ways in which air pollutants can cause ill health or death are: day-to-day variations in exposure causing day-to-day increases in mortality; and long-term exposures causing disease in previously disease-free individuals.

### Indoors

120. Many sources of pollution are found in the workplace and at home. For indoor pollution, environmental tobacco smoke is the main source of concern in the UK. On its own, long-term exposure to environmental tobacco smoke does not appear to increase the risk of developing COPD, or cause exacerbations in people with pre-existing COPD, but the quality of life of people with severe COPD is significantly adversely affected by environmental tobacco smoke exposure,<sup>36</sup> and there is a suggestion that the severity of COPD may also relate to long-term environmental tobacco smoke exposure.<sup>37</sup>

## **Airborne pollution**

121. The air quality outside is also relevant. In the late 20th and early 21st century, the main sources of air pollution in industrialised countries have been and continue to be the combustion of fossil fuels, for example in motor vehicles, industry and energy generation (other than nuclear energy and non-combustion renewables). The major primary pollutants in ambient air that are detrimental to health are particles from these fuels and the gases sulphur dioxide, nitrogen oxides and carbon monoxide. Ozone is a secondary pollutant: it is produced by the action of ultra-violet light on nitrogen oxides and hydrocarbons emitted from sources such as industry and vehicles, as well as being emitted by natural sources.
122. In 1997 the Government published an air quality strategy for the United Kingdom. This described how improvements in air quality were to be achieved, setting out a framework within which air quality policies were to be taken forward in the short to medium term. This strategy was updated in 2007.<sup>38</sup> Achieving improvements in ambient air is also an important objective for the European Union. For many pollutants, transboundary contributions to UK air quality are highly significant, and so action across European Member States is crucial to achieving good air quality in the UK.
123. In 1998, the Committee on the Medical Effects of Air Pollutants (COMEAP) advised on the impact of certain pollutants on mortality and on respiratory admissions to hospital,<sup>39</sup> and in 2001 added to this with a statement dealing with admissions for cardiovascular disorders.<sup>40</sup> In addition, COMEAP provided advice on the health impacts of long-term exposure to particles.<sup>41</sup>
124. Local air quality management frameworks have a key role to play in delivering air quality and public health improvements. These involve reviews of air quality and the production of air quality action plans, where local councils set out plans to manage levels of pollution in areas that exceed national targets. Concentrations of air pollutants are monitored at a range of sites throughout the UK, details of which can be found on the UK Air Quality Archive website at: [www.airquality.co.uk](http://www.airquality.co.uk)
125. For contemporary air pollution, where motor vehicles are the major source, there is some evidence to suggest that long-term exposure is also associated with an increased risk of developing COPD. There is some evidence that exposure to air pollution during childhood is associated with reduced lung growth, but the overall effect is small,<sup>42</sup> these changes are at least partly reversible and to what extent this leads to an increased risk of COPD in adulthood is unknown. However, one study (limited to women) suggested that living within 100m of a busy road increases the risk of developing COPD by 1.8 times.<sup>43</sup>
126. Although we lack specific evidence to support this as an effective measure, those helping to develop the national strategy agreed that people with COPD and other respiratory conditions should



be advised by their care providers that when air pollution is high, staying indoors would be beneficial. Forecasting can also be used to forewarn air quality conditions and to trigger advice that will help people ensure that they keep their medication available. Advice to people with lung disease about what to do when air pollution increases is available on the Department of Health's website.

#### **Case study: airAlert**

airAlert is a free service for people with respiratory conditions. The service warns vulnerable people, by text, voice message (to home phones) or by email, that a pollution episode is forecast in their area. This intervention allows people to be informed and to give them choices to prepare and manage their own health.

airAlert was established by the Sussex Air Quality Partnership (Sussex-air) in 2006. During 2006 and 2007 airAlert sent over 10,000 alerts to vulnerable people in Sussex. airAlert also provides information to schools and radio stations across Sussex.

In 2007, research by the University of Brighton found that 73% of the service users agreed that airAlert helped them with their health management, with 64% utilising airAlert to make behavioural changes. Many took preventive medicines or action to reduce their exposure to polluted air.

For more information contact: [www.sussex-air.net](http://www.sussex-air.net) or [www.airalert.info](http://www.airalert.info)

The service now also operates in Hertfordshire and Bedfordshire.

127. The weather can affect those with lung disease:

- In winter, cold air may cause a narrowing of the airways (bronchoconstriction), increasing symptoms of breathlessness.
- In winter, there is a general increase in the number of chest infections, often caused by an increased circulation of viruses that are the major cause of exacerbations and which account for increased hospital admissions during the winter months.
- In summer, air pollution, heat and humidity can cause breathing difficulties.

128. This means that changes of temperature and other aspects of the weather, such as humidity and air pollution, may worsen symptoms of lung disease and lead to exacerbations, especially in cold winter weather. At such times the need to ensure that treatment is optimal and symptoms remain well controlled is paramount.

#### **Common symptoms**

129. It is recommended that we help the public understand common symptoms of early lung disease, including cough, breathlessness and wheezing. Chronic cough is often the first symptom of a respiratory condition to develop. People often ignore it, or treat it as a normal consequence of smoking, or other exposures. Persistent and progressive breathlessness is also a characteristic of a respiratory illness. People experience breathlessness at lower levels of exercise than healthy people of the same age, which

often leads to a change in behaviour so that strenuous exercise is avoided. As the condition deteriorates, people can become breathless during everyday activities (for example dressing or washing) or while at rest.

**Recommendation 4: Further evaluation work should be undertaken on the impact of the use of lung age tests on individuals' motivation for smoking cessation and testing for lung disease as a case-finding approach.**

130. The health gains achieved by stopping smoking are indisputable. These gains are not just in COPD, where stopping smoking is of proven benefit, but also in other conditions such as asthma, cancer, cardiovascular disease, diabetes and osteoporosis.
131. Mass media campaigns aimed at the general population of smokers are part of national policy on tobacco control and will remain so, as it is recognised that they do have some effect on young people, and that changes to how smoking is perceived in the adult population will have a knock-on effect on younger generations.
132. However, a new focus in prevention is the shift from viewing smoking as a lifestyle issue to viewing it as a preventable cause of premature death and disease for which there are psychosocial and pharmacotherapy treatment options.
133. Promotional campaigns aimed at current smokers could do more to emphasise the links between smoking and lung health,

and this will be investigated further by the Department of Health. Our evidence base shows that smoking cessation with behavioural support and pharmacotherapy offers the best chance of stopping smoking and so avoiding or significantly reducing the impact of COPD.<sup>44</sup>

134. Stop smoking services offer potential case-finding opportunities and we will be exploring the relative benefits, practicality and efficacy of case-finding methods to maximise this potential. We will also be exploring the opportunity to use lung age test to help increase individuals motivation to smoking cessation. Indeed, if using lung age measurement is successful in England, we estimate that over a ten-year period an additional 10,000 smokers who are diagnosed with COPD could potentially quit smoking long-term, thus helping to meet our aspiration to reduce adult smoking rates.

## What employers can do

**Recommendation 5: Employers should look to minimise the risks of workforce exposure to known risk factors and work with partners from health and social care to support people with COPD to manage their condition and remain in work.**

135. As described above, the majority of those who develop COPD in England will have done so from smoking. Many will be diagnosed while they are still employed. However, data from a number of surveys in industrialised populations estimates that approximately 15% of the attributable risk of lung disease arises from exposure

to gases, dusts, vapours and fumes at work. Although none of these studies included a UK population, they are likely to be relevant to the occurrence of lung disease here, and previous data suggests that around 4,000 lung disease-related deaths each year are due to workplace exposures.

136. Where exposure to a substance encountered at work can have an adverse effect on health, there are specific obligations under health and safety laws for employers, and those working for them, to prevent – or, if that is not possible, then properly control – that exposure. Where healthcare professionals are concerned about the possible role of work in causing an individual case of lung disease, they need to consider the need for specialist advice in pursuing this, for example occupational health advice, taking due note of the need to consult with the person and gain consent before taking any action. Action to benefit the individual may also benefit the health of others in the same workplace.
137. In some circumstances, employers are obliged to undertake special measures (health surveillance) both to monitor and protect the health of individuals, and to provide feedback on the effectiveness of controls. Where serial lung function testing is required, it is essential that this is done to appropriate standards if adverse effects are to be detected early.
138. Application of a workplace-based training and spirometry programme in Canada recently led to a reduction in observed cases of occupational lung disease due to isocyanates over a sustained period of time.<sup>45</sup> Similarly, there is good data from other industry sectors suggesting that workplace-based spirometry is helpful in identifying occupational lung disease (specifically asthma) in, for example, bakers.<sup>46</sup>
139. Access to workplace spirometry in the UK is variable, and there is no data currently assessing this provision. **As part of the strategy, the Department of Health will take action to promote the use of spirometry in at-risk workplaces integrated into occupational health services, improving the prevention and early identification of occupational risk to lung health.**
140. Minimising inhalational exposure among the workforce will help at-risk people remain in work. This applies even where the workplace itself is not considered a factor, for example where an employer encourages smoking cessation for the sake of the health and well-being of staff.
141. Finally, a diagnosis of COPD need not be a barrier to work. Those with COPD may have little or no disability, or may be very disabled: the converse of this is that their work ability will be equally diverse. The fitness of individuals for the work they do will vary with circumstances, but guidance is available.<sup>47</sup> Minimising the impact of COPD on peoples' general health and fitness will also help them remain in work.
142. It is well recognised that being in employment confers many benefits, including benefits to health.<sup>48</sup> This is particularly important for people with COPD given the high incidence of depression among these groups.



# 3. Finding the 'missing millions'



143. The strategy is designed to support early identification, so that people recognise the symptoms of lung disease and seek assessment and advice from a qualified healthcare professional.
144. An estimated 2 million people in England have undiagnosed COPD, and many of these individuals are unaware that they might have the condition. The majority have mild or moderate disease, but if they were diagnosed early they could take steps to improve the outcome of their disease and prevent its progression. In addition, there are a small proportion of people with severe COPD which remains undiagnosed until they are disabled by the condition. At that point the potential benefits of treatment are greatly reduced and the costs to the healthcare system are high.
145. We think it vital that people get an accurate, quality assured diagnosis and that there is clear differentiation of COPD from asthma and other diseases. This differentiation is critical if there is to be appropriate intervention and management of the condition, the natural course of the disease in an individual is to be modified and more cost-effective treatment is to be provided.
146. A clear assessment of the severity of disease and the presence of any co-morbid conditions will lead to appropriate treatment, as well as a more accurate identification of risks, prognosis and potential longer-term interventions for the individual.
147. The establishment of comprehensive and accurate disease registers that capture all elements of the diagnostic and severity

assessment are clearly important to taking a proactive approach to the identification and management of people with COPD. This, together with better information at the point of diagnosis, will support and engage people and carers as partners in care, encourage health and well-being, and improve outcomes and experience.

### Summary of recommendations

**Recommendation 6: Healthcare professionals should understand the risk factors for COPD and offer advice or an appropriate intervention to those who are at risk.**

**Recommendation 7: In line with WHO advice, all people with a diagnosis of COPD and/or a history of adult asthma should be assessed for alpha-1-antitrypsin deficiency.**

**Recommendation 8: A diagnosis of COPD should be confirmed by quality assured spirometry and other investigations appropriate to the individual.**

**Recommendation 9: An assessment of the severity and presence of co-morbid conditions should be made at the point of initial diagnosis, and at least every three years.**

**Recommendation 10: Disease registers should be accurate and used to improve COPD outcomes.**

**Recommendation 11: Good-quality information should be provided at diagnosis and delivered in a format that any person can understand.**



**To support implementation, the Department of Health will take the following actions (subject to available funding).**

Action 4: Ask the UK National Screening Committee to advise on whether there is a case for introducing a national population screening programme for alpha-1-antitrypsin deficiency.

Action 5: Work with the Child Health Promotion Programme to identify interventions that have synergy with this strategy.

Action 6: Investigate the feasibility and potential costs and benefits of identifying and assessing children and young people at risk of developing lung disease and, if appropriate, ask the UK National Screening Committee to advise.

Action 7: Support work to test a range of approaches to identifying adults at risk of developing (or having) COPD or other forms of lung disease and, if appropriate, ask the UK National Screening Committee to advise.

Action 8: Appraise the costs and benefits of identifying people at risk of developing COPD at the age of 25, and also at 40, and, if appropriate, ask the UK National Screening Committee to advise.

Action 9: Evaluate a case-finding approach to help identify people with COPD.

Action 10: Evaluate the potential benefits of the use of high resolution computed tomography (HRCT) and other imaging modalities in the initial diagnosis and assessment of COPD and other forms of diagnostics to better characterise COPD phenotypes.

Action 11: Publish advice on spirometry.

Action 12: Work with NHS Choices and others on information for people with COPD.

## Early identification

**Recommendation 6: Healthcare professionals should understand the risk factors for COPD and offer advice or an appropriate intervention to those who are at risk.**

**Recommendation 7: In line with WHO advice, all people with a diagnosis of COPD and/or a history of adult asthma should be assessed for alpha-1-antitrypsin deficiency.**

### At-risk groups in children and young people

148. The vast majority of adult diseases have their origins before birth (genetic) or during early childhood (environmental). COPD is no exception, and there is good evidence to suggest that identifying those with known risk factors or evidence of early lung function changes will enable a proactive approach to both monitoring any changes in lung function/damage and providing appropriate treatment, including during acute episodes of respiratory illness.
149. There are several identifiable risk factors for COPD that affect children:
- alpha-1-antitrypsin deficiency;



- smoking in pregnancy;
- small babies, either born early or with growth retarded during gestation;
- severe viral and other infections in infancy, asthma and wheezing in childhood;
- environmental pollution, including tobacco smoke;
- smoking in childhood; and
- combinations of the above, together with poor nutrition/obesity.

#### *Alpha-1-antitrypsin deficiency*

150. Alpha-1-antitrypsin deficiency was discovered in 1963. Alpha-1-antitrypsin is an enzyme inhibitor secreted by the liver to protect the lungs from permanent damage. Low levels in the circulation are associated with the development of early onset emphysema, as well as the development of clinically active liver disease (in some people). Smoking can exacerbate the effect of the low level of inhibitor and lead to severe COPD in young to middle-aged adults.
151. Cigarette smoking and some occupations lead to amplification of the susceptibility to develop lung damage for those with alpha-1-antitrypsin deficiency, but it is well recognised that even non-smokers with the deficiency can develop significant emphysema, although usually later in life than smokers.

152. There is some evidence that the early detection of alpha-1-antitrypsin deficiency results in increased awareness of the dangers of smoking and environmental pollution.<sup>49</sup> This suggests that there is potential to encourage the modification of harmful behaviours. There are also trials taking place across the world where the enzyme inhibitor is replaced by means of an inhaler. However, there is considerable debate in the clinical community of how best to find people with this genetic defect. One option considered by the External Reference Group (ERG) was the introduction of a national screening programme, as part of the heel prick test at birth, but they were concerned about the clinical and cost effectiveness of such a programme, as well as about the impact on individuals of introducing such a test. Given the lack of evidence, we are not currently recommending alpha-1-antitrypsin deficiency testing through a national screening programme. We will, however, work to improve the evidence base for future consideration, and will ask the UK National Screening Committee to advise whether there is a case for a national screening programme.
153. While we are undertaking this work, our preferred approach is to focus testing for alpha-1-antitrypsin deficiency on those diagnosed with COPD and/or a history of adult asthma. The early detection of alpha-1-antitrypsin deficiency results in increased awareness of the dangers of smoking and environmental pollution.<sup>50</sup>

154. In 1997, the World Health Organization (WHO) recommended that all people with a diagnosis of COPD and/or a history of adult onset asthma should be assessed for alpha-1-antitrypsin deficiency.<sup>51</sup> Under this scenario, those individuals identified as having such a deficiency would have their lung disease assessed more closely and receive appropriate genetic counselling, and their relatives would be offered assessment. The WHO considered that this would detect individuals earlier in the course of the disease, and so facilitate advice on smoking cessation and the avoidance of occupational dusts to prevent the further development of COPD. Affected relatives could also be monitored for the development of liver disease.

155. We therefore recommend that the WHO advice is followed and that all people with a diagnosis of COPD and/or history of adult onset asthma should be assessed for alpha-1-antitrypsin deficiency, and, if positive, their relatives should be offered assessment and follow-up.

#### *Environmental factors*

156. The updated Child Health Promotion Programme, published in March 2008,<sup>52</sup> provides greater emphasis on promoting the health and well-being of children from conception and throughout the first five years of life. Maternal smoking cessation is a key focus and is directly relevant to the aims of this strategy. Other relevant actions include work to:

- reduce the proportion of low birth weight babies;

- reduce exposure to tobacco smoke in the home;
- promote complete vaccination; and
- promote good nutrition/prevent obesity among children.

#### *Smoking in pregnancy*

157. There is strong evidence that maternal smoking during pregnancy may predict the development of asthma and reduced lung function later in life.<sup>53</sup> It affects the overall development of the foetus and, specifically, the foetal development of the respiratory system. The main airways are well developed by 16 weeks gestation. Maternal smoking (and other substance addictions) in pregnancy reduces in-utero growth rate, producing babies with airways that are smaller and narrower than those born at normal weights. This is associated with deficits in lung function, measured by forced expiratory volume (FEV1), in school-aged children.

158. The National Institute for Health and Clinical Excellence (NICE) is developing public health guidance on quitting smoking in pregnancy and following childbirth, due to be published in May 2010.

#### *Small babies born early or with limited growth during gestation*

159. Babies born prematurely also suffer from having less well-developed peripheral airways (respiratory bronchioles), which can result in abnormal lung function through to their late teens. Extremely premature babies may well have abnormal lung

function through into adult life. The association between low birth weight and decreased FEV1 in later life also applies.<sup>54</sup>

#### *Severe viral and other infections in infancy*

160. A history of severe childhood respiratory infection is associated with reduced lung function and increased respiratory symptoms in later life.

#### *Environmental pollution, including tobacco smoke*

161. There is an increased risk of acute lower respiratory infections and onset of childhood asthma when either parent has smoked.<sup>55,56,57,58</sup>

#### *Smoking in childhood*

162. Avoiding harmful exposures (principally smoking) is generally considered very important to lung health, but there is particular evidence that smoking during childhood leads to a greater risk of developing COPD in later life. This is due in part to the increase in the length of time that a person smokes, but in women, childhood smoking leads to an increased risk of developing COPD regardless of the length of time the person smokes for.<sup>59</sup>

163. Tobacco control measures, such as the rise in age for purchasing cigarettes from 16 to 18, will help deter young people from becoming addicted adult smokers. However, local surveys have identified that in some areas around a third of 12–13-year-olds have smoked. Although the proportion of regular smokers in that

age group may be considerably lower across England, 6% of 11–15-year-olds were noted as regular smokers in 2008.<sup>60</sup>

164. NICE has published public health guidance, *Preventing the uptake of smoking by children and young people* ([www.nice.org.uk/PH14](http://www.nice.org.uk/PH14)).

#### *The effect of these factors on lung development*

165. In various conditions it is possible to identify those children at high risk of developing symptoms in adult life. Examples of these conditions are:

- type 2 diabetes;
- cardiovascular risks;
- psychological illness and depression; and
- obesity.

166. For practical purposes, the earlier a potential life-threatening condition or the risk of developing one is identified, the more opportunity there is to encourage the individual to adopt a lifestyle conducive to reducing damage and worsening of symptoms. Early identification also allows the NHS to monitor an individual's health and well-being over time and to consider the optimum stage to offer treatments that can slow down or stop deterioration of the condition.

167. Normal age-related decline in lung function starts from around the age of 25. Optimum lung development in childhood can help to ensure that this is less likely to impact on the individual's health, well-being and independence in later years.
168. Diseases such as asthma have been shown to exhibit 'tracking' of lung function, i.e. children with more severe asthma symptoms have reduced lung function early in childhood. This reduced lung function persists into adult life whereas children with milder, intermittent symptoms have lung function within the normal range.
169. Growth patterns in lung development can be:
- normal in childhood, with normal decline in adult life;
  - normal in childhood, with accelerated decline in adult life;
  - reduced in childhood, with normal adult decline; or
  - reduced in childhood, with accelerated adult decline.
170. Deciding whether interventions are needed requires not only the mechanisms to identify those at risk of developing lung disease (particularly asthma and COPD) and the establishment of risk registers, but also the use of appropriate diagnostics by skilled and trained healthcare professionals to assess and monitor any lung damage.
171. Spirometry remains the gold standard for lung function in children, especially in its prediction of adult values. This can be particularly difficult and challenging in small children. Seven is recognised as the earliest age at which good reproducible and repeatable measurements of lung function can be obtained by spirometry.
172. Spirometry at the age of 14 may also be useful, as children are well on their way to adulthood. A repeated low value at 14 would increase the likelihood of respiratory problems in adult life.
173. Lung function testing could potentially be carried out at the time of other childhood healthcare contacts (such as height and weight measurement for 11-year-olds), but generally we think we need to consider further its effectiveness at the ages of 7 and 14. Together, these two values have the potential of singling out a group of young people at a very high risk of developing future respiratory disease.
174. However, while lung function could be tested at ages 7 and 14, there is currently no evidence to suggest the feasibility of undertaking this nationally, and what model would be most practical. We will therefore be determining whether there is any evidence of the clinical and cost effectiveness of such an intervention and, if appropriate, ask the UK National Screening Committee to advise.

175. Three main actions are proposed while we undertake this work:

- We will work with the Child Health Promotion Programme to identify initiatives that have synergy with this strategy.
- We will explore the feasibility of establishing an at-risk register of low birth weight babies, given their potential for developing later respiratory disease, and that it is these children who are likely to be most at need of lung function testing at a later date.
- We will support pilot/research studies to examine the feasibility of introducing a system to capture information relating to potential risk and to assess lung function and symptoms in children.

#### **At-risk groups in adults**

176. As stated in Chapter 2, a major cause of the development of COPD in adults is smoking. However, there is a range of other risk factors, including occupation, environment and family history. As discussed above, health events in childhood and genetic susceptibility are also associated with its development and with the presence of lung damage.<sup>61</sup>

177. We think that prevention and early identification effort for COPD needs to promote a focus on general lung health in young adults, as well as looking for COPD in certain priority audience groups. One advantage of this combined approach is that, as well as finding cases of COPD, other common lung diseases such as asthma or restrictive ventilatory defects may be detected at an

earlier stage. All early identifications enable treatment and regular review to be initiated where appropriate, which improves the chances of a potential modification of the disease profile before or without reaching a more severe state (which would have a greater cost to the system and, importantly, to the individual).

178. More specifically, there is evidence that those with symptomatic airflow obstruction benefit from treatment, self-management education and lifestyle modification, and that the earlier these steps are taken the better the outcomes in terms of quality of life and healthcare consumption.<sup>62</sup>

179. The following information is based on the expert opinion of the ERG. It is proposed that these approaches are the subject of pilot testing or further research before any recommendation for potential roll-out across England.

180. There is a requirement to improve the recognition of COPD within the community in a cost-effective and efficient manner. There is also a need to ensure that, in addressing any COPD under-diagnosis, this does not increase the burden of COPD misdiagnosis.

181. A related concern is the number of individuals currently diagnosed with COPD and/or on medication without a clear or accurate diagnosis of COPD having been established in accordance with the Global Initiative for Chronic Obstructive Lung Disease/ British Thoracic Society (GOLD/BTS) standards 1 and 2. This is

an area for early work by the NHS to potentially reduce costs and improve quality.

182. Given our knowledge of the epidemiology and natural history of COPD, a preliminary diagnosis can be made using spirometry before people present with obvious signs of respiratory disease.<sup>63,64,65</sup> Diagnosis may persuade an individual to try to slow the progression of their disease by avoiding other environmental exposures, making other lifestyle changes (eg. exercise), securing better symptomatic treatment, and recognising their risk of likely co-morbidities.
183. In order to identify adults with early signs of COPD, we believe that there needs to be more use of symptom questionnaires and 'case-finding' spirometry (for the purposes of detecting airflow obstruction). However, there is little evidence to support the effectiveness of these questionnaires, nor is there clear evidence of the benefits of using a simple device that measures FEV1 to identify those with a low probability of having COPD before moving on to a confirmatory diagnostic assessment.
184. We will therefore develop a programme to help evaluate an appropriate case-finding approach before issuing further guidance to the NHS.

### **Case-finding programme**

A 'case-finding' approach will be piloted in which individuals are only selected for more formal confirmatory diagnostic spirometry testing after first harnessing symptoms, patient characteristics, 'case-finding' spirometry or the referral filter in order to rule out those individuals at very low risk/probability of having COPD.

The study population will consist of current smokers (aged 40 or older) attending smoking cessation sessions. Individuals will be excluded if they have a cognitive or physical condition that precludes them from completing the questionnaires or undergoing lung function testing.

Four selection mechanisms will be tested:

- the use of symptoms and symptom-based questionnaires;
- the use of features in the individual's medical history;
- the use of 'case-finding' spirometry and/or peak flow measurement; and
- the use of referred populations.

The use of symptom-based questionnaires and spirometry in order to distinguish COPD from asthma will also be tested. The study will report in 2010.



*Potential groups*

185. While the pilot programme outlined above will be using a study population of smokers aged over 40, the ERG also recommended that people over 40 with any of the following characteristics should also be identified and invited for further investigation:

- ex-smokers;
- previous pulmonary tuberculosis;
- first-degree relatives of those with COPD;
- those with a known occupational exposure;
- those with chronic asthma;
- those requiring frequent courses of antibiotics for lower respiratory tract infections and/or inhaled medication;
- those with a known environmental exposure (e.g. coal mining, those from abroad exposed to wood-burning stoves); and
- those with symptoms, i.e. chronic cough, sputum, breathlessness and/or exercise limitation.

186. Out of this group, the ERG recommended that smokers with 20 'pack years' who were aged over 40, those who have been treated with frequent courses of antibiotics and/or inhaled medication or those with symptoms such as chronic cough or breathlessness could be a priority and be regarded as being most at risk.

187. However, given that NICE has recommended case finding for certain groups in those aged over 35, we will need to undertake further work to determine which are the most appropriate groups and, in the light of the outcome from the programme outlined above, what the best approach is to proactively case find people most at risk. We will therefore undertake further work to appraise the costs and benefits of introducing systematic case finding at the age of 25 and 40, and, if appropriate, ask the UK National Screening Committee to advise.

188. We believe that specific targeting of people will lead to an earlier diagnosis of those with mild (or even moderate) COPD than would happen if we left diagnosis until individuals present themselves to their GP when their respiratory symptoms have started to limit everyday activities more significantly.

### Accurate quality assured diagnosis

**Recommendation 8: A diagnosis of COPD should be confirmed by quality assured spirometry and other investigations appropriate to the individual.**

189. While screening tools and lung health checks are useful in identifying people who may have COPD, further diagnostic tests are required to make an appropriate diagnosis, to assess the severity of the disease and to determine appropriate treatment.

190. Making a diagnosis relies on clinical judgement, based on a combination of history, physical examination and confirmation of the presence of airflow obstruction using quality assured spirometry. It is also critical for evaluating the influence of some co-morbid conditions and in assessing the severity of the disease.
191. Access to respiratory investigation services vary throughout the country. In primary care, while spirometry has become more widely available, access to accurate spirometry performed by well-trained staff competent in lung function measurement and interpretation has been a concern.<sup>66</sup> The Chief Medical Officer's 2004 annual report stated: "More primary care staff should be provided with training in the use of spirometry as a tool to detect COPD."<sup>67</sup> While there are examples of good-quality spirometry being carried out in primary care, even with proper training and the use of appropriate equipment, accuracy of the result and its quality control remain an important issue.<sup>68</sup>
192. In secondary care, most hospital trusts in England have well-equipped lung function laboratories staffed by individuals with experience in assessing a wide range of people with respiratory disease/impairment. Importantly, models of care are emerging across England where this expertise is being taken into the community and/or training and support are being provided for primary care professionals, as well as direct access for primary care to the array of lung function investigations. These shall be encouraged. There are many opportunities for innovative approaches to future delivery and for ensuring that a quality assured confirmatory diagnosis of COPD can be achieved, and this will be explored as part of the national Lung Improvement Programme. However, given the potential benefits and cost savings of ensuring accuracy of diagnosis, the NHS should respond to this recommendation before the pilot studies report.
193. There will be several benefits in improving quality assured confirmatory diagnoses. Failing to perform accurate spirometry after the delivery of a bronchodilator can overestimate the prevalence and severity of COPD and thus lead to wasted resources.<sup>69</sup> Inaccuracies in assessing lung function can also impact on the type of treatment that people receive (with the consequent knock-on effect on cost); for example, inhaled corticosteroids are only recommended for those with recurrent exacerbations and FEV1 <50% of the predicted level.<sup>70</sup>
194. Measures to improve the accuracy of spirometry are discussed below. However, it should be noted that spirometry is not the only diagnostic test that may be required at the initial diagnosis stage to ensure that the disease and its impact are physiologically fully characterised in an individual. For example, the presence of emphysema is not reflected in spirometric measurements and is likely to have a greater impact on measures of gas transfer. Investigations such as radiology using HRCT and a measure of gas transfer or of exercise tolerance may be more informative in the assessment and monitoring of some individuals.<sup>71</sup> For those with coexistent heart failure, an assessment of both the lung and cardiac contribution to breathlessness will need to be established

through the use of both spirometry and echocardiography. For these reasons, it is important that access to such tests is readily available for a comprehensive evaluation at the point of initial diagnosis. Through pilot projects, we will explore different models of providing a diagnostic hub that would better support primary care healthcare professionals in their assessment.

195. We do not currently recommend the widespread use of computerised tomography (CT) scanning as part of the diagnosis of COPD, but further research and feasibility testing in this area is needed as a way of complementing physiological testing and characterising the structural damage due to COPD.

## Spirometry assessment in COPD

196. Spirometry is the test that measures exhaled volume and/or flow against time from a maximum intake of breath. It can detect the presence of airflow obstruction and even the site of that obstruction in the lung (for example in the small airways), as well as how reversible the airflow obstruction will be with treatment. It is often difficult to get an accurate result and it is not straightforward because it requires co-operation and co-ordination from the individual being tested, which can be particularly challenging in people who have moderate to severe COPD and prolonged expiratory times.
197. Problems operating and maintaining equipment are common and lack of interpretative skills has led to a high degree of

misdiagnosis. As the Chief Medical Officer highlighted in his annual report in 2004, and as reiterated by the Healthcare Commission, it is vitally important to get an accurate diagnosis and, once diagnosed, to provide information on how to manage the condition and what further investigations are required.

198. There are internationally recognised guidelines for performing spirometry and for ensuring that the results are quality assured and interpreted correctly. We will include these, and specifications for achieving accurate spirometric data, within a guidance document for the NHS to be published alongside the strategy.

### Case study

A recent examination of the records of 3,217 patients with COPD from 38 practices in Rotherham revealed that **only 31%** of the spirometry measurements involved three readings of FEV1 and forced vital capacity (FVC), two of which were within 5% or 100ml of one another in contravention of recommended BTS and GOLD spirometry standards.

### Assessing severity of COPD

199. There are three sets of guidelines that classify the severity of lung damage due to COPD, with the NICE, GOLD and American Thoracic Society/European Respiratory Society (ATS/ERS) documents being the most widely used in England. Each relies on forced expiratory volume provided in one second (FEV1). FEV1 provides an objective guide to the physiological damage

that COPD causes, although it bears only a general relationship to how badly the disease affects the individual and their quality of life, as well as to the lung damage that may have already occurred but which cannot be measured by FEV1. Hence, a full evaluation of the severity and impact of COPD involves additional clinical assessments. Nonetheless, an understanding of the degree of spirometric impairment does help in the initial approach to COPD management, and can often indicate whether COPD is the principal cause of the person's symptoms or is only playing a minor role.

200. The major difference between the three sets of classification guidelines is that ATS/ERS and GOLD define mild COPD as those people who have a FEV1 predicted as being = or > 80% predicted, whereas NICE only recognises COPD as being reliably present for those people whose FEV1 is less than 80%. This influences the subsequent classification as outlined in the table below.

**Table 1: Differences in COPD severity classification**

		NICE	ATS/ERS	GOLD
Post-bronchodilator FEV1/FVC	FEV1 % predicted	Severity	Severity	Severity
<0.7	= or > 80%		Mild	Stage 1 – mild
<0.7	50–79%	Mild	Moderate	Stage 2 – moderate
<0.7	30–49%	Moderate	Severe	Stage 3 – severe
<0.7	< 30%	Severe	Very severe	Stage 4 – very severe

201. During the development of the strategy for COPD, it became apparent that the current GOLD guidelines have the confidence of many specialists. These are recognised in many countries of the world and therefore allow comparison within similarly categorised populations.<sup>72</sup>
202. As part of the forthcoming review of the current NICE clinical guideline for COPD, NICE draft recommendations related to drug treatment make reference to FEV1 being above or below 50% but no mention is made of the stages of severity.
203. The reference definition used in developing this strategy has been the GOLD definition, since this also underpins much of the material drawn on by the NICE clinical guideline, particularly in relation to evidence-based treatment recommendations, although the cost effectiveness of this classification and its impact has not been assessed by NICE. NICE is currently reviewing the responses to their review of clinical guidelines in COPD, and we will work to ensure that there is a consistent approach when the finalised strategy is published. Final recommendations will also inform the development by NICE of a new quality standard for the disease.
204. There has been debate in the clinical community as to whether people with mild COPD as defined by ATS/ERS and GOLD represent a clinically significant group. In population-based studies, respiratory symptoms are more significant in predicting long-term clinical outcomes in subjects with COPD with mild obstruction.

205. It has been shown that those with symptomatic GOLD stage 1 COPD had a faster decline in FEV1, increased respiratory care utilisation and a lower quality of life than asymptomatic subjects with normal lung function. In contrast, individuals with asymptomatic GOLD stage 1 COPD had no significant differences in FEV1, respiratory care utilisation or quality of life scores compared with the reference group.
206. These findings have important implications for case-finding and review strategies that we will explore further through the pilot studies.

**Table 2: GOLD definition**

Stage	Severity	FEV1 %
Stage 1	Mild	FEV1/FVC < 0.70 FEV1 ≥ 80% predicted
Stage 2	Moderate	FEV1/FVC < 0.70 50% ≤ FEV1 < 80% predicted
Stage 3	Severe	FEV1/FVC < 0.70 30% ≤ FEV1 < 50% predicted
Stage 4	Very severe	FEV1/FVC < 0.70 FEV1 < 30% predicted or FEV1 < 50% predicted plus chronic respiratory failure

FEV1: forced expiratory volume in one second; FVC: forced vital capacity; respiratory failure: arterial partial pressure of oxygen (PaO<sub>2</sub>) less than 0.0 kPa (00 mmHg) with or without arterial partial pressure of CO<sub>2</sub> (PaCO<sub>2</sub>) greater than 6.7 kPa (50 mmHg) while breathing air at sea level.

207. Although the GOLD guidelines have the confidence of the specialists, population studies based on spirometry alone may not correctly estimate the prevalence of clinically relevant COPD. This is because the process of ageing affects lung volumes. The use of the fixed ratio represented by FEV1 may result in over-diagnosis of COPD in the elderly, especially of mild disease, as well as under-diagnosis of COPD in young adults.
208. Using lower limit of normal (LLN) values for FEV1/FVC is one way to minimise the potential misclassification of all people. LLN values are based on the normal distribution and classify the bottom 5% of the healthy population as abnormal. However, reference equations using post-bronchodilator FEV1 and longitudinal studies to validate the use of the LLN are needed and will not be available for some time. The use of LLN therefore needs to be kept under constant review and will not at this stage be recommended for widespread adoption.

**Recommendation 9: An assessment of the severity and presence of co-morbid conditions should be made at the point of initial diagnosis, and at least every three years.**

209. COPD is a progressive disease, and once a diagnosis has been confirmed regular reassessments will be needed to gauge the progression of the disease, and ensure that treatment pathways are appropriate and that people are being given access to appropriate support and advice. We recommend that it is

appropriate that a full assessment is offered every three years regardless of how well the person seems to be doing.

210. During the course of the disease, assessments other than the first diagnostic check will be needed, and the results of these should be documented. We will be supporting a pilot project to develop and test a template to enable these tests to be undertaken and the information collected in primary care and to test the cost effectiveness of this approach.
211. There is sufficient evidence to suggest that body fat and general fitness need to be part of the initial COPD assessment (e.g. baseline body mass index (BMI), fat-free mass and waist measurement documented).<sup>73</sup> People with COPD who have a BMI of < 20 are likely to need to be referred for specialist dietary advice, as should those with a BMI of >30. Even those people with a normal BMI between 20 and 30 should be offered advice on healthy eating, since they are likely to experience a progressive decrease in their physical activity.
212. As for everyone, a high BMI is also associated with increased mortality for people with COPD,<sup>74</sup> and it will contribute to other pre-existing conditions such as diabetes and obstructive sleep apnoea. People with obesity are also at risk of nocturnal hypoventilation that will make them more susceptible to developing respiratory failure.<sup>75</sup>

213. The ERG also suggested the inclusion of a range of other parameters as part of the initial COPD diagnostic assessment that would form part of the information held and provide a more holistic view of the person. These included the following:
- symptoms;
  - exercise tolerance assessment or Medical Research Council (MRC) dyspnoea score;
  - oxygen assessment (oximetry or gases);
  - echo if heart failure suspected;
  - full lung function tests to characterise phenotype;
  - HRCT if breathlessness is disproportionate to functional impairment;
  - alpha-1-antitrypsin deficiency; and
  - sputum culture.

## Disease registers

**Recommendation 10: Disease registers should be accurate and used to improve COPD outcomes.**

214. Disease registers are held by primary care and have been used to improve the care of people with COPD. They could, however, become a richer source of information when used on a proactive basis and could further underpin efforts to improve outcomes for



people with COPD. There is good evidence that they are currently far from accurate.<sup>76</sup> To understand their accuracy it is essential that actual spirometric readings are recorded, and also whether they meet national and international standards (i.e. quality assurance).

215. Once a person has a diagnosis of COPD, the following should be recorded on a disease register:

- FEV1, whether the readings are pre- or post-bronchodilator and severity characterisation according to GOLD guidelines;
- other symptoms that contributed to the diagnosis of COPD (cough, sputum and breathlessness);
- functional impairment (e.g. MRC dyspnoea scale);
- exacerbation frequency;
- BMI;
- smoking history and status (what methods, if any, of smoking cessation are being provided<sup>77,78,79,80,81</sup>);
- oxygen and blood gas assessment;
- educational knowledge of COPD;
- co-morbidities (include psychological conditions (anxiety, panic disorder and depression), cardiovascular disease, diabetes and osteoporosis);

- ethnic group; and

- wishes for palliative and end-of-life care when identification of advanced disease has taken place.

216. At present other biomarkers are not recommended, but ongoing research may validate their use in predicting subjects at risk, identification and management.

217. **The Department of Health will be supporting a pilot project to develop and test a template for primary care disease registers.**

#### **Case study: Plymouth PCT**

In Plymouth, 632 patients on COPD registers in primary care practices were seen by a visiting respiratory specialist nurse. Diagnoses were made according to the NICE guidelines. Reversibility testing was carried out either routinely or based on clinical indication in two sub-samples. Dyspnoea was assessed. Data was entered into a custom-built IT software, which computed guideline-based treatment recommendations. Current and recommended treatments were compared.

Of the 632 patients, 580 had spirometry. Diagnoses of COPD were confirmed in 422 patients (73%). Some 39 patients were identified as having asthma only, 94 had normal spirometry, 23 were restrictive and 2 had a cardiac disorder. Reversibility testing changed the diagnosis of 11% of patients with airflow obstruction, and severity grading changed the diagnosis of 18%. Some 75% of patients with

COPD had been offered practical help with smoking cessation. Short- and long-acting anticholinergics and long-acting beta-2 agonists had been under-prescribed; in 15–18% of patients they were indicated but not received. Inhaled steroids had been over-prescribed (recommended in 17%, taken by 60%), whereas only 4% of patients with a chronic productive cough were receiving mucolytics. Pulmonary rehabilitation was not available in some areas and was under-used in other areas.

The study is one of the first to report the true levels of severity of COPD and the provision of appropriate treatments in primary care. The study demonstrates that, compared with diagnoses made by expert nurses with the help of a standardised, guideline-based computer program, the disease registers in primary care are inaccurate in 27% of cases. The role of reversibility testing was examined and it was found that pre-bronchodilator readings alone overestimated both the prevalence and the severity of COPD. Reversibility testing was useful in detecting some cases where a diagnosis of asthma was considered. On this basis it is suggested that only post-bronchodilator readings should be used routinely in primary care, but reversibility testing is appropriate in specific cases where asthma is suspected. The management of patients with COPD seldom followed guideline-based recommendations in terms of drug treatment and pulmonary rehabilitation.

## Information

**Recommendation 11: Good-quality information should be provided at diagnosis and delivered in a format that any person can understand.**

218. Knowledge empowers people to manage their own health. To be effective, educational and information needs should be addressed from the individual's perspective and delivered in a format that they can understand.
219. In stakeholder workshops with people with COPD and their carers during the development phase of the ERG's advice, key topics were identified. These were:
- education about the disease;
  - management of breathlessness;
  - pharmacological treatments;
  - management of exacerbations;
  - psychological support; and
  - guidance on welfare benefits.
220. Education and information on these topics need to be provided to people on diagnosis, and then on an ongoing basis at cyclical reviews. We will develop standardised material in conjunction with people with COPD, their representatives and healthcare

professionals, and use this to inform the following ways of supporting service providers and people through information:

- NHS Choices;
- the Expert Patients Programme; and
- information prescriptions.

### **NHS Choices**

221. NHS Choices is a comprehensive information service to support those who are looking for more control of their healthcare. The service is intended to help us make choices about our health, from lifestyle decisions about things such as smoking, drinking and exercise through to the practical aspects of finding and using NHS services in England when we need them. It draws together the knowledge and expertise of:

- NHS Evidence;
- the NHS Information Centre for health and social care;
- NICE; and
- the Care Quality Commission and many other organisations.

222. Since the integration of the online arm of NHS Direct in October 2008, NHS Choices provides a single 'front door' for the public to all NHS online services and information, and hosts the country's biggest health website blog on COPD. Videos are currently being developed for NHS Choices on areas such as pulmonary

rehabilitation. We will be discussing with them other areas, including:

- correct use of inhalers and spacers;
- recognition of exacerbations; and
- preparation and instructions for spirometry.

### **Expert Patients Programme**

223. The Department of Health published *The expert patient: A new approach to chronic disease management for the 21st century* in 2001.<sup>82</sup> This promoted the concept of user-led self-management programmes. The programme offers courses to help people with long-term conditions to better manage their condition on a day-to-day basis.

224. Since the programme was introduced there is evidence that participants have felt more confident in managing their condition, made more effective use of healthcare resources, with fewer attendances at accident and emergency departments and hospital admissions, and felt better prepared for consultations with professionals.<sup>83</sup>

### **Information prescriptions**

225. Information prescriptions (IPs) ensure that people with long-term health conditions or social care needs receive timely information in order to help them manage their condition. They include helpful and relevant information about conditions and treatments,

care services, support groups etc. They also contain links and signposts to sources of information about local health and social care services. They are given to people by health and social care professionals, and will help individuals to access information when and where they need it and in a format that is best suited to their needs.

226. To ensure the successful design and delivery of IPs, the Department of Health recruited 20 pilot sites to test and provide evidence of their effectiveness and their impact on individuals, professionals and organisations. The piloting phase closed in January 2008 and an evaluation report was produced for August 2008, which is available at: [www.dh.gov.uk/informationprescriptions](http://www.dh.gov.uk/informationprescriptions). The report showed that 76% of those receiving an IP felt more confident about managing their condition. The experiences and momentum built through the piloting phase have been used to shape the support that is needed nationally to help organisations consider how to implement IPs locally.
227. Case studies and templates from the pilots, along with detailed guidance to help other health and social care organisations to implement IPs, are available in the online resource pack available at: [www.informationprescription.info/resource](http://www.informationprescription.info/resource)
228. Other national resources to assist implementation include NHS Choices, where IPs can be generated for a number of long-term conditions ([www.nhs.uk/informationprescriptions](http://www.nhs.uk/informationprescriptions)). A more

sophisticated tool is being developed to allow professionals to create more tailored prescriptions, pulling together national content, information from key third sector organisations and locally uploaded information, along with a facility to write personal notes specific to the patient. Workforce support tools are currently in development, including an e-learning module and a state of readiness self-assessment tool. Additionally, the Department of Health is commissioning an implementation support programme to work with primary care trusts (PCTs) and their partners in order to develop local solutions to delivering IPs as part of a personalised care plan.





# 4. High-quality care and support





229. People with diagnosed COPD need to be recognised as having lung damage that will be progressive. Depending on contributory factors such as the frequency of episodes of exacerbations or the rate of worsening symptoms, the disease will, over time, result in further lung function impairment, disability and – for some – death. Hospital data clearly shows that the majority of admissions for COPD are unscheduled and, as such, present a high burden of cost to the NHS.<sup>84</sup>
230. However, a deteriorating course of the disease is by no means inevitable. With the right care and treatment at the right time, there is the potential to slow down or modify this progressive nature of the disease in an individual. This is also the best way to prevent the acute exacerbations that impose the most significant burden on NHS resources.
231. In order to move away from the current models of care, which are largely reactive, it will be necessary to develop an organised, proactive, multidisciplinary approach to the management of COPD, including both chronic and acute care. It is reasonable to assume that such a structured approach to the management of COPD will produce some of the benefits that have been seen in other chronic conditions, such as diabetes and heart failure. The broad chronic care model developed for these other long-term conditions (LTCs)<sup>85</sup> is designed to ensure that people are dealt with in an anticipatory ‘preventive’ manner, and that they develop appropriate skills and expertise to help manage their condition well.
232. Ensuring that the right care and treatment are provided at the right time requires COPD to be managed within a similar approach that embraces all elements of pharmacological and non-pharmacological treatment according to published guidelines. Optimal care for COPD requires a partnership between the person with COPD and the healthcare professional associated with regular review, adherence and compliance to treatment, and good communication and exchange of information.
233. Even if the above proactive measures are introduced, it is inevitable that a proportion of people with COPD (and particularly those with more severe disease) will be referred to hospital for possible admission. Specialist respiratory assessment on referral will ensure that people with COPD are dealt with in a pathway that is most appropriate to meet their clinical needs. Early discharge schemes or Hospital at Home (HAH) services can prevent hospital admission but still provide the person and their carer with all the support they require.<sup>86</sup> A more structured and systematic approach to any admission, similar to approaches in other diseases such as cystic fibrosis, would help to ensure that any hospital stay results in optimal assessment and treatment from specialist respiratory professionals, a potential reduction in length of stay and subsequent readmission rates.

## Summary of recommendations

**Recommendation 12:** Chronic disease management approaches should be adopted in health and social care for all people diagnosed with COPD, irrespective of severity or symptoms.

**Recommendation 13:** All people with COPD should receive evidence-based treatment using a structured medicines management approach. A step-up approach to smoking cessation intervention as part of preventive management strategies should be taken.

**Recommendation 14:** All people with COPD and hypoxaemia should be clinically assessed for long-term oxygen therapy and reviewed at regular intervals, and existing home oxygen registers should be reviewed.

**Recommendation 15:** All people with COPD should be advised to undertake moderate exercise according to their condition. People with functional impairment should be referred for quality assured pulmonary rehabilitation.

**Recommendation 16:** People with COPD should be encouraged to learn how to help manage their condition themselves and how to have positive interactions with healthcare professionals and others about their condition. They should also be encouraged to engage with others who have COPD in order to promote exchanges of information, support and advice.

**Recommendation 17:** The quality of the identification and management of exacerbations should be improved and all people with COPD who have an exacerbation should be reviewed afterwards to ensure that their treatment remains optimal and relapses are reduced to a minimum.

**Recommendation 18:** All people with COPD in respiratory failure should be issued with oxygen alert cards, and ambulance staff should be able to recognise and respond appropriately to respiratory failure in COPD.

**Recommendation 19:** People with COPD should receive a specialist respiratory review when acute episodes have required referral to hospital. They should be assessed for management by early discharge schemes, or by a structured hospital admission, to ensure that length of stay and subsequent readmission are minimised.

**Recommendation 20:** All people with acute respiratory failure should be identified and investigated promptly and offered treatment with non-invasive ventilation (NIV) with access to mechanical ventilation, if required.

**To support implementation, the Department of Health will take the following action (subject to available funding).**

Action 13: Support NHS Improvement in developing networks to underpin the introduction and evaluation of chronic disease management models and methodologies for COPD.

Action 14: Explore options for ensuring access to 24-hour advice on exacerbations of COPD and more generally for ongoing advice.

Action 15: Support the testing and evaluation of different methods for assessing the impact of the disease and patient outcomes.

Action 16: Submit suggestions to NICE to investigate whether clinical reviews for people with COPD could be considered for inclusion in the Quality and Outcomes Framework.

Action 17: Publish a medicines management guide alongside the finalised strategy.

Action 18: Support a pilot study into the benefits of embedding cognitive behavioural therapy (CBT) principles into regular review and programmes of pulmonary rehabilitation. We will also review methods for identifying people with COPD who would most benefit from psychological interventions or complementary and alternative medicine (CAM) therapies.

Action 19: Develop a pathway of care for early assessment for surgical and non-surgical interventions for COPD.

Action 20: Develop advice on the content of a home oxygen assessment and review service.

Action 21: Bring together information for the NHS on high-quality pulmonary rehabilitation programmes, and invite NICE to make it available through NHS Evidence.

Action 22: Develop standardised tools to support the implementation of self-management plans.

Action 23: Support a project to evaluate the training and support needs of people with COPD to self-manage or to engage better with their local health and social care professionals.

Action 24: Pilot different models of providing specialist COPD exacerbation support.

Action 25: Evaluate and develop improvements to the transfer of information between care sectors.

Action 26: Publish advice on workforce training/capabilities that includes the training requirements of ambulance staff on exacerbations of COPD and the management of respiratory failure.

Action 27: Develop advice for structured hospital admissions for COPD and evaluate this as part of the national Lung Improvement Programme led by NHS Improvement.

Action 28: Publish guidance on the provision of invasive and non-invasive ventilation.

Action 29: Develop a pathway of care for early assessment for surgical and non-surgical interventions for COPD.

## Adapting the chronic care model for COPD

**Recommendation 12: Chronic disease management approaches should be adopted in health and social care for all people diagnosed with COPD, irrespective of severity or symptoms.**

234. The central aim of chronic disease management is that interactions between those with COPD and health and social care professionals are productive, and that people are seen as partners in the management of their condition. This means that while health and social care professionals have access to up-to-date information, decision support and the resources needed to deliver care that is of a high-quality, people with COPD should also have the information, skills and confidence needed to make decisions about their health in order to better manage their condition, and be motivated to do so.

### The chronic care model of Wagner

235. The chronic care model<sup>87</sup> has identified four essential elements in structured care that are likely to have a major impact on the quality, effectiveness and efficiency of care. These components are the promotion of self-management, a comprehensive system to support clinical management, evidence-based support for decision-making and the use of clinical guidelines. The presence of at least two of these components is associated with improvement in outcomes, particularly with respect to unscheduled care.

236. There is considerable scope for improving the quality of care and support in COPD against this overarching chronic disease management framework. Its introduction will rely on the efforts of commissioners and providers alike. To support this we need to ensure the development of integrated care pathways for COPD, which reflect the NICE clinical guidelines and other reliable sources of evidence for assessment and intervention. If PCTs decide to introduce and evaluate new models of care they should involve all sectors and agencies, including social care, so that high-quality care that is effective, efficient and offers value for money can be put in place to meet the needs of their local populations. Good clinical leadership will also be needed to ensure uptake across care sectors and agencies, and to reduce duplication in care provision.
237. Support for clinical networks, as outlined earlier in the strategy, provides a good means of encouraging the consensus that is critical to the adoption of new models of care, and the Department of Health has established a Lung Improvement Programme as part of NHS Improvement. Networks and supporting pilot projects will be developed (subject to available funding) to gather further information on innovation and improvement and to evaluate different models and approaches to COPD chronic disease management, including both the ongoing chronic element as well as episodes of acute care.
238. As part of this work, the options for providing 24-hour advice and information on care and identifying exacerbations will be

explored. NHS Improvement will also explore the important links between respiratory disease and cardiovascular disease, given the coexistence of these conditions in many people, and the opportunity for delivery of integrated care.

#### **Case study: South East Essex PCT**

South East Essex PCT has commissioned an integrated COPD service. This service has been planned through the local COPD network group. It was agreed that the respiratory consultants would provide clinical leadership for the whole COPD service. The network has developed guidelines for managing COPD, a self-management plan and a patient pathway. The respiratory consultants have started holding clinics in the community. Two-thirds of the clinics are conventional and the other third are multidisciplinary clinics where staff (usually community matrons) bring cases to be discussed without the individuals with COPD having to attend. This arrangement is outside of tariff and operates through a contract variation.

Integrated services include the Hospital at Home service to help prevent admission and discharge people earlier. People are assessed in hospital by the respiratory team and the care is provided by a generic intermediate care team. A community oxygen team has been established so that almost all oxygen assessments are now done in the community. In the first year this resulted in a cost saving of £129,812 in oxygen. Spirometry is provided in GP practices by an open access service at the hospital, and by a community service that is managed locally but is clinically accountable to the hospital.

Pulmonary rehabilitation has been provided for many years, but referral was only via respiratory consultants. The PCT has commissioned

the hospital to provide community pulmonary rehabilitation with direct access from primary care.

A course has been developed by the network in collaboration with the University of Essex. Respiratory consultants and respiratory clinic nurse specialists will be the course tutors. The course counts as 60 credits towards a BSc or MSc. A two-day course has also been developed for other staff caring for people with COPD (junior staff nurses, health care assistants in the community and in hospitals). This course includes areas such as spirometry and oximetry. A training course for spirometry has also been developed with the help of a local Breathe Easy group.

The philosophy of integration has led to improved communication with secondary care. The community staff now have access to hospital discharge summaries. Further IT solutions are being explored. These measures have reduced attendances and visits relating to COPD at hospitals and in the community.

A telemedicine monitoring scheme for people with COPD is being evaluated to investigate whether this reduces healthcare utilisation in both the community and hospitals. The smoking cessation programme has been extended to provide an increased service for secondary care patients. A case-finding programme for COPD in smokers is being developed.

Offering support to patient has been increased by providing improved patient information and by using Breathe Easy groups to introduce the concept of NIV. The hospital provides a home NIV service.



## Regular clinical review

239. Regular clinical review provides the best mechanism for anticipatory chronic disease management. Over time, regular reviews should reduce demand for unscheduled care and provide an opportunity to review the diagnosis and symptoms of people with COPD. A review allows clinicians to determine the appropriate timetabling of further assessments, consider current treatment, spot the emergence of complicating associated conditions and determine the need for specialist referral (including for surgical intervention or for transplantation) or for support from other agencies such as social care.<sup>88</sup>
240. Reviews should include the consideration of medication. The importance of reviewing a person's medication regimen at regular intervals has long been recognised and considered as good practice. The dangers of prescribing and taking inappropriate medicines are extensively documented; the practice leads to secondary morbidities from inappropriate medicines, wrong doses, incompatibilities and confusion from the multiplicity of medicines prescribed. Regular review of treatment and effective medicine management can help to avoid medication-related problems.<sup>89</sup>

### Elements of a regular clinical review

*GOLD stage 1 (Mild) FEV1/FVC <70%, FEV1 80% predicted*

Content: Update COPD register, smoking cessation advice, medication review and educational advice on how to stay healthy, promotion of exercise, immunisation, impact assessment.

*GOLD stage 2 (Moderate) FEV1/FVC <70%, FEV1 50%  
80% predicted*

Content: Update COPD register, smoking cessation advice, medication review and educational advice, participation in rehabilitation referral and exercise therapy, exacerbation review and advice, immunisation, impact assessment.

*GOLD stage 3 (Severe) FEV1/FVC <70%, FEV1 30%  
50% predicted*

Content: Update COPD register (including End of Life if relevant), smoking cessation advice, medication review, oxygen assessment, rehabilitation and exercise maintenance, exacerbation review and advice, surgical assessment, self-management action plan review, immunisation, impact assessment.

*GOLD stage 4 (Very severe) FEV1/FVC <70%, FEV1 30% predicted*

Content: Update COPD register (including End of Life), smoking cessation advice, medication review, oxygen and nasal ventilation assessment, rehabilitation referral, surgical assessment for volume reduction surgery or transplantation, exacerbation review and advice, self-management action plan review, immunisation, impact assessment.

As recommended by NICE, as a minimum, those with mild and moderate COPD should have their management plans reviewed annually, and those with severe/very severe COPD six monthly, or as clinically indicated.

Review should also be triggered by any change in symptoms or following an exacerbation. When any new treatment or medical device is started the patient should be reviewed within one month.

241. Critically, such a review would provide the opportunity for partnerships to be developed, self-management plans to be reviewed and further educational and information needs to be addressed. Ideally, we need to find simple composite outcome measures for use in regular review that are valid, reproducible and responsive to change. The Clinical COPD Questionnaire (CCQ)<sup>90</sup> has these characteristics, but is composed of ten questions. Shorter questionnaires need to be developed similar to the recently launched COPD Clinical Assessment Tool, which measures the impact of the disease on an individual. **The Clinical Assessment Tool will be piloted and evaluated to assess its value within regular reviews.**

### COPD Assessment Test

The COPD Assessment Test (CAT) is a new patient-completed instrument that has been designed to provide a simple and reliable measure of health status in COPD. It will complement existing approaches, such as FEV1 measurement, in assessing COPD patients by providing a simple method of quantifying the impact of COPD on the patient's health. The CAT has undergone a rigorous, scientific development process, and the first validation studies show that it has properties very similar to much more complex health status questionnaires, such as the St George's Respiratory Questionnaire, that are used in research studies. However, it takes only a fraction of the time to complete, making it suitable for routine use. Further validation studies are under way in Europe, the USA and Asia.

242. Patient Reported Outcome Measures (PROMs) also measure the impact of diseases or conditions on individuals, since they are measures of an individual's health-related quality of life. They are short, self-completed questionnaires, which measure health-related quality of life at a single point in time, using items that have been validated as being of importance to those people who suffer with the diseases or conditions in question. The Department of Health will be piloting the collection of PROMs data for several LTCs, including COPD and asthma, during 2009/10. The ambition is to begin an initial rollout of PROMs for LTCs from 2010, followed by full national implementation from 2011/12. Any new data collections would need to be cleared by the Review of Central Returns (ROCR).

### Re-assessment

243. We also recommend that people diagnosed with COPD, irrespective of severity, should have the following investigations and assessments performed every three years, in addition to any that may have been undertaken as part of other review processes:

- spirometry, performed by competent and, trained individuals to national standards and subject to quality assurance processes;
- blood gas status (by both oximetry and, for those with an oxygen saturation less than 92%, arterial or capillary blood gases);
- MRC dyspnoea scale; and
- HRCT, if breathlessness is disproportionate to functional impairment or if the individual is displaying bronchiectatic phenotype.

244. Further research is needed on the observable physical characteristics of people with COPD, and how these might affect their clinical management. The reliability of different clinical phenotypes in identifying discrete groups with different outcomes is uncertain, but their incorporation into care delivered by the strategy should be encouraged as this data becomes available.

### Quality and Outcomes Framework

245. The Quality and Outcomes Framework (QOF) is part of the General Medical Services contract for general practices; it provides financial rewards to general practices for the provision of high-quality care. The changes to the QOF in 2009/10 are intended

to benefit both people with COPD and the NHS, and will support the introduction of a review processes.

246. Two further additions have been recommended to the QOF, and have been submitted to NICE through the QOF Topic Selection facility:

- the percentage of people with COPD with an MRC dyspnoea score of 3 or higher who have been offered pulmonary rehabilitation; and
- the proportion of people with COPD with an MRC dyspnoea score of 3 or higher who have had pulse oximetry recorded during the previous 15 months.

247. Current QOF indicators require practices to hold a register of people with COPD. The practice is also required to record FEV1 and MRC dyspnoea score. Therefore, adding an oximeter reading to this register is feasible. Referral to pulmonary rehabilitation could also be added to the register, although for the data to be meaningful, a mechanism for reporting whether people with COPD had completed a course of pulmonary rehabilitation would need to be found and would be subject to ROCR approval. However, NHS Employers and the General Practitioners Committee have agreed that there will be no changes to the QOF in 2010/11 ([www.nice.org.uk/aboutnice/qof/qof.jsp](http://www.nice.org.uk/aboutnice/qof/qof.jsp)).

248. A key element associated with the NHS implementing the strategy relates to the establishment of integrated models of care involving other sectors such as social care.

## Evidence-based treatment and management

**Recommendation 13: All people with COPD should receive evidence-based treatment using a structured medicines management approach. A step-up approach to smoking cessation intervention as part of preventive management strategies should be taken.**

249. Evidence-based treatment recommendations for people with COPD form a central part of the clinical guidance issued by NICE, which has been updated and is out for consultation ([www.nice.org.uk/guidance/index.jsp?action=folder&o=46080](http://www.nice.org.uk/guidance/index.jsp?action=folder&o=46080)). All people with COPD should receive treatment in accordance with this guidance and which is based on presenting symptoms, their wishes and the clinical views of healthcare professionals who are looking after them. In all cases of COPD (irrespective of severity), treatment should be optimised to control and/or minimise symptoms to ensure that people living with the disease can play an active part in everyday life.
250. Medicines management refers to the systems and processes to achieve the clinical, cost-effective and safe use of medicines to ensure that people get the optimum benefit from their medicines, while at the same time minimising potential harm.
251. Medicines are an integral part of the treatment of people with COPD. As with the treatment of many LTCs, medicines bring a number of benefits to people with the disease. However, the realisation of these benefits, and the avoidance of ineffective or harmful medicines use, requires the appropriate choice and use of medicines by healthcare professionals, people with COPD and their carers.
252. Medicines form an important part of the integrated care of the person with COPD, but are not the only way of improving well-being. Other strategies, such as pulmonary rehabilitation, are also considered in the strategy, as are the ways in which these different approaches to the management of COPD can be combined.
253. A medicines management guide, which will support NICE guidance on medicines adherence, will be published by the Department of Health alongside the strategy. This guide will not set out to provide detailed evidence-based recommendations about the finer points of medicines use or treatment guidelines; its purpose will be to provide practical ideas and suggestions about the safe and effective use of medicines for people with COPD.
254. The guide will help PCTs and NHS trusts to implement the medicines management aspects of the national strategy for COPD. It will also provide guidance for people with COPD, helping to ensure that they are fully engaged in decisions about the medicines prescribed for them and the impact these decisions may have on their daily activities.
255. The guide will deal with a range of broad issues that, if properly addressed, should result in the safe and effective management of medicines by healthcare professionals, resulting in improved health outcomes for people with COPD.

## Smoking cessation interventions

256. The health gains achieved by stopping smoking are indisputable. These gains are not just in COPD, where stopping smoking is of proven benefit, but also occur in other conditions such as cancer, cardiovascular disease, diabetes and osteoporosis. Stop smoking services need to offer a long-term programme that is flexible enough to deal with an individual's needs. It can take as many as seven or eight attempts for a smoker to quit; therefore programmes need to consider this and have robust systems to follow up those who have used the service and offer further help if needed.
257. It is important that there is access to behavioural support and recommended stop smoking pharmacotherapies (e.g. nicotine replacement therapy including combination therapy, varenicline and bupropion) that greatly increase the chances of stopping smoking. Evidence-based stop smoking interventions, which combine behavioural support and pharmacotherapy, offer the best chance of stopping smoking, and therefore avoid or significantly reduce the impact of lung disease. NHS Stop Smoking Services are available throughout the country offering free stop smoking support to all smokers through a range of interventions and a variety of access points.
258. Extensive literature on stopping smoking demonstrates that success rates increase with the intensity of the intervention provided, ranging from 2% for brief opportunistic advice

from a GP to 13–19% for intensive behavioural support plus pharmacotherapy. The advent of varenicline as a stop smoking treatment approved by NICE may further enhance quit rates within certain groups.

259. Stop smoking services should also take into account other smoked substances that may have an impact on lung health, such as cannabis. Links could be made with local drug teams to address this issue.
260. NICE has published public health guidance on *Workplace interventions to promote smoking cessation* (<http://guidance.nice.org.uk/PH5>), *Brief interventions and referral for smoking cessation* (<http://guidance.nice.org.uk/PH1>) and *Smoking cessation services* (<http://guidance.nice.org.uk/PH10>).

## Reducing psychological distress

261. Many people with COPD have psychological problems, including depression and anxiety. Recognising these issues is an important aspect of COPD care. Psychological problems can be treated by a range of pharmacological and non-pharmacological treatments, including complementary and alternative medicines (CAM), although the majority of research in this area has been conducted on people who do not have COPD.



262. In providing a recommendation for the management of psychological distress in people with COPD, the data from depression in general suggests that the type of therapy is unimportant. What does matter is the therapist's effectiveness and belief in the therapy and the person's confidence in and liking for the therapy.<sup>91,92</sup> It should be noted that people with cancer are often given an option of a range of psychological therapies including CAM, and these therapies palliate the psychological distress associated with the disease. People with COPD would also benefit from a range of therapeutic options.
263. There is some evidence in COPD of the potential value of using validated tools for identifying individuals who are most in need of more formal psychological interventions, and of embedding cognitive behavioural therapy (CBT) principles into review assessments and pulmonary rehabilitation/self-management programmes. However, there are clear merits and benefits from the inclusion of a psychologist within a multidisciplinary respiratory/ COPD team to provide input, where necessary, for people with severe anxiety and depression and guidance for improving the mental health and well-being of all people with COPD.<sup>93</sup>

#### **Case study: Promoting self-management and psychological well-being**

South West London and St George's Mental Health NHS Trust piloted a programme funded by Integrated Primary Care Commissioning to support self-management and well-being in an area covered by approximately 27,000 people. Out of 589 people with COPD, it was estimated that around 25% were likely to have anxiety or depression. This led to an increase in the functional limitations caused by COPD and increased utilisation of healthcare resources. These people were offered a six-week psychoeducation group supported by a respiratory nurse and a mental health worker. Approximately 60 people attended the group. Family and friends were welcome to attend, and twice-yearly workshops were run to help them increase their knowledge and help support those with depression.

Provisional results suggest that there have been substantial health gains – with a PHQ-9 reduction from a pre-intervention mean of 9 to a post-intervention mean of 4. The pilot also demonstrated considerable cost savings of nearly three times the cost of intervention. Average length of stay for this group fell from 14 to 6.6 days, and there was an 11% drop in occupied bed days.

264. In order to better inform the NHS in this area, we will review methods for identifying those people with COPD who have more severe needs and who require intervention, and for embedding CBT principles more broadly into ongoing assessment and review, as well as into pulmonary rehabilitation programmes. Where possible, these methods will be incorporated into pilot projects being undertaken by the national Lung Improvement Programme.

#### **Surgical and non-surgical physical interventions**

265. There is a range of surgical and non-surgical physical interventions in COPD. With advances in science and technology, together with improved outcomes in the NHS, these will need to be considered as part of the treatment pathway for the future.

266. Currently, relatively small numbers of people with COPD receive assessment for surgical or non-surgical physical intervention, often later on in their disease. In order to achieve better outcomes for people by early assessment for suitability of surgical and new non-surgical techniques, a pathway of care will be developed considering each of the interventions outlined below and piloted as part of the national Lung Improvement Programme.

#### **Lung volume reduction surgery (LVRS) for emphysema and lung transplantation**

267. This approach is where an area of poorly functioning lung is removed by surgery in order to give the remaining lung more 'room' to work and to improve chest wall and respiratory muscle mechanics. The surgical technique has evolved and the usual

approach is now by unilateral video assisted thoracoscopy (VATS). The technique is best suited to people with severe exercise limitation and target areas (heterogeneity) of emphysema in the upper lobes. Where bilateral heterogeneous disease is present, a bilateral (often-staged) procedure is favoured. Several studies have confirmed the effectiveness of the procedure in carefully selected people with emphysema. Mortality rates are around 5% and, despite careful selection, about 25% of people still fail to benefit. Careful case selection is important and the procedure is best performed in centres with experience and with a multidisciplinary approach.<sup>94</sup>

#### **Non-surgical volume reduction techniques**

268. Further approaches are likely to include non-invasive techniques such as endobronchial valves, biological volume reduction and airway bypass.

#### **Bullectomy**

269. Patients with giant emphysematous bullae benefit reliably from excision by the same mechanism as those with heterogeneous emphysema. Such patients are less common, but are more likely to benefit from open or VATs surgery.

#### **Lung transplantation**

270. In the UK there are five centres undertaking lung transplantation for patients with COPD. A shortfall in suitable donor organs means there is an upper age limit of 65 years for transplantation

of a single lung. However, the increase in associated co-morbidities in patients over 60 means that in practice very few patients over the age of 60 can be considered for transplantation. Transplantation is considered for a patient with a poor quality of life whose life expectancy is less than two years. Referral for transplantation in COPD should only be considered in patients who continue to deteriorate despite optimal medical and surgical therapy, including smoking cessation, maximal bronchodilator treatment, rehabilitation, long-term oxygen therapy and endoscopic or surgical lung volume reduction, where feasible. The definition of the appropriate timing for transplantation is complicated because symptomatic COPD patients may have a relatively good prognosis. Referral for transplantation could be considered when there is:

- a history of hospitalisation for exacerbations associated with acute hypercapnia (carbon dioxide retention);
- pulmonary hypertension or cor pulmonale or both, despite oxygen therapy; and/or
- FEV1 of less than 20% and either a reduced carbon monoxide transfer factor of less than 20% or homogenous distribution of emphysema.

271. Providing patients are appropriately selected, the results of heart–lung transplantation, single lung transplantation and bilateral sequential single lung transplantation are good. The one-year survival rate for patients receiving such transplants at centres in

the UK lies between 70% and 80%, with a three-year survival rate of 55–60% and a ten-year survival rate of 40%. The most important complications leading to death are opportunist infections and the development of obliterative bronchiolitis.

### Home oxygen

**Recommendation 14: All people with COPD and hypoxaemia should be clinically assessed for long-term oxygen therapy and reviewed at regular intervals, and existing home oxygen registers should be reviewed.**

272. People with severe COPD need regular assessment for the presence of arterial hypoxaemia. Those who meet the clinical criteria for prescription of home oxygen need specialist assessment with arterial blood gas measurement according to current guidelines.
273. Home oxygen therapy includes a number of modalities for oxygen provision:
- Long-term oxygen therapy (LTOT) refers to the use of home oxygen, usually provided by a concentrator, to patients with evidence of arterial hypoxaemia. It is usually given for at least 15 hours per day. There is no evidence for benefit in people with COPD with a PaO<sub>2</sub> greater than 8kPa (2). As the prescription of home oxygen is based on blood gas levels, all those who are candidates for home oxygen must undergo a full

assessment with blood gas analysis in a specialist home oxygen assessment service.

- Ambulatory oxygen therapy refers to the use of portable oxygen during exercise and activities of daily living; it is used for patients on LTOT. It may also be useful in a smaller group of people with COPD without hypoxaemia, who have evidence of exercise-associated hypoxaemia.

274. However, many people with COPD have considerable disability and the prescription of ambulatory oxygen, which in England and Wales is based on hours of usage per day, has to be carefully matched to need. Those people requiring ambulatory oxygen to assist with daily activities will need further specialist assessment to determine the correct flow of oxygen. A small group of people with COPD who are not hypoxaemic at rest, but who develop exercise-associated hypoxaemia, may also be suitable for ambulatory oxygen and require specialist assessment according to current guidelines. All those suitable for ambulatory oxygen should be monitored to ensure that its provision is allowing greater exertion and freedom of activity outside the home. They should also be offered pulmonary rehabilitation and subsequent maintenance exercise programmes.
275. Short burst oxygen therapy is the use of short periods of oxygen to relieve breathlessness. Despite widespread prescription of home oxygen for this purpose, evidence for benefit is currently weak. Thus, people with severe breathlessness should be referred

for specialist review to manage their condition and short burst oxygen therapy should only be considered if other interventions have not been effective. Short burst oxygen therapy should not be normally prescribed for the relief of breathlessness in people with COPD.

276. All those on home oxygen require follow-up, as their condition may deteriorate with worsening hypoxaemia and higher flow rates may be required. At the same time, the level of use of ambulatory oxygen may change and the prescription should reflect the current requirements.
277. The Department of Health will be developing advice on the content of a home oxygen assessment and follow-up service for people who might require oxygen therapy.
278. The Home Oxygen Service provides oxygen therapy in their own homes to around 85,000 people in England, of whom about 60% have COPD. The total cost of the service in England is around £110 million. In some areas there is no quality assured assessment of people being prescribed oxygen. In PCTs that have introduced a review of their oxygen registers, coupled with the introduction of a formal assessment service, up to £400,000 has been saved in one year. We estimate that by reviewing existing home oxygen registers and by proper assessment of potential savings in this area, if this scale of savings were replicated it could amount to between £10 million and £20 million of savings a year across England.

## Exercise and pulmonary rehabilitation

**Recommendation 15: All people with COPD should be advised to undertake moderate exercise according to their condition. People with functional impairment should be referred for quality assured pulmonary rehabilitation.**

279. People with COPD develop progressive and irreversible narrowing of the airways that is associated with muscle weakness, causing breathlessness and reduced capacity for activity. This results in respiratory disability, especially in those with more severe disease, and a corresponding increase in dependence on health and social care resources.
280. People with mild COPD are generally not sufficiently disabled by their condition to warrant participation in formal pulmonary rehabilitation programmes (MRC dyspnoea grades 1 or 2). However, our focus on the promotion of physical activity for the population of England is changing.
281. The Department of Health recently launched a £75 million integrated campaign called Change4Life to promote physical activity in the context of the prevention of obesity/overweight. In addition, a national Physical Activity Action Plan was launched in early 2009 and the Olympics Legacy Action Plan will seek to encourage 2 million more people to be physically active by 2012. The success of these initiatives will influence the future health and well-being of the whole population, potentially including those with COPD. Those with mild disease will get particular benefit if they are encouraged to take exercise as part of their regular control regime.
282. People with mild COPD should receive the same physical activity messages as the general population – at least 30 minutes of physical activity, 5 times a week. This message may need to be tailored to overcome negative expectations about physical activity, including getting out of breath. Positive messages need to underscore the importance of maintaining an ability to carry out activities of daily living. The important message is about volume (150 minutes per week, which can be broken down into chunks of 10 minutes or more). In addition the meaning of ‘moderate’ needs clarification (feeling warm and breathing more heavily than usual).
283. Until now, the amount of public funds spent on promoting physical activity by the NHS have been relatively low. In London, whereas physical inactivity has been estimated to cost the NHS around £17 per person per year, PCTs spent only an estimated 85 pence per person to promote physical activity in 2008/09.<sup>95</sup> This funding difference is relevant to the management of COPD, as there may be insufficient good-quality physical activity programmes within a given area to meet the physical activity needs of those with the condition, from prehabilitation through to maintenance options after rehabilitation.



284. For those with moderate or more advanced COPD, pulmonary rehabilitation is an essential part of the non-pharmacological treatment pathway. Pulmonary rehabilitation refers to a combination of supervised exercise training with a comprehensive education programme and psychological support aimed at changing behaviours. There is very strong evidence that it improves exercise tolerance and health-related quality of life, as well as reducing breathlessness and an individual's use of the healthcare system.<sup>96</sup>

**ATS/ERS definition of pulmonary rehabilitation (PR)**

**'An evidence-based multidisciplinary and comprehensive intervention for people with COPD who are symptomatic and often have decreased daily life activities. Integrated into the individualised treatment of the patient, PR is designed to reduce symptoms, optimise functional status, increase participation and reduce healthcare costs through stabilising or reversing systemic manifestations of the disease.'**

285. Most supervised programmes in England run twice weekly for 6 to 12 weeks (the length of programmes where demonstrable benefits have been observed), but there are also shorter programmes on offer and, in some areas, longer-term maintenance programmes. Although physical training is the central focus of programmes, this is normally accompanied by disease education and self-management advice.

286. The National Audit for COPD has found that the number of areas offering pulmonary rehabilitation has increased in the last three years, but questions remain about the overall quality of these services.<sup>97</sup> Coverage is not currently equitable across England, programme content varies (potentially affecting effectiveness and benefits to the individual and the system), and access may often be limited by low capacity and long waiting lists. There is also no consensus on how the improvements gained by a pulmonary rehabilitation programme can be maintained, or what elements of the programme are critical to success.

287. **For this reason, we propose to publish advice on pulmonary rehabilitation providing:**

- **advice to commissioners on specifications for high-quality rehabilitation services; and**
- **practical advice for healthcare practitioners and service providers.**

288. As identified in our Consultation Impact Assessment, ensuring the widespread use of pulmonary rehabilitation would bring annual savings of around £5.5 million a year.

**Recommendation 16: People with COPD should be encouraged to learn how to help manage their condition themselves and how to have positive interactions with healthcare professionals and others about their condition. They should also be encouraged to engage with others who have COPD in order to promote exchanges of information, support and advice.**

289. People with COPD want information, advice, education and support. Many will want to understand their condition in detail. Those that do should be encouraged to take ownership of their condition and thus feel more confident in managing it.

290. *The expert patient*<sup>98</sup> suggests that, among other things, patients will need to know how to:

- recognise and act on symptoms;
- make most effective use of medicines and treatment;
- comprehend the implications of professional advice;
- access social and other services;
- manage work and access the resources of employment services;
- access chosen leisure activities; and
- develop strategies to deal with the psychological consequences of illness.

291. While some people may not want to be active participants in care, they should be encouraged to develop an understanding of their condition.

#### **Case study: Birmingham OwnHealth**

In 2007, Birmingham East and North PCT teamed up with Pfizer Health Solutions and NHS Direct to trial Birmingham OwnHealth, a telephone-based self-management service for people with a range of chronic conditions, including COPD.

Having already achieved real improvement in very high patient satisfaction, the PCT has committed to spreading the programme to reach 27,000 people by 2013.

The programme is seeing tenfold savings across the PCT. Birmingham OwnHealth is projected to make savings in the region of £32 million a year from 2012.

292. Self-management is the term applied to the programme that teaches the skills required for concordance with medical treatment, gives encouragement as necessary to change behaviour, provides emotional support and promotes an active lifestyle. Recent reviews suggest that this approach is beneficial in reducing hospital admissions.<sup>99,100</sup>

293. Self-management education and an action plan need to be provided to every person with COPD, even if their condition is not yet severe. This information should also be combined with

an action plan for worsening symptoms or exacerbations, with appropriate rescue medication supplied or arrangements made to receive this at an individually agreed point. An assessment of the individual's ability to self-manage (in conjunction with their carer as appropriate) should be part of the regular review process.

294. An individual's personal goals are an important consideration. These are likely to be quite modest and achievable. For example, a goal may be to return to work or simply to conduct the basic activities of daily living. Realistic goals should be discussed with the person with COPD and should provide a target for improvement. They should be informed by an assessment of the impact of the disease on an individual using, for example, the recently published CAT that will be formally assessed as part of the pilot projects.
295. The overall aim of self-management is to ensure that the individual lives with dignity, equality and respect in daily life, and allow them to live the life they choose to live, while working with them to ensure that they receive the information and care they need.

#### **Case study: Telehealth**

NHS Direct and NHS South East Essex Community Healthcare have embarked on an exciting partnership project, to pilot 'telehealth' services to people in the NHS South East Essex area.

Telehealth involved using technology in a person's own home to record clinical information that is specific to a person's long-term medical

condition, such as weight or blood pressure. The clinical information (commonly referred to by healthcare professionals as 'clinical indicators') will then be monitored in a remote location by NHS Direct.

Analysing any trends that may occur within specific medical conditions is very important, as this enables clinicians to take regular remedial actions before a patients' condition becomes worse or severe (acute).

Commissioned by NHS South East Essex, this project brings together NHS Direct, NHS South East Essex Community Healthcare, Docobo Ltd, Choose Independence Ltd and local patients.

This project has four main aims:

- To improve people's understanding of their condition, and how they can manage and cope with symptoms better.
- To improve the way in which healthcare staff prioritise their workload through effective use of vital signs data.
- To create case management capacity because of more informed home visits and interventions.
- To reduce the number of hospital admissions through effective case management.

To achieve this, carefully selected people with a primary diagnosis of COPD will be able to regularly record agreed data in their own homes. This information will be monitored by staff at NHS Direct, who will then contact the person to provide support and advice about taking medicines and using equipment. After examining

the information and using agreed protocols, NHS Direct will then alert the community services teams to make a decision on the appropriate level of intervention required.

This partnership work has already enabled the rapid procurement and deployment of telehealth equipment with full support structures, which means the project has gone from the drawing board to monitoring 65 patients in only 7 months.

Throughout the inception of this project, the community services teams have continued to provide full support to people with COPD. It is hoped that in the future this service will enhance their ability to provide first-class care to patients in the community, even though patients may be at home with a medical condition.

296. Currently there is no consistent approach to the provision of self-management tools for people with COPD. **As part of our work programme, toolkits will be developed to support implementation, drawing on evidence that demonstrates quality outcomes.**
297. Self-management skills can be taught within a formal pulmonary rehabilitation programme or separately by interview or training manuals. **However, we will support a project to evaluate the training and support needs of people with COPD, both to self-manage and to engage better with their local healthcare professionals.**

## Personalised care planning

298. The 2006 White Paper on community health services, *Our health, our care, our say*,<sup>101</sup> makes a commitment that everyone with an LTC will be offered a personalised care plan by 2010. This is re-affirmed in *High Quality Care for All*<sup>102</sup> – the final report of the NHS Next Stage Review. Personalised care planning means that people with COPD should be offered a discussion about their condition, what is important to them and what their goals are. They should also be offered information (this could be in the form of an information prescription, as described on page 57) and support for self-care as part of the discussion.
299. Personalised care planning is not a one-off discussion or tick-box paper exercise. As stated earlier, clinicians working with people with COPD should approach the discussion with a view to listening to what is important to the individual, and supporting them to understand their condition, the impact it will have on their life and what they can do for themselves to be confident to manage it better. They should see the individual 'in the round' and recognise that there are many other things that could be significantly impacting on their health and well-being, such as anxiety, isolation and care needs.
300. The care plan is a record of the outcome of this discussion and can be a written or electronic document. Specific actions to achieve goals such as getting out more, stopping smoking or

getting back to work can be recorded in the care plan. The care plan should always be owned by the individual and may be called different things; for example, for people with COPD this is often known as an action plan or a self-management plan. The important point is that a discussion has taken place focusing on the individual's wider needs with the aim of supporting them to understand their condition and to take control, and that this is recorded in whatever form is appropriate.

301. Further information and guidance on care planning can be found at: [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_093354](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093354)

### **Support for self-care**

302. Self-care is about people taking responsibility for their own health and well-being, such as taking their medication properly and taking action to be fit and healthy. Supporting people to self-care means supporting them in the decisions they make to manage their LTC. It is also about offering individuals the right to information and support at the right time, empowering them to take a more active role in their health and well-being in order to improve their quality of life.

303. *Your health, your way* sets out to patients and the public for the first time what services should be available to support them to self-care. These fall under five key pillars of self-care:

- education and training;

- peer support;
- tools and devices;
- information; and
- healthy living.

304. More information on *Your health, your way* can be found on NHS Choices at: [www.nhs.uk/Planners/Yourhealth/Pages/Yourhealth.aspx](http://www.nhs.uk/Planners/Yourhealth/Pages/Yourhealth.aspx)

305. Proactive management of LTCs through these approaches has been shown not only to improve patient satisfaction but also to reduce the use of primary and secondary care services through reductions in GP appointments, outpatient appointments and emergency admissions.

306. Pharmacy is well positioned to provide personalised health advice within local communities. Guidance on how pharmacy staff can be enabled to become health champions and health trainers will be published.<sup>103</sup>



## Management of exacerbations

**Recommendation 17: The quality of the identification and management of exacerbations should be improved and all people with COPD who have an exacerbation should be reviewed afterwards to ensure that their treatment remains optimal and relapses are reduced to a minimum.**

307. For the purposes of the strategy for COPD, and as a minor modification of the definition in the NICE COPD guidelines,<sup>104</sup> an exacerbation of COPD is a sustained worsening of an individual's symptoms from their usual stable state, which is rapid in onset. Commonly reported symptoms are worsening breathlessness, cough, and increased sputum production and change in sputum colour. Worsening of these symptoms often necessitates a change in treatment. Other diagnoses (such as pneumonia, pneumothorax, pulmonary embolus and cardiac failure), which may mimic or complicate exacerbations, should be considered and excluded when appropriate.
308. COPD exacerbations are associated with worse quality of life,<sup>105</sup> faster disease progression<sup>106,107</sup> and increased mortality.<sup>108</sup> They are also a significant cause of hospital admission, readmission and considerable healthcare costs.<sup>109</sup> Some people with COPD are prone to frequent exacerbations; these 'frequent exacerbators' are people requiring two or more courses of antibiotics and/or corticosteroids in a 12-month period.
309. Prompt or early presentation for treatment from the onset of exacerbation symptoms has been shown to improve outcomes.<sup>110</sup> Thus, it is important that people who develop exacerbations, together with their carers, are able to understand and recognise exacerbation symptoms. As outlined earlier in the strategy, options for access to 24-hour advice for people with COPD will be investigated as part of the national work programme so that people receive optimal information and advice about their worsening symptoms and exacerbations.
310. Most COPD exacerbations can be assessed and managed in the community. When people have developed exacerbations, specialist advice on COPD will need to be available that should be part of a locally agreed, integrated care pathway. Models of provision will be piloted and evaluated for their ability to impact on reducing hospital admissions or readmissions as part of the national Lung Improvement Programme. Some exacerbations may be mild and self-limiting and may only require an increase in regular inhaled medication.
311. However, most exacerbations require therapy with antibiotics and/or corticosteroids, depending on their severity and effect on the person's daily activities. People with more severe exacerbations will require access to specialist care to undergo investigations such as measurement of arterial blood gases, a chest radiograph and assessment of therapy, and this needs to be built into local commissioning arrangements.

312. The severity of an exacerbation is also affected by other pre-existing conditions (co-morbidities) that are commonly found in this group and need to be recognised.<sup>111</sup> Thus, a complex exacerbation has one or more of the following features:
- the presence of respiratory failure;
  - the presence of co-morbidities requiring active intervention;
  - failure of first-line therapy; and
  - any other cause for concern by a member of the multidisciplinary team.
313. Given the impact of exacerbations on the progressive nature of COPD, they should be followed up with a review when the individual is clinically stable to ensure that treatment remains optimal and any residual or changed symptoms are dealt with promptly. After severe exacerbations, individuals may require a further course of pulmonary rehabilitation, especially the exercise component.
314. There should be effective communication between all those involved in the care of the person with COPD, particularly following a review after an exacerbation. Particular problems arise with medications (including oxygen therapy), for example, following hospital admission. Strategies to improve communication include appropriate and prompt communication of discharge summaries and the use of paper-based or IT-based patient-held records.

315. Some people will manage their own exacerbations – either with increased inhaled medication if the exacerbation is mild in severity, or with oral corticosteroids and/or antibiotics if the exacerbation is more severe, according to their individual care plan. People who are able to self-manage their exacerbations should receive clear instructions as to how to make contact with a healthcare professional in the event of failure of therapy.
316. Where people have managed their COPD exacerbation themselves, they should inform a healthcare professional, ideally within two days of the start of exacerbation therapy. In these circumstances, the care plan and self-management plan need to be reviewed within six weeks of the onset of symptoms of exacerbation.

## Acute care

**Recommendation 18: All people with COPD in respiratory failure should be issued with oxygen alert cards, and ambulance staff should be able to recognise and respond appropriately to respiratory failure in COPD.**

### Transfer to hospital

317. People with COPD may need transport to hospital if they develop a severe exacerbation. These people may be in respiratory failure complicated by hypercapnia. Any oxygen provided must be at a low flow setting to prevent worsening

hypercapnia. All ambulance staff therefore require training in the presentation of COPD exacerbations and management of respiratory failure in such individuals, according to the British Thoracic Society (BTS) acute oxygen guidelines, which will be addressed as part of the guidance document on workforce requirements to accompany the finalised COPD strategy.<sup>112</sup>

#### Case study: London Ambulance Service

The London Ambulance Service is working with the Whittington Hospital in the development and implementation of a joint scheme that aims to transport people with COPD who need to be hospitalised, assess individual cases, and enable the person to stay at home where possible. This is done through the following process:

- The lead clinician involved in a person's care provides information to the London Ambulance Service on the name, address, diagnosis, treatment approach and agreed care pathway.
- This data is stored on the London Ambulance Service database, and alerts the ambulance crew in the event of an emergency call.
- Data provided enables the crew to assess a person's condition accurately and reduces the risk of crews providing inappropriate treatment.

318. At present, ambulances do not carry equipment for blood gas estimation, but oximeters should be available to detect

hypoxaemia. All people with COPD who are at risk of developing hypercapnia with an exacerbation should be provided with oxygen alert cards, where details of their blood gases and use of supplemental oxygen are documented.

#### Early discharge and care by specialist teams on presentation

**Recommendation 19: People with COPD should receive a specialist respiratory review when acute episodes have required referral to hospital. They should be assessed for management by early discharge schemes, or by a structured hospital admission, to ensure that length of stay and subsequent readmission are minimised.**

319. People with COPD presenting to hospital often have severe exacerbations complicated by respiratory failure. It is important that the exacerbation is accurately diagnosed,<sup>113</sup> that complications of the exacerbations are treated, including respiratory failure, and that other conditions that can mimic the exacerbation are considered.<sup>114</sup> Pre-existing conditions also need to be recognised and treated.
320. Evidence from a UK audit of management of COPD exacerbations in secondary care has shown that outcome is improved in hospitals where specialist respiratory physicians are present.<sup>115</sup> Thus, people require assessment by medical teams with experience in the management of respiratory failure in COPD.

321. People presenting with hypercapnic respiratory failure need to be assessed rapidly for suitability for non-invasive ventilation (NIV). Hypercapnia may be exacerbated by use of supplemental oxygen therapy as people with COPD exacerbations and respiratory failure have reduced respiratory drive. Controlled oxygen therapy must therefore be used in this setting according to the BTS acute oxygen guidelines.<sup>116</sup>
322. People with COPD who have hypoxaemia should receive controlled oxygen therapy to achieve a target oxygen saturation of 88–92%, and then further therapy needs to be adjusted with arterial blood gas measurements.
323. There are various models of care available for people presenting with exacerbations, including self-management and avoidance of hospital admission, with schemes such as Hospital at Home and early supported discharge once assessed and reviewed in a hospital setting by specialist respiratory healthcare professionals.<sup>117</sup> These Hospital at Home and early supported discharge schemes have been shown to be as effective as similar schemes in reducing rates of hospital readmission, but are preferred by people with COPD and are cheaper than usual care.<sup>118</sup> Currently the availability of these schemes is patchy across England, but they have the real potential to improve both the quality and efficiency of services and to reduce the cost of the acute episode.
324. People with COPD, their carers and anyone involved in their care in the community, such as primary care physicians, community matrons or the ambulance service, may require access to specialist advice, either by phone or by direct contact. The options for this provision will be explored as part of the national Lung Improvement Programme.
325. Transfer of information between all health and social care professionals involved in the acute care of people with COPD is required, as is the development of shared records. How this can be improved and streamlined will be explored, together with potential improvements, as part of the work of the national Lung Improvement Programme.

#### **Hospital admission**

326. During admission, the opportunity should be provided for education and review of the management of an individual's COPD by the specialist respiratory team. This is to ensure that treatment remains optimal and the impact on progression of the disease is minimised, that there are clear discharge plans in place, including the early engagement and involvement of social care agencies, if appropriate, and that continued improvements in the length of stay and subsequent readmission rates are made. There is some evidence that exercise training early in the course of exacerbation recovery may reduce hospital admission, although studies to date are small and larger controlled trials of early intervention with exercise are required before firm recommendations can be made.<sup>119</sup>

327. It is suggested that a framework for a structured COPD hospital admission plan should be developed along the lines of the recently introduced cancer hospital admission plan, outlined below, and piloted and evaluated as part of the national Lung Improvement Programme before further advice is issued to the NHS. Given that hospital admission and readmission remains one of the most costly areas of COPD management, this is an area that the NHS itself needs to focus on and find its own solutions for ahead of further national guidance following piloting.

328. Work undertaken by NHS Improvement in the last two years focused on transforming care for cancer inpatients. The work focused on emergency admissions and identified four winning principles that made the difference:

- assessment prior to admission in accident and emergency departments/primary care and link to a specialist at the front door;
- defined inpatient pathways;
- daily senior decision-making ward rounds; and
- development of self-management models of care that help to prevent emergencies.

329. By applying any of these principles with some relatively simple innovations, the net result was at least a 25% reduction in bed days/length of stay. We will test these principles with the piloting as part of the national Lung Improvement

Programme. We believe that, if replicated on COPD, this could equate to a reduction of around 23,500 admissions, saving around £38 million per year.

### **COPD in hospital**

In hospital, the person with COPD has:

- a review of the management of their condition, treatment regimens, need for other investigations, and assessment of psychosocial and social needs and supportive care pathway requirements;
- a review for co-morbid conditions, as clinically indicated;
- an assessment of adherence and concordance with current medication and other interventions;
- access to physical mobilisation/exercise and assessment of the need for post-exacerbation rehabilitation programmes;
- the requirements for ongoing community-based interventions established, e.g. oxygen therapy, nasal ventilation; and
- information about:
  - diet;
  - recognising the symptoms of an exacerbation;
  - who to contact in the event of a future attack if this is not part of their current care plan;
  - stop smoking interventions, where appropriate;



- vaccinations, i.e. influenza and pneumococcal, where appropriate; and
- discharge arrangements, including a review two weeks after discharge.

### Invasive and non-invasive ventilation

**Recommendation 20: All people with acute respiratory failure should be identified and investigated promptly and offered treatment with non-invasive ventilation (NIV) with access to mechanical ventilation, if required.**

330. Non-invasive ventilation (NIV) through a nasal mask or facemask has been shown to reduce mortality, tracheal intubation and complications associated with invasive ventilation.<sup>120</sup> The use of NIV has also been shown to be highly cost effective.<sup>121</sup>
331. People with acute respiratory failure should be identified and investigated promptly and treated with NIV and controlled oxygen therapy, usually as the first-choice therapy, according to guidelines.<sup>122</sup> In view of the dangers of hypercapnia in such individuals, any supplemental oxygen therapy must be controlled during admission.<sup>123</sup>
332. NIV can be provided on specialist respiratory wards with appropriately trained staff and thus does not require intensive care admission. Facilities for NIV should be available in all acute hospitals where people with exacerbations complicated by

respiratory failure are managed. Some people will not be suitable for NIV, or will fail NIV, and will thus require access to invasive ventilation. People admitted to intensive care units should be those expected to receive sustained benefit in terms of both prolongation and quality of life. Respiratory physiotherapy during an acute exacerbation should be available for airway clearance, reducing the work of breathing and restoring functional status, and may include using the active cycle of breathing techniques,<sup>124</sup> the positive expiratory pressure mask,<sup>125</sup> positioning,<sup>126</sup> pursed lip breathing,<sup>127</sup> inspiratory muscle training<sup>128</sup> and rehabilitation early after onset of exacerbation.<sup>129</sup>

333. Those requiring invasive ventilatory support should be managed jointly by the critical care team and the respiratory specialist team. Equitable access to intensive care for all people with COPD should also be provided.
334. If not previously established, an individual's wishes should be sought about:
- accepting therapy with ventilatory support;
  - preferred place of care in conjunction with hospital-based pathways such as the Liverpool Care Pathway; and
  - advanced directives regarding escalation of care.
335. Any earlier decisions should be reviewed in light of the current condition of the person and with open and honest communication.

336. Those individuals with respiratory failure not suitable for ventilatory support should be offered and supported with an appropriate end-of-life care plan, with recognition of the individual's and relatives' wishes, which takes into consideration cultural and religious end-of-life care requirements. This is considered in Chapter 5.
337. **A supporting guidance document on the provision of ventilation services for people with COPD is due to be published alongside the national strategy.**

#### **Review following discharge**

338. Following hospital admission for an exacerbation, 30% of people with COPD are likely to be readmitted within a three-month period.<sup>130</sup> The reasons for readmission are complex and thus, after hospital admission, people require regular follow-up with a review of their medical condition, pre-existing conditions and psychosocial needs. In a community COPD study, 22% of people developed another exacerbation within 50 days,<sup>131</sup> and thus it is important that people who have been admitted to hospital are reviewed early, as mentioned earlier in this chapter.
339. All people who have suffered an exacerbation should be reviewed within six weeks following an exacerbation to ensure that recovery has occurred and management is optimal. Novel methods of remote monitoring may play a part in future care in people at high risk of hospital admission.

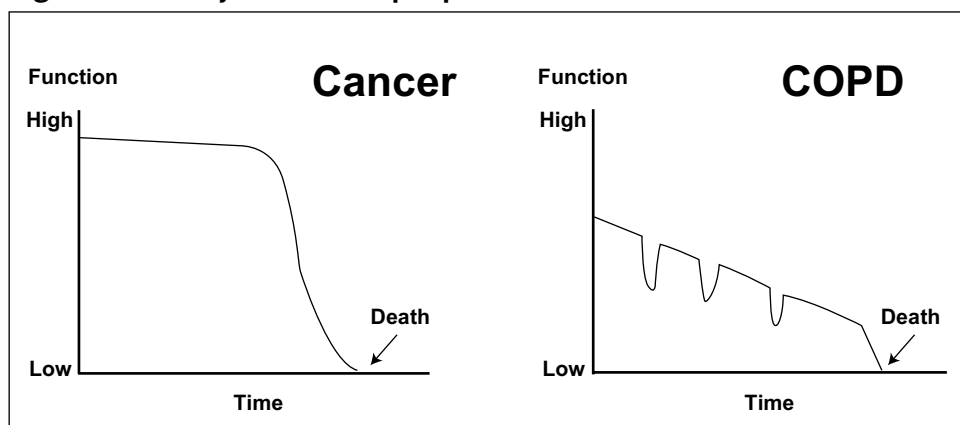
# 5. End-of-life care

The background of the slide is a photograph of tall grasses in silhouette against a sunset sky. The sun is a bright, glowing orb on the horizon, casting a warm orange and yellow light across the scene. The grasses are dark and thin, with long, pointed blades that catch the light from the setting sun, creating a delicate, ethereal effect. The sky transitions from a deep blue at the top to a soft orange near the horizon.

340. COPD is the cause of death for approximately 25,000 people a year. Despite a prognosis and morbidity rate comparable to lung cancer, people with COPD have far less palliative care input.<sup>132</sup>

341. There are two fundamental reasons for this: first, it is more difficult to give an accurate prognosis for COPD; and second, because only recently, specifically since the publication in 2008 of the Department of Health's Next Stage Review *Clinical Visions*<sup>133</sup> and the *End of Life Care Strategy*,<sup>134</sup> have specialist palliative care services become properly focused on the needs of people with conditions other than cancer.

**Fig: Disease trajectories for people with cancer and those with COPD**



342. The figure above illustrates the difference in disease trajectory between people with cancer and those with COPD. It is clear that it is difficult to determine the transition from diagnosis to the dying phase in those with COPD, and that people may either

continue for many years along this trajectory or could die during any acute exacerbation of the disease. In the UK, individuals with severe disease have a five-year survival rate of 24–30%.<sup>135</sup>

343. This prolonged trajectory towards death means that carers are often involved for many years in the care and management of their relative, often an all-encompassing role. Therefore, when the death eventually occurs it can affect the bereavement experience of those left behind.

### Summary of recommendations

**Recommendation 21:** There should be improved access to high-quality end-of-life care services that ensure equity in care provision for people with severe COPD, regardless of setting.

**Recommendation 22:** Access to information and appropriate support should be available for carers and those who are bereaved.

**To support implementation, the Department of Health will take the following actions (subject to available funding).**

Action 30: Pilot markers of a prognostic indicator to identify the end-of-life care phase for people with COPD.

Action 31: Publish core workforce skill requirements for end-of-life care in people with COPD.

Action 32: Pilot and evaluate an end-of-life care pathway for people with COPD, and also evaluate different models of support for carers.



## End-of-life care

**Recommendation 21: There should be improved access to high-quality end-of-life care services that ensure equity in care provision for people with severe COPD, regardless of setting.**

344. As for other long-term conditions, people with COPD require ongoing care throughout the progression of their condition. However, the natural history of COPD means that there are people who, as their disease advances (particularly as the end of life approaches), require palliative care as well as continuing disease management. This need can be difficult to identify unless the impact of the disease on the individual's daily life is assessed.

345. Attempts to construct a prognostic index for COPD, the BODE index, have confirmed the importance of identifying certain key elements of a person's condition. There is now evidence to show that this index can predict mortality. If the component parts of the tool are already available then it should be used. However, it is difficult to justify the resource requirements to carry out a six-minute walking test in all cases.

346. There are a number of markers that would help identify those people who require palliative care. These could include the following:

- severe airflow obstruction FEV1 < 30% predicted;
- respiratory failure;

- low BMI (<19);
- housebound (MRC 5);
- history of two or more admissions for acute deterioration in previous year (COPD and heart failure); and
- need for non-invasive ventilation for acute exacerbation.

347. The 'surprise' question ('would I be surprised if the person died in the next year?'),<sup>136</sup> which is part of the assessment process outlined in the Gold Standards Framework, may also be helpful. These approaches will need to be tested in a pilot programme to determine their prognostic accuracy.

### A working definition of end-of-life care

End-of-life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

Source: National Council for Palliative Care, 2006

348. A survey by the National Council for Palliative Care and the British Thoracic Society (BTS)<sup>137</sup> showed that there was patchy

access to specialist end-of-life care services. The National COPD Resources and Outcomes Project survey found that only 42% of respondents (those providing clinical services in the NHS) had formal arrangements for people to receive end-of-life care services for COPD.<sup>138</sup>

349. People with COPD should have access to specific supportive care, including, where necessary:

- a comprehensive holistic needs assessment leading to a care plan;
- active management of dyspnoea;
- active management of pain;
- identification and management of anxiety and depression;
- management of cachexia and fatigue;
- management of nausea and vomiting;
- assessment and provision of home oxygen for palliation of symptoms;
- assessment of information needs;
- choice about place of care in management of acute exacerbations;
- preference for non-invasive or invasive ventilation and DNAR ('Do not attempt resuscitation');
- religious and spiritual support;

- recognition of the dying phase, with planned and co-ordinated care;
- preferred place of end-of-life care and death discussed with patient and relatives;
- social and financial support;
- advance care planning, for example using Preferred Priorities for Care;
- access to equipment; and
- support for carers, including into bereavement.

350. The needs of people within the terminal phase of their disease must be recognised and services put in place. At this phase of the disease, palliative rather than disease-modifying approaches are required that reflect the person's practical, social, psychological and spiritual needs. The needs of family and carer(s) should also be assessed, and support given by suitably trained and competent health and social care professionals throughout the last phase of the person's life, and afterwards into bereavement.

351. This requires identification and management of people with terminal illness. These people will need to be managed according to best practice guidelines, for example the Liverpool Care Pathway<sup>139</sup> or Gold Standards Framework.<sup>140</sup> The development of locality registers will help assist the identification and management of people approaching the end of life.



352. It is the responsibility of all health communities to ensure that there are clear pathways to access end-of-life care. Suitably trained and competent health and social care professionals should provide for the needs of people approaching the end of life.

#### **Understanding COPD decisions regarding future treatment**

According to a study of people with COPD by the National Heart and Lung Institute at Charing Cross Hospital, discussions about end-of-life care need to be carefully tailored to individual needs.

This study, involving three focus groups of people with COPD whose condition had led to hospitalisation, discovered how far they wished to be involved in decisions about end-of-life care. The study revealed that people had mixed views about when it was appropriate to discuss future care treatment and that some were in denial about their disease. However, most felt it was clearly inappropriate to discuss these issues when they were ill and in hospital.

The authors of the study suggest the best time for this conversation might be at the first review after discharge, and this could be aided if patients were given some material in advance to help them think about the issues.

The study indicates that communication between doctors and people with COPD is often 'suboptimal', but most people said they would prefer to discuss end-of-life issues with their consultant, GP or a respiratory nurse.

353. The Department of Health and the National End of Life Care Programme have published, with Skills for Care and Skills for Health, core principles and competences for end-of-life care and for health and social care workers.<sup>141</sup> Further work is being undertaken to map these competences to existing nationally recognised competence frameworks, such as the Knowledge Skills Framework and the National Occupational Standards. E-learning modules are also being developed across four key areas (communication skills, assessment, care planning and symptom management). There are also 12 pilot sites supporting the development of communication skills for both health and social care staff at basic/essential, intermediate and advanced levels.

### **Bereavement information and support**

**Recommendation 22: Access to information and appropriate support should be available for carers and those who are bereaved.**

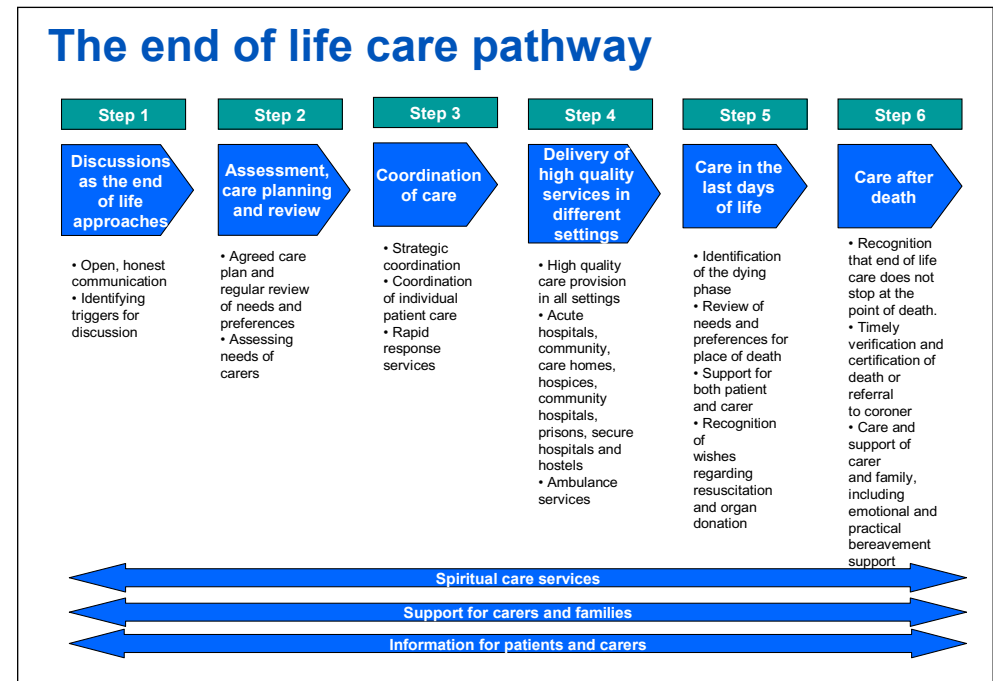
354. As outlined in the Department of Health's *End of Life Care Strategy* (2008), bereavement information and support should be available as part of end-of-life care provision. This was highlighted as an area of concern by carers of people with COPD.
355. Potential solutions range from formal bereavement services to less intensive bereavement care. Currently no model of provision exists for bereaved relatives of people with COPD who may

be long-term carers, although individuals do seek support from voluntary organisations such as Cruse Bereavement Care. National work is under way through the Bereavement Partnership Project funded by the Department of Health and co-ordinated by Cruse and the Bereavement Services Association, which aims to provide a menu of solutions bridging the gap between acute hospital and voluntary bereavement support organisations.

356. This work will be used to inform a national pilot and evaluation, aimed at supporting individuals with COPD and their relatives along the end-of-life and bereavement pathway.

357. The Department of Health's *End of Life Care Strategy* set out a commitment to pilot and roll out surveys of bereaved relatives as a way to measure the quality of care that people receive at the end of life. Previous research has shown that surveying the views of relatives provides a valid proxy measure in an area where it is difficult, if not impossible, to obtain feedback from the patients themselves. The pilot will run until January 2011, and the end product will both inform how the national survey will be taken forward, and also provide guidance for commissioners and service providers to support them in undertaking their own local surveys.

Figure 5: The End of Life Care Pathway



# 6. Asthma



358. Asthma is a long-term condition that primarily affects the air passages in the lungs.<sup>142</sup> Classic symptoms include breathlessness, tightness in the chest, coughing and wheezing. The symptoms are frequently variable and worse at night. Asthma may start at any age and is common in childhood. In adults it needs to be carefully differentiated from both COPD and other lung disorders. The condition can be controlled although, at present, there is no cure.
359. Disease onset reflects host factors (genetic and familial) and interaction with environmental factors. Once the disease is established, environmental factors such as viruses, allergens, pollution, tobacco smoke, workplace sensitisers, or exercise may all make the condition worse.
360. In England, the prevalence of asthma is among the highest in the world, with Quality and Outcomes Framework records suggesting that approximately 5.9% of the English population, around 3 million people, were affected in 2008.<sup>143</sup>
361. Asthma UK estimates that the direct healthcare costs associated with this condition are £1 billion,<sup>144</sup> and the latest available statistics on incapacity benefit suggest that asthma is responsible for at least 12.7 million lost working days per year.<sup>145</sup> GP prescriptions alone were estimated at £600 million a year in 2002.<sup>146</sup> Research shows that 80% of asthma expenditure is spent on 20% of people with the most severe asthma.<sup>147</sup>
362. Despite an increasing prevalence of asthma up to the 1990s, the last ten years have seen some progress. Overall, deaths from asthma have declined over the past decade, although around 1,000 people still die from asthma each year in England and Wales.<sup>148</sup>
363. The UK was one of the first countries to develop treatment guidelines: 2003 saw the publication of the first British evidence-based guidelines, which are now updated yearly.
364. Therapies have been introduced that improve the management and control of asthma and if services were optimally configured, there is a real expectation that the burden would be containable. However, at present, comprehensive guidance on commissioning services for people with asthma does not exist, nor are personal action plans or self-management plans routinely used to help people manage their asthma. There is also an urgent need for more research to understand why the condition has become more common, and to determine how we may introduce a primary preventive strategy.
365. Research consistently shows a strong link between poor asthma outcomes and areas of high inequality. For example, four in five spearhead primary care trusts (PCTs) have higher than average emergency hospital admissions for asthma, although it should be noted that a number of such PCTs in disadvantaged areas have lower than average admissions.<sup>149</sup> NHS trusts have recognised that access to good clinical care is influenced by levels of education, patterns of poverty and employment,



cultural attitudes and preferences, and location and accessibility of services. Addressing these local factors through effective commissioning is vital. Successful innovations have been piloted and evaluated locally, which need to be communicated within the NHS and adopted or adapted by commissioners with similar patterns of inequality. Similarly, some PCTs in spearhead areas have developed strategies to provide better integration of services to suit the needs of marginalised individuals. In general, good preventive care adapted to the diverse needs of local communities is effective in preventing and avoiding the cost of unnecessary hospital admissions. The priorities will vary according to local need.

366. The objectives of this chapter of the COPD strategy include recognition of the following:

- Prompt and accurate diagnosis of asthma is essential.
- In some cases expert assessment is necessary to separate the relative contribution of co-morbidities.
- Asthma exacerbations are potentially a failure in management of the person with asthma, and the circumstances surrounding the exacerbation need to be reviewed.
- Death from asthma should be regarded as an avoidable event and enquiry into each case is recommended.

- All people with asthma would benefit from self-management education, advice and support, including a personal asthma action plan, and services should be configured to ensure that this is available.

### Summary of recommendations

**Recommendation 23: The NHS should recognise similarities and differences between asthma and COPD, and should commission services accordingly to optimise the model of provision of care.**

**Recommendation 24: People should be managed according to evidence-based guidelines.**

**To support implementation, the Department of Health will take the following action (subject to available funding).**

Action 33: Develop a good practice guide on children's asthma and adult asthma.

Action 34: Subject to available funding, support pilot projects to gather further information on innovation and improvement in asthma care.

Action 35: Make recommendations to NICE on the development of asthma indicators in the Quality and Outcomes Framework.



## Two people's stories

### Case study 1

I often didn't take my preventer medicine during my early twenties because he felt my asthma had improved so that I didn't need to take my medicine so often. As a result, my asthma deteriorated and I suffered a serious asthma attack. I decided to visit my GP to seek advice on why my asthma had got worse and how I could achieve better control. The GP reviewed my asthma and explained the importance of taking preventer medicine on a daily basis and also checked my inhaler technique.

We also discussed whether I had been prescribed the most appropriate medicine and agreed a plan to monitor my symptoms. This included recommending that I use a peak flow diary to help me stay in control and to know when to go back to see my GP should my symptoms deteriorate.

I have now improved the management of my condition and continue to use my preventer inhaler on a daily basis. I also have an annual review with my GP and have used this opportunity to check my inhaler technique several times. As my asthma is now under control I rarely need to use my reliever medicine.

### Case study 2

I was diagnosed with asthma at age 45, 15 years ago. The diagnosis took some time, which I believe is quite common. I had a nasty chest infection and only after this had been successfully treated was asthma suspected. The condition was mild at first but has worsened in recent years. I do still get quite long periods of pretty good health but I also have periods of two to three months when I am significantly restricted by the condition and I am quite poorly. I am at stage 4 on the British Thoracic Society (BTS) scale. The medication seems to work for me some of the time but exacerbations can be quite nasty and prolonged. However, I have not yet had to be admitted to hospital on account of my asthma.

Throughout the 15-year period, I have had what I regard as excellent treatment from my GP surgery. One of the three GPs at the surgery is a respiratory specialist and I usually see him. I have always felt that my meetings with my regular GP have been genuine consultations. Treatment options have been explained and my views taken into account. It was some years before I knew there were BTS guidelines and that my GP had been following them. I had my first written personal asthma plan some years ago. These days I pretty much self-prescribe and see my GP only if I am particularly ill or have been using high dosages for a while to no effect, or if I suspect I have a chest infection as well as asthma. On two occasions my GP has felt it worthwhile for me to see a specialist to see if any other treatment could be helpful. Earlier this year the specialist I saw recommended I have some physiotherapy to help correct the way I breathe.

## Key similarities and differences

367. As outlined in the table below, there are both differences and similarities between asthma and COPD. This is followed by a description of some major issues for asthma.

**Table 3: Differences and similarities between asthma and COPD**

	<b>COPD</b>	<b>Asthma</b>
Age of patients	Generally older.	Asthma may start at any age, and is common in childhood.
Cause	Usually smoking related, but also linked to environment, employment and genetic pre-disposition.	Disease onset reflects host factors (genetic and familial) and interaction with environmental factors, but a strategy to prevent onset of disease is not yet possible. Once the disease is established, environmental factors such as viruses, allergens, pollution, tobacco smoke, workplace sensitisers, or exercise may all make the condition worse.

	<b>COPD</b>	<b>Asthma</b>
Diagnosis	Spirometry and other tests.	Careful history-taking, and trials of therapy monitored by recording symptoms, lung function, and other tests where appropriate. Under-diagnosis and delayed diagnosis may occur, and over-diagnosis may occur with insufficient diagnostic rigour.
Case finding	Value in case finding of undiagnosed COPD but no case for population screening at present.	No useful pre-symptomatic intervention and no case for population screening. Early diagnosis of cases of occupationally induced asthma is essential so that avoidance strategies can be undertaken.

	<b>COPD</b>	<b>Asthma</b>
Prognosis	People's symptoms deteriorate over time. They move through the tiers of the long-term conditions 'pyramid' over time, becoming increasingly reliant on intensive health services.	People's symptoms can be well controlled and they can maintain normal activities of daily life into old age with appropriate treatment – except those with the most severe asthma. Lack of control may result from both under-treatment or disease progression or both. Only a minority of people may be in tier 3 of the pyramid. Others have more variable disease necessitating increased support and care for only some of the time.
Predictability	The progression of COPD is relatively predictable, with function declining with time albeit at different rates in different individuals.	Asthma is not progressive but can be unpredictable, with people moving between different levels of severity with little warning.

	<b>COPD</b>	<b>Asthma</b>
Aims of care	To manage or slow the declining lung function and maximise the quality of life. Best treatment can improve quality of life and reduce the frequency of exacerbations.	To restore and maintain normal lung function and help people achieve as near normal activities of daily life as possible for the duration of their lives. To avoid acute attacks.
Management	COPD requires many different types of input to co-ordinate care, due to hospitalisation and treatment of exacerbations, need for pulmonary rehabilitation, management of co-morbidities and, for many, end-of-life care.	Largely managed in primary care by GPs, practice nurses and pharmacists. Specialist services will be needed for severe and potentially fatal asthma. There should be clear, agreed criteria to ensure there is appropriate referral from primary to specialist care. More severe asthma requires a multidisciplinary team-based approach to co-ordinate care and achieve best outcomes.

	<b>COPD</b>	<b>Asthma</b>
Treatment	Treated with some of the same medicines as asthma. Symptomatic COPD is treated with regular bronchodilation with high-dose inhaled steroids or ICS/LABA combinations reserved for more severe cases.  Long-term oxygen therapy improves prognosis in advanced disease.	Inhaled steroids are the cornerstone of treatment, with add-on, long-acting bronchodilators or other agents if necessary. Other anti-inflammatory or anti-allergic medicines are sometimes needed, e.g. oral steroids.  Oxygen is only used during severe exacerbations.
Triggers of symptoms	A person's COPD will become poorly controlled because their treatment is suboptimal or their condition is deteriorating.	A person's asthma will become poorly controlled for a variety of reasons, including under-treatment, infection or exposure to triggers, particularly allergens. People with asthma need to be taught how to recognise a deterioration in their condition and how to promptly adjust therapy and start reserve therapies to avoid progression.

	<b>COPD</b>	<b>Asthma</b>
Compliance problems	May be more about physical disability – inability to use an inhaler, or lack of access to care due to social isolation.	Due to range of factors – reduced perception of need for medication, associated with intermittent nature of the condition and tolerance of symptoms due to low expectations of control, lack of perceived efficacy, excessive concern about side effects, or lack of desire to take regular medication, or may simply be due to forgetting to take their medication if they are feeling well.
Co-morbidities	Many people with COPD may also have smoking-related co-morbidities such as coronary heart disease, and systemic problems such as osteoporosis, cardiac failure and muscle wasting.	Many people with asthma will have other allergic conditions, including hay fever and allergic rhinitis. In some cases expert assessment is necessary to separate the relative contribution of co-morbidities.

	<b>COPD</b>	<b>Asthma</b>
Exercise	<p>People with mild COPD should be encouraged to take regular exercise.</p> <p>Pulmonary rehabilitation programmes for moderate to severe COPD.</p>	<p>People with asthma should be encouraged to take regular exercise in order to be able to achieve normal activities of daily living.</p>
Avoidable death vs. condition causing death	<p>People with COPD usually die of COPD or an associated condition. Only smoking cessation and long-term oxygen use can reduce mortality.</p>	<p>The majority of deaths have avoidable factors. Death from asthma should be regarded as an avoidable event and enquiry into each death is recommended. With appropriate treatment most people with asthma die of other unrelated causes late in life.</p>

	<b>COPD</b>	<b>Asthma</b>
Palliative and end-of-life care	<p>Relevant for COPD where it is widely recognised that there is a major need for improvements to meet the specific needs of people with COPD at the end of their lives.</p>	<p>Deaths from asthma tend to occur acutely, so there is rarely a need for palliative care for asthma. However, because death is likely to have been unexpected, specialist bereavement support should be available for relatives, especially when the deceased was a young person.</p>



	COPD	Asthma
Self-management	There is evidence in other disease areas that outcomes are improved – more research is needed for COPD.	There is overwhelming evidence that outcomes are improved if the person with asthma has been given appropriate education and advice as to how to recognise a deterioration in their condition, if they have been taught how to increase their usual therapies and if they know when to start reserve therapies and when to seek urgent medical attention. Regular support and planned review are essential parts of this process.

368. In summary, the main differences between COPD and asthma are that:

- asthma is common in childhood;
- asthma is more common than COPD;
- the cause of asthma is not known;

- the airway narrowing in asthma is usually reversible and variable but gives rise to intermittent symptoms;
- optimal care for asthma should result in control of symptoms and reduced demands on healthcare; and
- the evidence in favour of education and self-management is strong for people with asthma.

### Overall aims of treatment

369. The overall aim of asthma management is to control the condition. With the correct treatment and care, in most cases, the symptoms of asthma can be well controlled and most people can enjoy a healthy and active life.
370. Some people have mild or infrequent episodes of coughing, wheezing and breathlessness that are easily controlled with occasional inhaled treatment. Others suffer physically and psychologically disabling symptoms on a daily basis. For many people and their families, asthma (and its treatment) is a cause of anxiety and distress: it often has a serious impact on the quality of life of both the individual and their family.

## Diagnosis and initial management

371. Not all wheezing and breathlessness is due to asthma; prompt and accurate assessment and diagnosis are essential if the appropriate management is to be given. Similarly, sometimes asthma can present without the symptom of wheezing. While asthma is a variable condition, the disease is often lifelong and people with asthma and healthcare professionals should be aware that respiratory symptoms occurring after a period of apparent good health are likely to represent a recurrence of the condition.
372. Asthma should be considered in anyone presenting with more than one of the following symptoms – wheezing, coughing, difficulty breathing, chest tightness – particularly if these symptoms:
- are frequent and recurrent;
  - are worse at night and in the early morning;
  - occur in response to, or are worse after, exercise or other triggers, such as exposure to pets, cold or damp air or with emotions or laughter; or
  - occur apart from colds,
- and if other features are present such as:
- a personal history of allergic disorder, such as hay fever or eczema;
  - a family history of allergic disorder and/or asthma;
- widespread wheezing heard on auscultation; or
  - a history of improvement in symptoms or lung function in response to adequate therapy.
373. Most asthma presents first in childhood, and accurate history-taking is important.
374. Investigations may include testing for allergic status, spirometry (or, if not available, peak flow), bronchodilator reversibility and, where appropriate, bronchial hyper-responsiveness using methacholine, exercise or mannitol, and/or testing for eosinophilic airway inflammation.
375. In adults with suggestive persistent or recurrent chest symptoms but a low probability of asthma, investigation should be undertaken for the possibility of an alternative diagnosis – such as COPD, bronchiectasis, obliterative bronchitis, large airway stenosis, lung cancer and sarcoidosis. In children who are investigated for asthma in primary care, but are found not to have it, the symptoms are usually due to recurrent infections, and no further investigations are necessary.
376. In most cases of airway obstruction in adults, differentiation between asthma, COPD and other diagnoses such as bronchiectasis is possible. Overlooking the possibility of reversible disease can result in significant unnecessary morbidity, and so tests to assess the degree of reversibility of airway obstruction are important before a definitive diagnosis of COPD is made.

377. The assessment of symptoms and lung function before and after high-dose inhaled or oral corticosteroids can be extremely helpful in distinguishing adults with asthma from those with COPD. People with asthma should have a review of possible co-morbidities. This may necessitate review of the upper airways and of allergic skin conditions. Psychological needs require sympathetic evaluation, and people with asthma may need access to cognitive behavioural therapy services. Dysfunctional breathing may require the intervention of speech therapy and physiotherapy services.
378. The initiation of treatments should be individualised and patient centred, reflecting the person's symptoms and severity of asthma including associated conditions. All people diagnosed with asthma should have appropriate access to the full range of treatments and interventions identified in evidence-based guidelines such as the BTS/SIGN (British Thoracic Society/Scottish Intercollegiate Guidelines Network) British Guideline on the Management of Asthma. People with asthma should only be prescribed an inhaler after receiving training in the use of the device and having demonstrated satisfactory technique.
379. As in COPD, smoking plays a part in asthma: stopping smoking is of great importance in asthma management because of smoking's adverse effect upon inhaled corticosteroid treatments and the increased risk of the development of fixed airways obstruction. Stop smoking services should be available to all people with asthma, and they should be offered support to stop smoking at

every opportunity. Those who are motivated to quit, but who are not successful, should be followed up and offered the next step up in treatment available.

## Environmental factors

380. Removal from exposure to an occupational sensitiser represents the only current cure for asthma. In asthma presenting in adult life, the possibility of an occupational cause should always be considered and appropriate specialist advice taken as necessary.
381. In other cases avoidance of an environmental trigger, where possible, may reduce morbidity. While many environmental triggers (e.g. viruses or grass pollens) are not avoidable, reduction of exposure to others (such as aspirin use in an aspirin sensitive individual, or exposure to cats in a cat allergic person) can be very beneficial. Similarly, damp housing may be the trigger for asthma triggered by mould.

## Asthma control and exacerbations

382. The aim of asthma treatment is to achieve high levels of control – defined by the removal of symptoms, quality of life impairment and exacerbations – which is of key importance to people with asthma both in terms of their current health status and their risk of future adverse outcomes.

383. Exacerbations are frightening and potentially dangerous for the individual and a cause of major expense for the health service. Each exacerbation, or requirement for emergency treatment, should be regarded as potentially representing a failure of management and should be used as an opportunity to improve the individual's understanding of their condition so that they can manage their asthma more effectively and reduce the risk of future exacerbations.
384. Asthma severity refers to the intensity of the underlying illness and the intensity of treatment required to achieve asthma control, and varies between people. Even in people with severe asthma, high levels of control should be possible with optimal treatment.
385. An integrated asthma service should be available to ensure that people with asthma and their carers can identify the symptoms of an exacerbation, self-treat where appropriate, and have access to prompt and appropriate treatment.

#### **Case study: Leicestershire**

A GP practice in Leicestershire has only 12% of people with asthma who classify as 'poorly controlled'. In contrast, Asthma UK believes that, across the country, 67% of people with asthma are poorly controlled. The Leicestershire practice puts its excellent care down to various factors.

- Every person with rhinitis is checked to see whether they have asthma and vice versa, and the practice ensures that control in these higher-risk patients is optimised.
- People who smoke are at higher risk of developing asthma, so smokers are also actively checked for asthma and are urged to take their asthma treatment regularly to avoid attacks.
- Inhaler technique is checked by doctors and nurses at every single visit.
- The practice has improved its patients' understanding of asthma by using a FeNO machine. This is a device that the patient breathes into, and it tells them instantly the level of their nitric oxide, which indicates the amount of inflammation in their lungs. People can therefore see how important it is to comply with treatment, and that taking their medicines regularly reduces the amount of inflammation in their lungs. Each test costs only £5, which is around the same price as a full blood count.

386. As with COPD, people with asthma admitted to hospital should be managed proactively and within a defined and agreed clinical protocol, by a specialist respiratory service. A difference between COPD and asthma is that Hospital at Home services (admission avoidance and assisted early discharge) have not been evaluated in asthma, and premature discharge can be dangerous. Structured handover of care back to primary care services is important, with early primary care follow-up and subsequent review by a community or hospital-based clinician trained in asthma management.
387. Emergency hospital admissions are extremely costly and account for £61 million of the estimated £1 billion cost of asthma to the NHS each year. However, it has been estimated by Asthma UK that at least £4.5 million could be saved if PCTs with higher than average admissions for asthma committed to reducing their rates to the national average.<sup>150</sup>
388. Nebulised treatment is rarely needed in asthma; and even in acute asthma, administration of bronchodilators via a metered dose inhaler (MDI) and spacer is usually preferable to the nebulised route. Routine inhaled preventive and reliever treatment is principally given by the inhaled route, via an MDI or a dry powder inhaler; choice of inhaler device should be influenced by a person's ability to use the device, and by their preference.
389. For those without life-threatening or severe features, guidelines recommend the use of press and puff inhalers plus spacer devices to administer bronchodilators in both adults and children (rather than the use of nebulisers).
390. The post-exacerbation review for people with asthma should:
- check inhaler technique and prescribe an appropriate device with which the person is confident and that they are competent to use;
  - review adequacy of previous therapy and that they are compliance;
  - assess possible avoidable precipitating causes (e.g. adverse reactions to alcohol, aspirin, non-steroidal anti-inflammatory agents, or occupational sensitisers);
  - identify the rare case where the worsening of the condition was truly sudden (brittle asthma) and where different self-treatment advice is appropriate; and
  - review the person's personal asthma action plan and ensure that they have adequate supplies of their reserve medications.
391. An important area for improvement in services is to ensure better liaison between hospital and community services in the follow-up of people after asthma exacerbations that require hospital attendance.
392. Primary care arrangements for the supply of repeat asthma medications should be optimised, with every person being encouraged to obtain repeat supplies when they start using their last full inhaler(s) so that exacerbations do not develop simply because of medication supplies running out.



393. Asthma is a highly prevalent condition but with a low mortality rate. Nevertheless, asthma deaths are often sudden and unexpected, and confidential enquiries into the circumstances of such deaths have proved helpful by focusing upon potentially avoidable factors from which lessons may be learnt for the benefit of others. Bereavement services are required for family, parents and carers of those who die from asthma.

### Self-management education and regular review

394. The evidence in favour of self-management support and regular review in asthma is overwhelming, but support is poorly implemented. As with COPD, all people diagnosed with asthma should be assessed for their ability to manage their condition and information should be given according to their needs and preferences. Any areas where knowledge, skills or confidence is lacking should be addressed through education and reinforcing strategies.

395. People with asthma should have a comprehensive care plan that they have been involved in developing and that is available to healthcare professionals and to other professionals such as teachers and social workers who may be involved with the person. The care plan should adopt an integrated approach ensuring that interventions are delivered in a timely manner by competent health and social care professionals with access to specialist services. It should include:

- a treatment and exacerbation plan (personalised asthma action plan);
- occupational advice where appropriate;
- the need for psychological support; and
- any other needs.

396. A written personal asthma action plan is a document that should be held by the person with asthma and should be delivered as part of structured self-management education based on symptoms, and where desired or appropriate. Such an action plan should contain three action points advising the person:

- when to increase their usual therapy;
- when to commence steroid tablets; and
- when to seek urgent medical attention.

397. Where objective monitoring is incorporated within such a plan, the person's best peak flow should be utilised to determine thresholds for action. The introduction of the personal asthma action plan should normally begin at the point of diagnosis and should be reviewed on a regular basis.

## Education and information for people with asthma

This list is intended as an example, which health professionals might adapt to meet the needs of individuals or carers. The purpose of education is to empower people to undertake self-management more appropriately and effectively. Information given needs to be tailored to the individual's social, emotional and disease status, and their age. Different approaches are needed for different ages, literacy levels and ethnicity factors, including on:

- nature of the disease;
- nature of the treatment;
- personal targets;
- identification of areas where the person most wants treatment to have effect;
- how to use the treatment;
- development of self-monitoring/self-assessment skills;
- negotiation of the personalised action plan in light of identified goals;
- recognition and management of acute exacerbations; and
- appropriate allergen or trigger avoidance.

Source: British Guideline on the Management of Asthma, *Thorax* 2008, 63, supplement iv, page 83.

398. Asthma can be a variable condition: monitoring of the condition and accurate assessment of control are important to reduce the risk of exacerbations and to maintain optimal lung function. Assessment of asthma should involve assessment by spirometry and peak expiratory flow rate and the use of structured questions and questionnaires, such as the Royal College of Physicians (RCP's) three questions, the Asthma Control Questionnaire (ACQ) or the Asthma Control Test (ACT). Results of these tests and questions, should be systematically recorded in the patient's medical records to allow comparisons over time and population estimates of asthma morbidity.
399. People with a confirmed diagnosis of asthma need to be assessed for severity and control of their disease, the presence of other coexisting conditions and the impact of the disease on the abilities and expectations of the individual.
400. Regular structured review and support of the person in their self-management is essential.

A review by a healthcare professional should include:

- an assessment of morbidity using a recognised and ideally validated instrument (e.g. RCP, ACQ, ACT);
- an assessment of the person's condition, including a self-assessment by the individual;

- an assessment and review of adherence/compliance with treatment, and side effects;
- observation of inhalation technique;
- consideration whether to step up or step down treatment;
- advice where appropriate regarding stop smoking therapies/referral to smoking cessation clinic;
- for those with difficult asthma (persistent symptoms and/or frequent exacerbation despite treatment at step four or step five), reassessment and reconfirmation of the diagnosis of asthma;
- assessment of any coexisting psychological morbidity (e.g. anxiety and depression) – it may also be appropriate to include assessment of the family. Specialist psychological assessment is recommended in cases of difficult asthma;
- assessment of co-morbidity, including associated allergies, upper airway disease and the possibility of dysfunctional breathing;
- for women, pre-pregnancy counselling regarding the importance and safety of continuing their asthma medications during pregnancy to ensure good asthma control;
- for those requiring steroid tablets either intermittently or continuously, assessment for bone density and medication for bone protection; and
- an assessment of ability to undertake activities of daily living and current exercise/activity levels, and advice on pre-exercise treatments.

401. Many people live with asthma for many decades. Arrangements for healthcare and review should be undertaken in a manner that is convenient for those with asthma – telephone follow-up has been shown to be suitable and effective for some.

### **Good practice guides**

402. The asthma field is already well provided for in terms of evidence-based guidelines, and the British Asthma Guidelines (a BTS/SIGN initiative) are regularly and dynamically updated.

403. At the end of December 2008, we established a multidisciplinary asthma steering group to extend the British Asthma Guidelines to include comprehensive guidance on commissioning services for people with asthma. It was further envisaged that this group would engage in other activities designed to improve asthma care, including production of a good practice guide for commissioners to guide them in developing and commissioning appropriate services for asthma.

404. As a separate but allied initiative, under the auspices of the National Clinical Director for Children, Young People and Maternity, a paediatric sub-group was set up to initially produce a good practice guide for asthma in children in a similar format to those previously produced by the Department of Health in other collaborative ventures.

### Quality and Outcomes Framework

405. The Department of Health has made the following three suggestions to NICE regarding asthma indicators within the Quality and Outcomes Framework:

- A new indicator on self-management support for adults and older children with asthma.
- ASTHMA 8 – on diagnosis using measures of variability or reversibility

*Proposed indicator: the percentage of patients diagnosed as having asthma from 1 April 2010 in whom the basis for a diagnosis of asthma, consistent with British Asthma Guidelines, has been clearly documented in the patient's medical record within three months of the diagnosis having been first recorded.*

- ASTHMA 6 – asthma review

*Proposed indicator: the percentage of patients (all ages) who have had an asthma review within the last 15 months undertaken by a healthcare professional with appropriate training, including specifically assessing control, and recording the result, using a recognised measure of asthma morbidity (the RCP's three questions, or similar); for example, Record: Daytime symptoms – yes, Night-time symptoms – yes, Activity impairment – no.*

406. These suggestions will be considered as part of the Quality and Outcomes Framework's topic selection facility at NICE.





# 7. Activities to support implementation of the national strategy





407. In accordance with the drive to devolve responsibility for NHS services to local organisations, this strategy lays great emphasis on local health and social care communities and the third sector taking responsibility for contributing to service change and improvement. But the Department of Health also has a role to play in developing tools, harnessing expertise and giving advice where appropriate on wider policy contexts; in providing support to the NHS to stimulate change, achieve integrated care pathways and new models of care provision; and to engage and involve clinicians to ensure that services meet the needs of local populations and drive up quality and efficiency.
408. In order to finalise the strategy, we will be considering responses to the consultation and developing a final equality impact assessment and other related documents. In order to deliver the strategy, we plan, subject to available funding, to undertake work on piloting different models of care, to help improve monitoring of data, to issue further guidance to the NHS, and to develop and deliver a workforce document and e-learning modules. While exact timings for delivery are not yet known, these will be clarified as we further develop our plans and will be clearly articulated in the finalised strategy. Most people present their action plan in the form of an 'action and timescale' table. We will also update the strategy with associated documents as and when the results of the pilots and research are known.
409. Targeting variation in primary care provides a major opportunity for improving quality and increasing cost effectiveness in the management of people with COPD. Across the length of the clinical pathway, from prevention to acute and chronic management to end-of-life support, activity in primary care will have a significant impact on patient outcomes. Although specialist care will be needed from time to time, the majority of contacts between most individuals with COPD and health professionals, and therefore most opportunities for proactive management, will take place in primary care.
410. At the same time, the primary care experienced by people with COPD varies substantially from place to place: even in similar populations, rates of diagnosis, prescribing and emergency admission can be very different. Therefore, an individual's chance of being admitted to hospital with a flare-up or even of having their COPD diagnosed can depend on which practice they are registered with. Such variation may adversely affect a patient's quality of life and prognosis, and can be very expensive for those who commission services.
411. Commissioners can help drive up quality in the care of those with COPD, improve outcomes for patients and reduce expenditure on unnecessary admissions by targeting this variation in primary care. The overall aim should be to ensure that the person is treated with dignity, equality and respect in daily life, allowing them to live the life they choose, while working with them to ensure that they receive the information and care they need. Primary care trusts (PCTs) should also work to develop services that reflect the needs of their local communities.

412. The following case study illustrates how this can be achieved by engaging with clinicians to provide leadership and by taking a whole-system approach to reducing variation and promoting systematic management.

#### **Case study: Knowsley**

NHS Knowsley identified that there was substantial variation between practices in a range of primary care indicators (e.g. prevalence recording, prescribing rates, non-elective admission rates) in COPD and other disease areas. Evidence of this variation, which could not be fully explained by population differences or other factors, was examined by the three practice-based commissioning (PBC) consortia, which concluded that the variation could have a significant effect on patient experience and outcomes and waste valuable PBC resources on avoidable admissions. In order to reduce unwarranted variation, the three PBC groups collaborated to form a Community of Practice (a clinical network) with GPs, nurses, consultants, commissioners and pharmacists with an interest in COPD.

The Community of Practice recognised that tackling variation is not just about improving the performance of individual clinicians and that many factors may contribute to differences between practices – e.g. a lack of nursing staff trained to manage COPD, poor access to reliable spirometry, inadequate systems for recall and follow-up, limited access to specialist clinical support, and the educational needs of the GP or nurse.

The Community of Practice worked with the PCT to develop a systematic response to this complex range of factors, with initiatives partly funded through PBC savings:

- a community-based COPD service providing support with diagnosis, management of exacerbations, admission avoidance and pulmonary rehabilitation;
- a local enhanced service to incentivise case finding, validation of diagnosis in existing patients, enhanced clinical targets and a programme of educational master classes;
- a partnership with two pharmaceutical companies which funded respiratory specialist nurses to work with practices to case find, to identify patients with suboptimal treatment, to conduct clinical reviews and to provide training for practice nurses; and
- a local clinical pathway and drug protocol to guide systematic disease management in local practices.

Key learning for the PCT and PBC groups included the substantial potential impact on patients and resources of targeting variation in primary care, the central importance of clinical networks for building clinical engagement and leadership, and the value of taking a whole-system approach to driving improvement.

## SHA clinical leads

413. To assist the implementation of the strategy, each strategic health authority (SHA) will appoint, subject to available funding, a clinical lead and a small supporting team. These teams, led by a clinician, will work with PCTs to help the development of respiratory networks at a local level and to support pilot projects to gather further information on innovation and improvement where there are gaps in the evidence.

## NHS Improvement

414. A great deal of effort has been, and continues to be, invested in the development of clinical networks for a wide range of conditions in different parts of the country. These have been particularly effective in cancer, diabetes, heart disease and now stroke and renal disease. To support the development and implementation of the strategy, we are therefore looking to facilitate, subject to available funding, the establishment of respiratory networks at a regional level.

415. We have asked NHS Improvement to support the development of networks and the pilot projects, and these projects will explore the important clinical and network links between respiratory disease and cardiovascular disease, given the coexistence of these conditions in many people with COPD, and the opportunities for delivery of integrated care.

## Pilots

416. Although the strategy is due to be published and promoted in 2010, experience suggests that it will take more than three years to implement fully. The strategy sets out what needs to be done over the short, medium and long term to improve treatment, care and support for people with COPD. It underlines the need for appropriate, integrated care services planned and delivered to suit individual needs from diagnosis to end of life. However, after that, it is largely up to the NHS and the public to ensure delivery, although Department of Health officials and national clinical leads will also have a role to play.

417. In order to facilitate implementation of the programme, and subject to available funding, we will be developing models of care that can help commissioners better design services for people with COPD and more broadly for respiratory disease. The following areas will be a priority:

- improved management of long-term conditions (inclusive of COPD) in a chronic care model;
- better access to diagnostics earlier in the pathway;
- availability of specialist advice and pulmonary rehabilitation;
- streamlined acute and planned care provision;
- improved end-of-life and bereavement care for non-cancer-related conditions; and

- the introduction of strategies to detect risk factors and early onset of disease and to prevent disease.

418. Our aim is to pilot approaches in these areas examining a variety of options and models for future provision. This work will be led by each SHA with support from NHS Improvement. More details are at Appendix 6.

## Products and organisations to support implementation

419. A number of publications are being developed to support the national strategy for COPD.

### Developing a COPD competent workforce

420. We need to support delivery of the national strategy for COPD by ensuring that people are assessed and managed by appropriately trained professionals at all stages of their disease. The COPD workforce guidance will provide examples of best practice in order to support healthcare organisations to plan their own high-quality workforce development initiatives.

421. We will aim to describe a framework for service commissioners and providers that will help them meet the aspiration that all people with COPD will be cared for by a competent and confident workforce with the knowledge and skills to deliver complex care to people with a complex disease. It will align with the Modernising

Careers programmes and pay particular attention to specific professions where these are relevant to the strategy.

422. To support adoption of best practice, a range of initiatives will be put in place:

- A competency framework will be described for the health and social care workforce, people with COPD and carers (the latter will be linked to the already published document *Common core principles to support self care*).
- An e-learning programme, produced in conjunction with NHS E-learning for health, will be developed to support competency development.
- We will commission an online resource combining both national and international educational resources to support professional development.

423. We will seek to influence pre-registration and post-registration curricula to ensure that the content of undergraduate education supports the delivery of the national strategy for COPD. We will work with Medical Education England and others to achieve this.

### Specifications for pulmonary rehabilitation

424. A pulmonary rehabilitation sub-group has been convened, with representation from professional groups, people with COPD and the British Lung Foundation (BLF). The main purposes of the sub-group are:

- to advise commissioners on specifications for good quality exercise and rehabilitation services; and
- to provide practical advice for practitioners.

425. A report will be produced and published with the national strategy for COPD.

### **Spirometry**

426. Many healthcare providers find it difficult to distinguish between COPD and asthma, and many are not trained in carrying out or interpreting spirometry, which is the main tool for diagnosing COPD.

427. While there have been national and international guidelines on the standards for spirometry for some years, there is obviously some difficulty in how these are implemented. In order to meet one of the main aims of this strategy – accurate and prompt diagnosis – we will be exploring ways in which the performance of spirometry can be improved. We have established a small working group of clinical experts who will consider how best to implement the spirometry guidelines already in existence, e.g. through the production of a good practice guide for healthcare professionals, and guidance on commissioning spirometry services.

428. This group will also consider how spirometry can be used as a tool for finding people who may have COPD and referring them for specialist diagnosis. There is currently no advice for carrying out this type of spirometry, and no guidance on the level of training that is required for healthcare professionals to carry

out spirometry at this level. This group will look to provide the advice required.

429. Another area where we feel spirometry could be beneficial is in its use as a motivational tool either to direct people to see a healthcare professional or to help them with stopping smoking. Many hand-held spirometers can now give people an indication of their lung age. These type of spirometers are easy to use and can be used in a range of settings by a range of personnel, not necessarily clinical. The group will explore how best this type of spirometry can be used to meet the aims of the strategy and help with raising awareness of lung health.

### **Non-invasive ventilation**

430. A group has been set up to develop a guide on the use of non-invasive ventilation (NIV) (which refers to the administration of assisted ventilation through either a nasal mask or facemask). The use of NIV reduces mortality and the rate of intubation, shortens hospital stays and prevents complications. People also find NIV more acceptable than invasive ventilation.

431. The group will look to develop a clear local pathway of care for people who require NIV as part of their therapy in secondary care, setting out:

- what areas the clinical decision-making regarding the use of NIV should address;
- the types of facilities and equipment available;



- the expected success rates;
- ongoing care and monitoring;
- educational needs; and
- NIV in special situations.

432. There group is also looking at:

- the benefit in the long-term use of NIV at home in selected patients with hypercapnic respiratory failure;
- the use of NIV in weaning; and
- quality control.

433. The report from the group will be available on publication of the strategy.

### **Commissioning**

434. The World Class Commissioning (WCC) programme is designed to raise ambitions for a new form of commissioning that has not yet been developed or implemented in a comprehensive way anywhere in the world. It is about delivering better health and well-being for the population, improving health outcomes and reducing health inequalities.

435. In order to commission services for people with COPD (and more broadly for respiratory disease including asthma), PCTs should:

- undertake a detailed population analysis and joint strategic needs assessment to identify the current and predicted incidence

of COPD within the population, paying special attention to demographic factors shown to be associated with COPD, such as deprivation or ethnicity;

- commission and actively support/performance manage a comprehensive range of prevention and promotion services to target reductions in lifestyle issues such as smoking, or management of conditions, such as pulmonary rehabilitation;
- work with clinicians, patients and providers to develop and define the local pathway of care for people with COPD – contracts with providers should include a detailed service specification for COPD that is flexible enough to meet the needs of individuals, setting out the roles and responsibilities of the provider in question;
- ensure consistent review of the pathway and monitor delivery against specification by providers to confirm that it delivers improved outcomes for people with COPD and continues to deliver care that matches the needs of the individual; and
- involve service users and clinicians in pathway review.

### **COPD indicators**

436. Good information on COPD care is needed by people with COPD, carers, commissioners, clinicians, service providers, researchers and policy makers. Each group will have somewhat different questions to ask and therefore different priorities for information.

437. Ideally, measurement should focus on outcomes. However, in the first instance SHAs, PCTs and local authorities may wish to consider what measures of structure and process they wish to collect to demonstrate progress on the implementation of their strategies. The Department of Health will be identifying some potential measures and will publish these with the finalised strategy.
438. The strategy proposes initiatives that will lead to better delivery of care and improve the lifestyle and outcomes of people with the disease. They will aim to improve hospital and primary care and the interface between the two, and so the strategy has to develop indicators that reflect all these aspects of care.
439. The success of the National Service Framework for coronary heart disease was, in part, based on creating achievable objectives and ways by which the progress towards those objectives could be monitored. Thus the Myocardial Infarction Audit Project (now the Myocardial Ischaemia National Audit Project, MINAP) was able to create a simple data collection tool that allowed the 'time to needle', 'call to needle' and secondary prevention prescriptions to be monitored as close to real time as possible. The indicators were developed by the service with the involvement of, and buy-in from, frontline clinicians. Within three years there was a dramatic change in practice so that 85% of people were treated promptly, and the associated absolute reduction in deaths after heart attack went from 13.9% to 11.9%, or 1,200 lives saved per annum.
440. Unfortunately, many indicators proposed by national bodies have proved less useful as they have not been felt to be relevant by the frontline staff and thus have not been taken up and used. We believe it is possible to make greater use of some of the existing datasets by:
- adding creative clinical thinking to the analyses;
  - gaining the active support of clinicians for the reports generated; and
  - making the results available to those whose activity generates the data.

#### **Indicators for Quality Improvement**

441. The Indicators for Quality Improvement (IQI) have been developed with the NHS and stakeholders and were published in 2009, bringing together indicators from existing national indicator sets, such as WCC, Vital Signs, the Quality and Outcomes Framework and the Healthcare (now Care Quality) Commission Annual Health Check. Clinical teams are now able to benchmark their performance against these indicators to drive quality improvements. The list is not complete, and over time indicators will be developed to fill gaps within a governance structure that is being embedded from January 2010. This will also ensure that relevant indicators are developed alongside quality standards. The full IQI list can be viewed at: [www.ic.nhs.uk/services/measuring-for-quality-improvement](http://www.ic.nhs.uk/services/measuring-for-quality-improvement)

### **NICE Clinical Guidelines for COPD**

442. The National Institute for Health and Clinical Excellence (NICE) published guidelines on the *Management of chronic obstructive pulmonary disease in adults in primary and secondary care* in 2004. The guidelines highlighted the following as priorities for implementation by the NHS:
- ensuring that people have an appropriate diagnosis of COPD confirmed by a competent professional performing spirometry; and
  - ensuring all health professionals managing people with COPD have access to spirometry and be technically competent when testing the person to avoid misinterpretation and incorrect diagnosis.
443. The guidelines also recommended:
- encouraging people to stop smoking;
  - providing effective inhaled therapy;
  - providing pulmonary rehabilitation for all who need it;
  - the use of NIV; and
  - the effective management of exacerbations.
444. NICE is currently undertaking a partial review of these guidelines and its recommendations are out for public consultation. Wherever possible we have ensured that there is consistency

between NICE's recommendations and the contents of this document. Further details can be found at: [www.nice.org.uk](http://www.nice.org.uk)

### **Centre for Evidence-based Purchasing**

445. The Centre for Evidence-based Purchasing (CEP) was part of the Purchasing and Supply Agency and is now part of NICE. It provides impartial information about medical technology to help the NHS make better purchasing decisions. CEP published a buyers' guide to spirometers in March 2009, reviewing 54 devices that were on the market in 2008 ([www.pasa.nhs.uk/PASAWeb/NHSprocurement/CEP/CEPproducts/CEP+catalogue.htm#Evidence%20reviews](http://www.pasa.nhs.uk/PASAWeb/NHSprocurement/CEP/CEPproducts/CEP+catalogue.htm#Evidence%20reviews)). The buyers' guide is intended to assist in the selection of spirometers for use in both primary and secondary care. We will work with NICE on other products to support intelligent procurement decisions in the implementation of the COPD strategy.

### **Health and Safety Executive**

446. The Health and Safety Executive's (HSE's) mission is the prevention of death, injury and ill health for those at work and those affected by work activities. The HSE, together with local authorities, is the regulator of workplace health and safety. It provides strategic direction and advice as well as enforcing the Health and Safety at Work etc Act and associated legislation, but the primary responsibility for ensuring that workplaces are safe both for those who work there and for members of the public who may be affected by work activities lies with the owner of the

business. Suppliers of materials and equipment and employees have responsibilities too. One of the key aims of the new HSE strategy – The Health and Safety of Great Britain – is to create healthier, safer workplaces through partnerships with other stakeholders. For more information, see: [www.hse.gov.uk](http://www.hse.gov.uk)

447. The causes of accidents in the workplace are generally well understood and the HSE will continue focusing on prevention. However, this is not always the case for ill health. Some ill health is clearly work-related, albeit with long latency in certain cases, while in other instances the causes are not solely work-related, or the seriousness of an illness may be exacerbated by non-work factors. COPD and asthma can both be caused by exposures at work and work is thought to play a part in the development of about 15% of cases of each of them. The HSE's intention is to concentrate, with stakeholders, on preventing work-related ill health while offering its expertise to support other programmes addressing the wider issues, e.g. the Government's Health, Work and Well-being initiative.
448. Each year an estimated 10,000 people die because of past exposure to harmful substances during the course of their work – about 98% of occupational-related deaths. The vast majority of these deaths are caused by cancer and COPD – an estimated 4,000 deaths – due to inhalation of harmful fumes, chemicals and dusts. The latency period between exposure and onset of these diseases can be anything up to between 50 and 60 years.

449. There are many other causes of long-latency disease, and the HSE is planning activities, working in partnership with stakeholders and suppliers, to embed messages and encourage a change in behaviour among workers in targeted industries where there are large numbers of people exposed to chemicals or substances known to cause long-latency diseases or which present the highest rates of incidence of these diseases.
450. We will work with the HSE to align approaches in the area of risk reduction and public messaging, working with the industrial sector and developing a competent occupational health workforce to identify and manage COPD in the workforce.

## Contributing activity by the third sector

### The British Lung Foundation

451. The BLF ([www.lunguk.org](http://www.lunguk.org)) is a charity supporting everyone affected by lung disease and working for positive change by campaigning, raising awareness and funding world-class research.
452. The BLF is working with the Department of Health to support the COPD strategy in the following ways:
- by testing methods of raising public awareness of lung disease in various UK locations, including telemarketing campaigns aimed at helping people to identify symptoms; and
  - by supporting volunteer user representatives throughout England.

453. These activities use a social marketing approach, based on the BLF's *Invisible Lives* report, to identify those postcodes that contain the largest numbers of people at risk of hospital admission for COPD and then targeting these to find people with undiagnosed COPD. This work has been undertaken following successful pilots funded by the Department of Health – the most recent being with South Tyneside PCT, outlined earlier in the strategy.
454. In addition, the BLF has been working with Nottingham City PCT and Islington PCT to help raise awareness of COPD.
455. Workplace testing has also taken place and has produced interesting results in hard-to-reach groups. Further, the BLF has written and produced a *COPD Self-Management Plan* that is on sale to PCTs to assist in the delivery of the strategy. There is also an exercise diary that assists pulmonary rehabilitation and which has been in use throughout the NHS over the last three years.
456. The BLF has started a new commercial arm of its operations to concentrate on providing implementation assistance for the national strategy.

### **Asthma UK**

457. Asthma UK ([www.asthma.org.uk](http://www.asthma.org.uk)) is the charity dedicated to improving the health and well-being of people in the UK whose lives are affected by asthma. It works with people with asthma, carers, healthcare professionals, researchers, the NHS,

government, schools and other stakeholders to improve the quality of life for people with asthma. Its 2008–11 strategy has five goals.

- To support the best science and promote dialogue to advance knowledge and treatments and secure improvement for people with asthma.
  - To influence the provision of high-quality services across the UK, ensuring that they can be reached by all people with asthma, especially those with the worst health outcomes.
  - To give people with asthma and healthcare professionals across the UK the knowledge, confidence and support to manage asthma effectively.
  - To champion the interests and priorities of people with asthma and achieve positive change on their behalf.
  - To increase their capacity to make a difference for people with asthma.
458. Asthma UK is in receipt of grants from the Department of Health to support the following areas:
- Local Asthma Impact Project (LAIP) in the North West of England: Asthma UK and Yorkshire and the Humber NHS are working on a second LAIP to improve asthma services in one of the country's asthma hot spots. This SHA is the only one to have a specific target to reduce emergency childhood asthma



admissions by 50% over ten years. Building on the experience of the first LAIP in the North West, Asthma UK is working with service users, carers, local clinicians, NHS commissioners, schools and local authorities through the already established regional asthma network to improve asthma management.

- Black and Minority Ethnic Seminars: Asthma UK is delivering ten asthma awareness sessions for black and minority ethnic people with asthma.

459. Asthma UK is also supporting work on developing a good practice guide for children with asthma and will work with the Department of Health to help develop products and tools to support the implementation of this strategy.

## QUIT

460. QUIT is a UK charity providing telephone counselling, web-based, email and community-based support to smokers who want to quit. The telephone and online services are available for 12 hours every day.

461. QUIT provides all smokers with information about lung health and COPD, its impact and the best way to minimise the risk of developing COPD.

462. QUIT is working with smokers to provide a counselling intervention, taking into account family history, so the counsellors can assess potential high-risk lifestyles by asking questions about smoking, diet and physical activity. After the initial counselling session, either by telephone or email, QUIT provides each smoker

with appropriate information about COPD including printed literature and a dedicated COPD web page on the QUIT website ([www.quit.org.uk](http://www.quit.org.uk)).

463. Additionally, QUIT provides a dedicated counselling service via the Quitline for smokers who have already been diagnosed with, or affected by, COPD. The Quitline supports smokers to take control of their own health, to manage their quit attempt and share responsibility for treatment in partnership with healthcare professionals.

464. QUIT is also reaching out to key groups, including minority ethnic groups, smokers with mental health problems and young people, providing information about lung health and COPD, its impact and the best way to minimise the risk of developing the disease. The charity is working on COPD resources for adults in six languages and a cannabis and lung health resource for young people. There will also be dedicated lung health pages on three websites ([www.quit.org.uk](http://www.quit.org.uk), [www.quitbecause.org.uk](http://www.quitbecause.org.uk) and [www.asianquitline.org](http://www.asianquitline.org)).

## National Council for Palliative Care

465. The National Council for Palliative Care (NCPC) is the umbrella organisation for all those who are involved in providing, commissioning and using palliative care and hospice services in England, Wales and Northern Ireland. The NCPC promotes the extension and improvement of palliative care services for all people with life-threatening and life-limiting conditions in health and social care settings across all sectors.

466. The NCPC has established groups of experts to help address this remit. One of these is focused on the needs of people with chronic respiratory diseases and has developed guidance on end-of-life care. This includes:

- user and carer perspectives;
- a national survey of respiratory and palliative care teams;
- examples of good practice; and
- mapping the needs of people with respiratory disease along the nationally recognised end-of-life care pathway.

For more information, see: [www.ncpc.org.uk](http://www.ncpc.org.uk)

467. The NCPC is in the process of developing communications guidance for professionals to help them to broach end-of-life issues with people who have COPD. Guidance will be based on patient and carer views about when and how they would like the issues to be broached. This will be launched alongside the COPD strategy.

468. In addition, the NCPC regularly produces publications and guidance to share information and resources between stakeholders, including a quarterly magazine, *Inside Palliative Care*, and e-news bulletins.

469. The NCPC has a regional structure with an elected representative in each SHA area. A series of local NCPC conferences in 2009/10 included consideration of specific issues relating to COPD.

The NCPC is also one of the Department of Health's strategic partners, giving it excellent access to the network of other third sector organisations working in health and social care.

## Contributing activity by professional groups

### British Thoracic Society

470. The British Thoracic Society (BTS) is a professional body whose members include doctors, nurses, respiratory physiotherapists, scientists and other professionals with an interest in respiratory disease. Its objective is to improve the care of people with respiratory and associated disorders. The BTS aims to achieve this over-arching objective in a number of ways:

- by promoting optimum standards of care (the Clinical Information section of the BTS website contains treatment guidelines, good practice guides and related audit tools, see: [www.brit-thoracic.org.uk](http://www.brit-thoracic.org.uk));
- by promoting and advancing knowledge about the causes, prevention and treatment of respiratory diseases (the BTS runs two large conferences each year and a range of short courses, and is currently developing an e-learning resource, see the Education Hub); and
- by promoting and disseminating research (through the Winter Meeting as well as the journal *Thorax*, published jointly with the *British Medical Journal*, see the Research section of the website).

471. The BTS is committed to working in partnership with a range of organisations to achieve its objectives. These partners include other respiratory health professional groups, organisations representing people and carers, medical and surgical Royal Colleges and other specialist societies. BTS members receive a bi-annual newsletter and a monthly e-newsletter. The chief executive has been a member of the Department of Health's strategic communications working group, which was set up to explore strategic communications issues relating to the strategy. The development and eventual dissemination of the strategy are a key part of the BTS's conferences.

472. Much of the work which the BTS has been doing in preparation for the publication of the national strategy for COPD has been undertaken in partnership with the Primary Care Respiratory Society UK (PCRS-UK) in the IMPRESS project (see page 126).

473. Also of relevance is the work that the BTS is doing in relation to smoking cessation. The British Association of Stop Smoking Professionals (BASSP) was established within the BTS in 2006. BASSP has over 80 members in primary and secondary care and works in close collaboration with other stakeholders. In 2008 BASSP produced a statement of minimum training standards. It has held three successful annual conferences, and ran a short course in conjunction with QUIT and the Roy Castle Lung Cancer Foundation which focused on smoking cessation and mental health issues.

### **The Primary Care Respiratory Society UK (formerly the General Practice Airways Group)**

474. The PCRS-UK is a professional society representing primary care health professionals interested in delivering the best standards of respiratory care. It is dedicated to achieving optimal respiratory care for all through:

- facilitating and leading primary care respiratory research;
- promoting best practice in primary care respiratory health through education, training and other services;
- representing primary care respiratory health needs at policy level; and
- supporting the development of primary care health professionals in respiratory medicine.

475. A range of COPD resources for primary care health professionals has already been developed by PCRS-UK ([www.pcrs-uk.org](http://www.pcrs-uk.org)). However, to support the launch of the national strategy for COPD, a faculty of PCRS-UK members has been convened and a communications programme developed. This programme is being supported by educational grants from Allen & Hanburys, AstraZeneca UK and Boehringer Ingelheim/Pfizer, and from the Department of Health.

476. The overall aim of the programme is to create high awareness and understanding of the national strategy for COPD and what it means for primary care health professionals, encouraging them to

implement it in their own practices and to improve the care and services they provide to people with COPD.

477. The programme will recognise the different levels of respiratory expertise and interest and utilise the flow of endorsement to drive the awareness, understanding and ultimately engagement within practices. This programme is the first stage of a longer-term plan and will focus on raising awareness and engagement during the pre-launch and immediate post-launch phases of the national strategy during 2010. By the end of this initial phase it is hoped that at least one per person per practice will be engaged and driving change to improve the care of people with COPD within their practice.

478. The immediate post-launch phase includes a range of initiatives, tools and ongoing communications to raise awareness and engagement including:

- a members' communication to announce publication;
- a quick reference guide summarising key points relevant to primary care from each section of the national strategy, with links to supporting resources;
- PCT mailing to encourage local action and onward dissemination of PCRS-UK materials;
- *Primary Care Respiratory Journal* supplement – a practical guide to the aspects of the national strategy most relevant to primary

care (funded by the Department of Health);

- a series of practical case studies to demonstrate how changes in management will improve outcomes;
- a review of existing opinion sheets relevant to COPD and the development of new sheets to fill current gaps;
- a teaching resource pack – a practical, working tool to be used by respiratory leaders to engage primary care health professionals (available to members only); and
- a one-day meeting of national leaders to equip them to drive local change (at a PCT and practice level).

479. This comprehensive range of resources and information will support primary care health professionals to engage with and implement the national strategy within their practice. They will be accessible within a dedicated section on the PCRS-UK website.

#### **Improving and Integrating Respiratory Services in the NHS**

480. Improving and Integrating Respiratory Services in the NHS (IMPRESS) is a joint initiative between the BTS and PCRS-UK.

481. *Effective Care – Effective Communication: Living and Dying with COPD* is an educational package from IMPRESS consisting of a DVD and a CD of PowerPoint slides ([www.impressresp.com](http://www.impressresp.com)).

482. This package has been made available free to over 3,400 clinicians. The DVD comprises short film clips of people with

COPD, carers' stories and views on diagnosis and end-of-life dialogue, an expert panel discussion on ways to approach these issues and tips on how to improve the consultation. The CD also draws out the key learning points, references and links to the latest evidence about COPD and publications and will support the national strategy. The film clips tell a powerful story, but the material is best used by a facilitator as part of an educational package on communication skills or COPD care.

483. During its development, IMPRESS became increasingly aware of the complexities involved in ensuring it reaches the relevant professionals and can be accessed in the most useful way to inform and change professional practice. The learning is complex and nuanced and is likely to require multiple roles of clinician and educator skilled in COPD, communications skills and end-of-life care. There are currently few clinicians who could undertake all these roles and IMPRESS believes a local communication skills course would often need at least two skilled facilitators.
484. IMPRESS is running two sessions to train clinicians in how to deliver and use the package. The sessions will work with a local network led by NHS Bristol across three PCTs (North Somerset, South Gloucestershire and Bristol) and also a national training event working with a multidisciplinary group of respiratory clinicians from across the UK. The first sessions ran in October 2009 and a national event took place in February 2010.
485. IMPRESS has also developed a commissioning guide for clinicians, managers and commissioners ([www.impressresp.com/Portals/0/IMPRESS/BPG%20Final.pdf](http://www.impressresp.com/Portals/0/IMPRESS/BPG%20Final.pdf)).
486. IMPRESS also offers examples of how to move care closer to home ([www.impressresp.com/Portals/0/IMPRESS/DeliveringRespCare\\_Final.pdf](http://www.impressresp.com/Portals/0/IMPRESS/DeliveringRespCare_Final.pdf)) as well as a case study in procurement of a community COPD service ([www.impressresp.com/Portals/0/IMPRESS/CommissioningCOPDservicefv.pdf](http://www.impressresp.com/Portals/0/IMPRESS/CommissioningCOPDservicefv.pdf)) and a guide to respiratory coding which is a key building block of all contracts ([www.impressresp.com/Portals/0/IMPRESS/Aguidetorespiratorycoding.pdf](http://www.impressresp.com/Portals/0/IMPRESS/Aguidetorespiratorycoding.pdf)).
487. IMPRESS is working on two new tools to assist commissioners. First, for those who wish to integrate their commissioning of COPD services into their existing work plans, it highlights how policies on clinical engagement, long-term conditions, efficiency and end-of-life care all offer significant opportunities to benefit people with COPD, and gives examples of how. Second, it is producing an action plan with real examples, offering 'bite-sized chunks' to enable a commissioning organisation to be ready for implementation of the strategy. It considers, among other things, needs assessment, provision of spirometry and extension of pulmonary rehabilitation.



### **National Chronic Obstructive Pulmonary Disease Audit**

(carried out under the auspices of the National COPD Resources and Outcomes Project)

488. The National COPD Audit 2008 was carried out by a partnership between the Royal College of Physicians, the BTS and the BLF with the aim of improving NHS services for people with COPD. The audit achieved participation from 98% of acute trusts and 73% of primary care organisations (PCOs) throughout the UK. Data was submitted on over 9,700 clinical cases of exacerbation with COPD; 2,800 people with COPD completed a survey about their condition; and 2,700 GPs completed a survey about their patients' circumstances prior to and following admission.
489. The five emerging reports have been widely disseminated to stakeholders. Individualised, benchmarked reports were produced for all participating trusts and PCOs to facilitate comparison with the national figures.
490. The Department of Health has funded the National COPD Audit since April 2009, enabling the COPD audit team to maximise the output of the audit data through activities including writing papers for publication, speaking at regional BTS meetings, and other speaking engagements.
491. The COPD audit team will support the Department of Health's Listening Events, which are planned to take place at each SHA in early 2010. The purpose of the events will be to discuss the

content and implementation of the strategy and to feed back National COPD Audit results at SHA level.

492. For more information about the National COPD Audit, see: [www.rcplondon.ac.uk/copd](http://www.rcplondon.ac.uk/copd)

### **Association of Respiratory Nurse Specialists**

493. The Association of Respiratory Nurse Specialists (ARNS) exists to promote a higher level of respiratory nursing practice through leadership, education and professional development and to influence the direction of respiratory nursing care. As a major representative of respiratory nursing, ARNS seeks to collaborate with other respiratory care organisations and relevant government and NHS initiatives in order to influence policy and developments for respiratory services as well as to promote the raising of standards and clinical effectiveness of respiratory care.
494. Through its bespoke courses, study days and conferences, ARNS aims to support its members to deliver evidence-based practice within the rapidly changing healthcare environment. Via its website and other means of communication, ARNS provides a supportive network for its members and encourages information sharing, best practice and research collaboration.
495. ARNS has recently opened up its membership to nurses registered with the Nursing and Midwifery Council who have a post-basic qualification in at least one aspect of respiratory care.

496. ARNS will be working with the Department of Health to help promote the national strategy for COPD and to encourage its members to facilitate its implementation. ARNS included a session on strategy at its conference in October 2009 and also plans workshops about the implementation of the strategy at its spring conference in 2010; ARNS also has plans to work collaboratively with PCRS-UK to develop tools to aid those in primary care to understand and more easily implement aspects of the clinical strategy. For more information, see: [www.arns.co.uk](http://www.arns.co.uk)

#### **Association for Respiratory Technology and Physiology**

497. The Association for Respiratory Technology and Physiology (ARTP) provides the only national, professionally recognised, qualifications in respiratory function testing and spirometry and promotes the highest standards of physiological measurement and treatment in respiratory practice using applied physiology through leadership, education and professional development and to be the guardians of respiratory measurement. An important function of the ARTP is the provision of opportunities for continuing professional development. The ARTP organises meetings and courses for all health professionals on respiratory topics around physiological measurement.

498. The ARTP works in conjunction with the BTS, PCRS-UK and other relevant organisations to produce national guidelines and standards for good practice in the performance of respiratory measurement or treatment. It works closely with the Department

of Health in formulating policy and in the strategic direction of the profession and clinical services. Naturally, the ARTP has been closely involved in the development and implementation of the national strategy for COPD and will continue this work into the future.

499. The ARTP has developed web-based learning for spirometry, has published a book about respiratory physiology in conjunction with Professor Mike Hughes, and continues to support the national strategy in other ways. It also has close involvement with Assembly 9 (the Allied Respiratory Professionals Assembly) of the European Respiratory Society in establishing worldwide standards for lung function. For more information, see: [www.artp.org.uk](http://www.artp.org.uk)

# Appendices





# Appendix 1. Membership of External Reference Group

Professor Peter Calverley (co-Chair) – Professor of Respiratory Medicine, University of Liverpool

Professor Sue Hill (co-Chair) – Chief Scientific Officer, Department of Health

Julia Bott – Consultant Physiotherapist, Surrey RT

Brendan Cooper – Respiratory Physiologist, University Hospitals Birmingham NHS Foundation Trust

Marc Davis – NHS South West Essex

Chris Fox – Patient

Kevin Holton – Head of Respiratory Team, Department of Health

Dr Rupert Jones – Peninsula College of Medicine and Dentistry

Dr Jos Kleijnen – Director, Kleijnen Systematic Review, Ltd

Claire Mills – Former Head of COPD Team, Department of Health

Anne Moger – Nurse Advisor, Department of Health

Dr Mike Morgan – Respiratory Physician, Department of Respiratory Medicine, Glenfield Hospital

Anna Murphy – Pharmacist, Department of Pharmacy, Glenfield Hospital

Karen O'Brien PCT, Manchester

Dr Noel O'Kelly – GP, Spilsby Surgery, Lincolnshire

Sarah-Jane Peffers – Respiratory Nurse Specialist, Primary Care – Nurse

Fiona Phillips – Public Health Consultant, Department of Health

Ron Poulson – Patient

Samantha Prigmore – Respiratory Nurse Specialist, Secondary Care, St George's Hospital

Edna Robinson – Chief Executive, Trafford General Hospital

Dame Helena Shovelton – Chief Executive, British Lung Foundation

Professor Robert Stockley – Medical Director, Queen Elizabeth Medical Centre

Professor Wisia Wedzicha – Respiratory Physician, Royal Free Hospital, University College London

Dr Val Woodward – University of Plymouth

# Appendix 2. Membership of External Reference Group sub-groups

## **Chronic care and end-of-life care sub-group**

Sherwood Burge

Jess Callaghan – Occupation Therapist, NHS Surrey

Martin Carby

John Dark

Robert Freeman – Department of Health

Ram Gujarani

Claire Hallas

Sandy Harris

Sue Hawkett – Department of Health

Steve Holmes – GP

Nick Morrell

Professor Martyn Partridge – Respiratory Physician

Dennis Ramshaw – Patient

Jane Scullion – Respiratory Nurse Specialist, Department of Respiratory Medicine, Glenfield Hospital

Mike Ward – Consultant Physician, King's Mill Hospital

## **Acute care sub-group**

Professor Nigel Benjamin – Consultant in Acute Medicine, Plymouth Hospitals NHS Trust

Dr Craig Davidson – Director, Guy's and St Thomas' Foundation Trust

Lisa Davies – Consultant Respiratory Physician, Aintree University Hospitals NHS Foundation Trust

Dr Tony Davison – Southend University Hospital NHS Foundation Trust

Deborah Dawson

Mark Elliott

John Hurst – Royal Free Hospital, University College London



Dr Rupert Jones – GP Peninsula College of Medicine and Dentistry

Christine Mikelson – Consultant Physiotherapist, Royal Free Hampstead NHS Trust

Dr Hilary Pinnock – GP Clinical Research Fellow, University of Edinburgh

Samantha Prigmore – St George's Hospital

Professor Mike Roberts – Director, Royal College of Physicians Clinical Effectiveness and Evaluation Unit

Jude Smith – Respiratory Nurse Specialist

Professor Robert Stockley – Medical Director, Queen Elizabeth Medical Centre

David Whitmore

### **Prevention and awareness raising sub-group**

Professor Jonathan Ayres – University of Aberdeen

Alex Bobak

Professor John Britton – Centre for Respiratory Research, University of Nottingham

Ann Collins

Chris Dyer – Royal United Hospital, Bath NHS Trust

Angela Evans – University Hospital of North Staffordshire NHS Trust

Becky Farren – Department of Health

David Fishwick – Royal Hallamshire Hospital

Monica Fletcher – Chief Executive, Education for Health

Chris Flowers

Paul Jones – St George's, University of London

Professor Warren Lenny – University Hospital of North Staffordshire NHS Trust

David Lomas – Cambridge Institute for Medical Research, University of Cambridge

Dr John Osman – Health and Safety Executive

Professor David Price – University of Aberdeen

Stephanie Reilly

Michael Soljak – Department of Health

David Strachan – St George's, University of London

Professor Jorgen Vestbo – University of Manchester

Nicola Willis – Department of Health Tobacco Control Programme

**Management of medicines sub-group**

Jenni Burns – Sheffield Health and Social Care NHS Foundation Trust

Glenda Esmond – NHS Barnet

Jill Goddard – NHS Tower Hamlets

Kevin Gruffydd-Jones – Box Surgery, Wiltshire

Gerry Hagan

Professor Michael Hyland – University of Plymouth

Isabel Kuncewicz – Central Surgery, Oadby

Mrs Gul Root – Department of Health

Quentin Sayer – BOC Healthcare

**Patient-focused outcomes sub-group**

Professor Sam Ahmedzai – Royal Hallamshire Hospital

Mrs Pat Barlow

Jess Callaghan – Occupational Therapist, NHS Surrey

Ms Eve Cowdell – Patient

Jayne Din – Patient

Amy Grant – Physiotherapist, Lambeth and Southwark Pulmonary Rehabilitation Team

Professor Michael Hyland – Professor of Health Psychology, University of Plymouth

Professor Paul Jones – Professor of Respiratory Medicine, St George's Medical School

Vikki Knowles – Respiratory Nurse, NHS Surrey

Sue Matthews – Patient

Liesl Osmond – Senior Research Fellow, University of Aberdeen

Linda Pearce – Respiratory Nurse Consultant

Dr Sue Revill – Sherwood Forest Hospitals NHS Foundation Trust

Diane Scott – Carer

Jane Scullian – Respiratory Nurse Consultant, Leicester

Dr Karl Woodward – University of Plymouth

# Appendix 3. Policy environment

## The policy environment

### The wider policy context

1. This strategy is intended to assist the delivery of government policies that support improvements to the lives of people with chronic diseases as well as promote improvements in the health and well-being of the general population.
2. Services for people with COPD are not solely clinical, although we have paid close regard to the National Institute for Health and Clinical Excellence (NICE) clinical guideline 'Managing COPD' and the potential for its further development. Nor are they delivered in any single place or by one single part of the public sector – they are found in primary healthcare, specialist services and care provided in hospitals as well as social care provided by both local authorities and the voluntary and independent sectors. Furthermore, the size of the population with COPD means that the development of these services is influenced indirectly by many new policies for health and social care or even for public services in general.
3. During the development of this strategy we referred to the following general policy statements:
  - Public Service Agreement (PSA) target number 18 (promote better health and well-being for all)
  - High Quality Care for All (the Next Stage Review)
  - Our Health, Our Care, Our Say
  - Our NHS, Our Future
  - World class commissioning
  - From good to great.
4. We also looked closely at:
  - The Carers' Strategy
  - The National End-of-Life Strategy
  - The Pharmacy White Paper
  - Health Inequalities: Progress and Next Steps (2008)
  - Transforming Community Services (2009).
5. These statements have all been important but two in particular have helped to shape the development of the strategy: the PSA

target number 18, which shifted the emphasis given within the strategy to mutual effort on prevention as well as disease management; and High Quality Care for All, which has influenced the recommendations for future action across the NHS.

### Public Service Agreements

6. PSAs articulate the Government's highest priorities for delivery during a spending review period. For the current spending review, the Government set out to develop outcome-focused cross-government PSAs that brought together key delivery partners across public services to provide a more holistic service to the patient and user who needed health and social care.
7. The Department of Health lead on two PSAs and PSA 18 is supported through the implementation of the strategy.
8. PSA 18 (promote better health and well-being for all) sets out the Government's commitment to deliver the best possible health and well-being outcomes for everyone, helping people to live healthier lives, empowering them to stay independent for longer and tackling inequalities. There are three existing Spending Review 2004 commitments for delivery by 2010, which are to:
  - increase the average life expectancy at birth in England to 78.6 years for men and 82.5 years for women;
  - reduce health inequalities by 10% as measured by life expectancy at birth; and
  - reduce smoking rates to 21% or less by 2010, with prevalence among routine and manual groups to 26% or less.
9. The strategy document *Health Inequalities: Progress and Next Steps* (2008) gave a renewed commitment to achieve the health inequalities target in 2010, including targeted investment and increased support for primary care trusts (PCTs) and local authorities, and to set the direction for the future.
10. Life expectancy in England is the highest it has ever been, including in disadvantaged areas. Some of these areas are making impressive gains, saving real lives. However, the gap between the most disadvantaged areas and the rest of the country has not narrowed and this element of the target therefore remains very challenging.
11. Mortality related to respiratory diseases – including COPD – is one of the main drivers (along with vascular disease and cancer) of the gap in life expectancy. Tackling COPD in disadvantaged areas will go some way to help reduce the gap between those areas and the rest of England.
12. The newly updated Department of Health Health Inequalities Intervention Tool contains data showing the extent to which COPD (and other diseases) is contributing to the life expectancy gap in each local authority area in England, and is helping local partners to focus action.

## High Quality Care for All

13. *High Quality Care for All* set out a shared definition of quality – spanning the three elements of safety, effectiveness of care and patient experience, which requires a radical transformation across the entire healthcare system. Change on this scale, in a system as large and complex as the NHS, has not been achieved before.
14. The report also emphasised the four principles of implementation:
  - co-production;
  - subsidiarity;
  - system alignment; and
  - clinical ownership and leadership.
15. These have been the basis for the development and implementation of the national strategy for COPD.

**Co-production:** all parts of the system work together on shaping and implementing change. In essence, this entails engaging people across health and social care to work together to make change happen.

**Subsidiarity:** ensuring that decisions are taken at the right level of the system, as close as possible to the patient.

**System alignment:** all parts of the NHS to push in the same direction and towards a unifying principle.

**Clinical ownership and leadership:** the principle which lies at the heart of Lord Darzi's approach to the future of the NHS. It ensures the power to mobilise and empower clinicians.

16. *High Quality Care for All* also described a health service that empowers people and gives choice. It wanted to ensure that healthcare will be personalised and fair, including the most effective treatments within a safe system and help for people to stay healthy. The report made commitments to give people more say through initiatives such as care plans for those with long-term conditions, a guarantee that the most effective drugs will be available to all and the right to choose between care providers.



## The National Quality Board

17. One major recommendation in *High Quality Care for All* was the establishment of the National Quality Board (NQB). Its role is to provide strategic oversight and leadership across the NHS, including the health and social interface. By featuring all of the key national statutory bodies responsible for quality of the NHS, the NQB is uniquely placed to ensure that the health system is aligned to common quality aims.
18. The NQB's leadership role involves its working to align the NHS to quality; provide advice to ministers on clinical priorities; and oversee the development of tools and system levers to support frontline quality improvement. The NQB operates according to the principle of 'shared sovereignty' between independent organisations and individuals.
19. The NQB has considered the work on the new national strategy to improve quality in COPD and has agreed to play an active role in driving forward quality in this area. For instance, the NQB has commissioned NICE to develop quality standards on COPD, once it has piloted its approach in other disease areas, and to ensure that the new quality standards for COPD align with the planned partial review of the NICE Clinical Guidelines for COPD.

## The NICE quality standards and NHS evidence

20. The development of NICE quality standards was recommended in *High Quality Care for All* in response to a clear message that came out of the engagement process underlying that report: that there was a 'sea of standards' which often made it difficult to understand what a high-quality service looked like.
21. As a result, NICE quality standards will set out definitive markers of high-quality care for a particular clinical area, designed to be useful to clinicians, commissioners, providers and patients. Quality standards will span the three dimensions of quality set out in *High Quality Care for All* – safety, effectiveness of care and patient experience – and should help to bring best practice into the mainstream.
22. Any single NICE quality standard will focus on a particular clinical pathway or topic area and contain a small number of statements describing high-quality care, linked to indicators so that clinicians and commissioners are able to measure how well they are meeting the standard.

### **A quality standard – a definition**

A set of specific, concise statements acting as markers of high-quality, cost-effective care across a pathway or a clinical area. They are derived from the best available evidence and produced collaboratively with the NHS and social care sector, along with their partners and service users.

23. NICE has responsibility for developing quality standards. Over time, it is intended that quality standards will form a comprehensive library – with the NQB setting the target for how large this library should be.
24. NICE will be producing a NICE quality standard for COPD as part of its work programme for 2010/11 and intends to consult about its scope and content during 2010. This is based on advice from ministers following a recommendation from the NQB. As set out in *High Quality Care for All*, one of the roles of the NQB is to advise ministers on the topics for NICE quality standard production and to sequence the production of NICE quality standards from 2010/11 onwards.

## Other national programmes that the strategy is designed to work with

### 18-week 'breathlessness' pathway

25. In partnership with a wide range of stakeholders, the NHS has published, with endorsement from the Department of Health, an 18-week commissioning pathway for obstructive lung disease – Breathlessness ([www.18weeks.nhs.uk](http://www.18weeks.nhs.uk)).
26. This commissioning pathway is a tool to facilitate the commissioning of high-quality services for people with obstructive lung disease, including COPD, and asthma. The pathway describes an ideal, nationally endorsed pathway, meeting all best practice guidance and including the use of personal action plans for people with breathlessness, including COPD.

### Integrated Care Pilots

27. The programme of Integrated Care Pilots (ICP) has been established to address that need. It is an exciting and innovative way of exploring the benefits that greater integration could deliver for local health and well-being.
28. ICP is designed to examine different ways in which health and social care could be provided to help drive improvements in local health and well-being. It allows communities to take a fresh look at how to deliver such care, based solely on the needs of the local population. The aim is to look beyond traditional boundaries (e.g. between primary and secondary care) to explore whether new, integrated models can improve health and care services.
29. Each pilot will be exploring a new approach to a key health issue within the local community, and seeking to deliver improvements in quality, service user satisfaction and local health and well-being. Although the pilots have designed new models for delivering care, they must also ensure that key features of the current health systems are safeguarded, e.g. choice, competition and the role of the PCT as the commissioner of local health services.
30. The pilots will run for two years and will be evaluated over three years against a set of national and local measures. The criteria involved include impact on health outcomes, improved quality

of care, service user satisfaction, and effective relationships and systems.

31. ICP sits alongside other programmes, such as practice-based commissioning, to inspire innovation in service development and to encourage stronger partnership between clinicians and those working in local government and social care. It is an exciting opportunity to help deliver better health, better care and better value for local populations and for taxpayers.
32. Sixteen pilot organisations have been selected to put their proposed care models into practice over the next two years. These pilot sites have been selected from over 100 applications received after the programme was launched, and they cover a diverse range of models, across a wide variety of health and care categories.

#### **Northumbria Health Care NHS Foundation Trust**

This pilot will be exploring a new approach to helping patients with COPD to manage their own care. The pilot will ensure providers work together to co-ordinate care, provide consistent information and education, and help patients manage their own care (with assistance from their key worker). The pilot aims to increase patient satisfaction, reduce hospital admissions and reduce the length of stay in hospital when admission is required.

#### **Principa – Partners in Health**

This pilot is designed to help create more informed and empowered COPD patients. It will involve partners working together on two projects to identify 'at-risk' patients, and working with teams in community wards and with other partners involved in COPD treatment to integrate care along the clinical pathway. It is designed to improve co-ordination of care, increase patient satisfaction and reduce hospital admissions.

#### **Map of Medicine**

33. This is a clinical decision-making tool. It helps doctors to make clinical decisions about assessment and treatment options. The information is presented in the form of care pathways that are based on the best available evidence.

#### **National End of Life Care Programme**

34. The purpose of the national End of Life Care Programme is to support the implementation of the national *End of Life Care Strategy* by enabling, developing, supporting and sharing good practice emanating from different parts of the country on all aspects of the strategy. This is delivered in partnership with a variety of different NHS health, social care, patient/user groups and third sector organisations.
35. Sharing and disseminating examples of good practice from across the country is the cornerstone of the programme's work. This is being taken forward by the development of a website:

[www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk). This resource is aimed at the health and social care workforce, providers, commissioners and service managers working across all care settings, including homes, care home hospitals, hospices, extra care housing, hostels and prisons.

36. The website has over 150 active case studies, news updates, links to associated strategies and other useful information. A bimonthly newsletter is also produced and is disseminated electronically. Other resources include a DVD that highlights examples of advance care planning and dementia care, and a number of publications and fact sheets that cover a range of specific topics. Together these resources provide a comprehensive framework of care, covering all steps in the end-of-life care pathway.
37. The programme is taking forward a number of work streams that relate to the end-of-life care pathway; these include workforce development, primary care, advance care planning, locality registers, support for carers, care homes housing, prisons commissioning and working with a number of site-specific groups (e.g. kidney care) to customise the end-of-life care pathway, which focuses on the transition from active disease management to end-of-life care, identifying the patient, assessment of need, care planning involving the family and communications between all team members.

### Payment by Results

38. Payment by Results (PbR) is the name given to the transparent funding mechanism that is used to reimburse healthcare providers. Activity is paid for according to outpatient attendances and inpatient admissions. PbR uses Healthcare Resource Groups (HRGs) to describe the care given and then attaches a tariff (or set national price) to the HRG. For instance, in 2009/10 HRG4 DZ21F (Chronic Obstructive Pulmonary Disease or Bronchitis with NIV without Intubation with CC) had a tariff price of £2,871.
39. A new version of HRGs (HRG4) has recently been developed which identifies types of care recommended in this strategy, such as a non-invasive ventilation support assessment. The Department of Health is working to implement these new HRGs in 2010/11.
40. In addition, as part of future work on developing PbR, the Department of Health is keen to ensure that funding flows support good practice care for people with COPD, such as early supported discharge/Hospital at Home and pulmonary rehabilitation. To do this we are seeking to develop a discharge code that identifies whether a patient is being discharged from hospital to a clearly defined Hospital at Home care pathway.
41. For pulmonary rehabilitation, development would focus on defining a currency (i.e. what treatment is included in a nationally agreed standard programme of pulmonary rehabilitation) and then determining a price for that unit of care.

## Other contributing activity

### The Industrial Injuries Advisory Council

42. The Industrial Injuries Advisory Council (IIAC) has an interest in the research into work-related causes of COPD that mirrors our own.

### COMEAP

43. The Department of Health's Committee on the Medical Effects of Air Pollutants (COMEAP) advises the UK health departments on the effects on health of both outdoor and indoor air pollutants, on the basis of data currently available. It also assesses the need for further research and liaises as necessary with other government bodies to assess the effects of exposure and associated risks to human health.
44. Documents prepared by COMEAP are published on the COMEAP website: [www.advisorybodies.doh.gov.uk/comeap/index.htm](http://www.advisorybodies.doh.gov.uk/comeap/index.htm)
45. COMEAP has recently published its report *The Long-Term Exposure to Air Pollution: Effect on Mortality*.

### The Health Inequalities National Support Team

46. The Health Inequalities National Support Team (HINST) was launched in January 2007 and has visited over 50 spearhead areas (the 20% most deprived areas in England that have the poorest health). The team supports local partners in reducing inequalities in health, by focusing on a systematic and scaled-

up approach to commissioning and delivering interventions that will make a difference to health at a population level. The approach uses a diagnostic model for systematic analysis of the contributors to commissioning effective health outcomes, and a series of workshops drilling down to the contributors to the health inequalities gap as it relates to the local area.

47. One of these workshops looks at the use of population registers as a means of delivering better management of COPD. One of the key findings has been that to reduce inequalities in care, a systematic approach to minimising the variation in outcomes across primary care is needed. Developing an information 'dashboard' for practices, displaying on one page the major measures of the COPD programme, including prevalence, prescribing, admissions and deaths compared with the PCT averages, is a starting point for achieving this, followed by comprehensive and targeted training and support for practices. A focus on screening patients currently registered with COPD, for hypertension and raised cholesterol, is also important, as evidence suggests co-morbidity to be common and often under-diagnosed.

### The Improvement Foundation

48. The Improvement Foundation (IF) is a specialist quality improvement team, working with frontline services to deliver large-scale change. IF has a ten-year track record of demonstrating significant, sustainable impact and improved productivity.



49. The IF has improved the management of long-term conditions in primary care across thousands of practices in England, Scotland, Canada and Australia. Using the systematic improvement approach to spread and sustain best practice, highly significant improvements have been made in the areas of coronary heart disease, diabetes, mental health and COPD.
50. All PCTs in England took part in the COPD programme, including 1,931 general practices. Each PCT established an improvement team which included GPs, practice nurses, practice managers, a project manager, PCT senior managers and secondary care colleagues, and patient or carer representatives. Results included a 30% reduction in COPD acute admissions after 24 months, 120% improvement in the number of patients with COPD diagnosis confirmed by spirometry and a 22% improvement in patients with COPD for whom there is a record of smoking status.
51. The ongoing clinical management of people with long-term conditions, particularly those with complex needs, has to involve a multi-agency approach. The IF has extensive experience of how to bring multi-agency teams together to deliver service and health improvement.

# Appendix 4. Research

The External Reference Group (ERG) has recommended that there is a need to build the research base for COPD. Other than the areas already identified in the consultation document, it recommended that further research is needed in the following areas:

1. Pulmonary rehabilitation: What are the benefits and feasibility of a course of pulmonary rehabilitation in patients after hospital admission for an exacerbation and those managed in the community for their exacerbations? More specifically:
  - What length of pulmonary rehabilitation?
  - Components included
  - How long after the exacerbation?
  - Patient benefits in terms of quality of life, recovery from the exacerbation and effect on future exacerbations
  - Cost effectiveness of providing the service.
2. Exacerbation follow-up: Does early follow-up of exacerbations at two weeks after end of treatment reduce recurrent exacerbation and readmission?
3. Computerised tomography (CT) scans: Are CT scans an effective and appropriate means of confirming a diagnosis of COPD and staging the severity of COPD? Can this be linked to the diagnosis of other lung conditions, e.g. lung cancer?
4. Telemedicine:
  - Is telemedicine an effective, safe and acceptable way of managing patients with COPD?
  - Do remote technologies allow patients with exacerbations to present themselves earlier for therapy?
  - Which patient groups benefit most from these devices and monitoring?
  - Do patients comply with the devices?
  - What is the effect on carers?
  - Are they cost effective?
5. Environmental effects: What is the interaction between pollution, temperature and respiratory viral infection, and the development of COPD exacerbation and subsequent hospital admission?

6. Ambulatory oxygen: What are the optimum assessment protocols or strategies for assessment of patients for ambulatory oxygen? Is there any benefit of using ambulatory oxygen in non-hypoxemic patients with exercise desaturation? What is the compliance with ambulatory oxygen, what factors affect compliance, including follow-up, and how can compliance be improved?
7. Lung cancer: Are there common genetic predisposing factors relating to COPD and lung cancer?

# Appendix 5. Glossary

## **Activities of daily living**

Activities of daily living are the things we normally do in daily living including any daily activity we perform for self-care (such as feeding ourselves, bathing, dressing, grooming), work, homemaking, and leisure.

Health professionals routinely refer to the ability or inability to perform activities of daily living as a measurement of the functional status of a person. This measurement is useful for assessing the elderly, the mentally ill, those with chronic diseases and others, in order to evaluate what type of healthcare services an individual may need.

## **Acute care**

Medical care administered for the treatment of a serious injury or illness or during recovery from surgery. Medical conditions requiring acute care are typically periodic or temporary in nature. Acute care can be provided in primary and secondary care and in a variety of community situations.

## **Airway bypass**

The use of a flexible bronchoscope to go through the mouth into the airways. There the physician will create new small pathways to

allow the trapped air in the lung to escape. People see an immediate improvement in dyspnoea (shortness of breath).

## **Alpha-1-antitrypsin deficiency**

Alpha-1-antitrypsin (alpha-1) is a protein that is produced mostly in the liver. Its primary function is to protect the lungs from neutrophil elastase. Neutrophil elastase is an enzyme in lung tissue which digests damaged or ageing cells and bacteria to promote healing. However, if the levels of neutrophil elastase increase, the enzyme may also attack healthy lung tissue. Alpha-1-antitrypsin in sufficient amounts will trap and destroy neutrophil elastase before it has a chance to damage lung tissue. Deficiency of alpha-1-antitrypsin is a genetic defect, and lung damage usually occurs in the form of emphysema.

## **Ambulatory oxygen**

Ambulatory oxygen is supplemental oxygen during exercise and activities of daily living. Ambulatory oxygen therapy is often used for a person on long-term oxygen therapy during exercise and occasionally for those not taking long-term oxygen therapies who show evidence of arterial oxygen desaturation.

**American Thoracic Society (ATS)**

The ATS is a society set up to prevent, control, treat and promote research into respiratory disease.

**Association for Respiratory Technology and Physiology (ARTP)**

The ARTP is the sole professional organisation in the UK for practitioners working in clinical respiratory physiology and technology.

**Body mass index (BMI)**

A measure of body size relating to height and weight. Calculated as height in metres divided by weight in kilograms. A BMI of between 20 and 25 is considered normal; less than 20 underweight; 26–30 overweight; and over 30 obese.

**British Thoracic Society (BTS)**

The BTS promotes research into respiratory disorders and disseminates information on prevention of these disorders.

**Bronchodilator**

A pharmacological therapy that provides airway dilation and is normally a beta agonist or an anticholinergic agent. Bronchodilators may be short (under 24 hours) or long acting (over 24 hours).

**Bupropion**

Bupropion (trade names Wellbutrin and Zyban) is a treatment which changes the way in which the body responds to nicotine. The patient starts taking bupropion one to two weeks before stopping smoking,

and treatment lasts up to nine weeks, helping the patient through the withdrawal cravings. It is only available on prescription and is not available to pregnant women.

**Cachexia**

Weight loss, wasting of muscle, loss of appetite and general debility that can occur during a chronic disease.

**Care plan**

The care plan is the documented, mutually agreed journey that identifies when self-management education, action plans and other treatments have been offered. The care plan also provides information on how to seek contact with knowledgeable health professionals both through the planned review schedule and for unscheduled advice.

**Chronic obstructive pulmonary disease (COPD)**

COPD is a preventable and treatable disease with some significant extra pulmonary effects that may contribute to the severity in individual patients. Its pulmonary component is characterised by airflow limitation that is not fully reversible. The airflow limitation is usually progressive and associated with an abnormal inflammatory response of the lung to noxious particles or gases.

The most common cause of COPD is smoking. Occupational factors (such as coal dust) and some inherited problems can also cause COPD. Indoor and outdoor air pollution as a factor causing COPD is currently under investigation.



In people with COPD, either of the following conditions may be present:

- Chronic bronchitis, which is defined clinically as chronic productive cough for three months in each of two successive years in a person in whom other causes of productive chronic cough have been excluded.
- Emphysema, which is defined pathologically as the presence of permanent enlargement of the airspaces distal to the terminal bronchioles, accompanied by destruction of their walls and without obvious fibrosis.

### **Co-morbidity**

The presence of coexisting or additional diseases, with reference to an initial diagnosis or with reference to the index condition that is the subject of study.

### **Computerised tomography (CT) scan**

A CT scan takes x-rays of an individual and uses a computer to put them together. CT scans can be used for detecting both acute and chronic changes in the lung parenchyma (the insides of the lungs).

### **Concordance**

Concordance describes a partnership approach to medicine-prescribing and taking. It is different from 'compliance', which describes patient medicine-taking in relation to the prescriber's instructions. Concordance recognises that people make their own decisions about whether or not to take a prescribed treatment, and acknowledges that a well-informed person may decide to decline treatment after learning about the relative benefits and risks.

### **Disease register**

A list of people who have been diagnosed with a specific condition.

### **Early discharge**

Early discharge refers to the discharge of a person from hospital as soon as possible after admission, with medical and social support at home.

### **European Respiratory Society (ERS)**

The ERS aims to alleviate suffering from respiratory disease and to promote lung health through research, knowledge-sharing and medical and public education.

### **Exacerbation**

An exacerbation is a sustained worsening of a person's symptoms from their usual stable state, which are acute in onset. Commonly reported symptoms are worsening breathlessness, cough, increased sputum production and change in sputum colour. The change in these symptoms often necessitates a change in medication. Other diagnoses (such as pneumonia, pneumothorax, pulmonary embolus and cardiac failure) which may mimic or complicate exacerbations should be considered and excluded when appropriate.

Exacerbation severity:

**Mild:** requiring an increase in inhaled bronchodilators alone

**Moderate:** requiring oral corticosteroids

**Severe:** requiring hospitalisation.

A complex exacerbation has one or more of the following features:

- the presence of respiratory failure;
- the presence of co-morbidities requiring active intervention;
- failure of first-line therapy; and
- any other cause for concern by a member of the multidisciplinary team.

A 'frequent exacerbator' is a person who requires two or more courses of antibiotics and/or corticosteroids for COPD exacerbation in a 12-month period.

#### **Fat-free mass**

An index which takes into account the amount of muscle mass a person is carrying in relation to their height.

#### **FEV1**

The FEV1 is the forced expiratory volume in one second, measured by spirometry. The ratio of the FEV1 to the forced vital capacity is a measure of the degree of an individual's airway obstruction.

#### **First-degree relative**

Any relative who is one meiosis away from a particular individual in a family (i.e. parent, sibling or offspring).

#### **Global Initiative for Chronic Obstructive Lung Disease (GOLD)**

GOLD works with healthcare professionals and public health officials around the world to raise awareness of COPD and to improve prevention and treatment of the disease.

#### **Heterogeneous emphysema**

'Emphysema heterogeneity' is considered important when assessing a person for lung volume reduction surgery. 'Upper zone' refers to the upper lobe of the lung, and people with upper zone emphysema are more likely to benefit from lung volume reduction surgery.

#### **Hospital at Home**

Hospital at Home schemes provide care in a person's home that is usually only available in hospital, such as observation, administration of drugs, support, nursing care and rehabilitation.

#### **Hypercapnia**

Increase in carbon dioxide in the blood due to hypoventilation that is commonly found in respiratory failure and leads to acidosis.

#### **Integrated care pathway**

A multidisciplinary outline of anticipated care, with an appropriate timeframe, which is designed to help a person with a specific condition or set of symptoms to move progressively through a clinical experience to positive outcomes.

#### **Invasive ventilation (IV)**

Ventilation delivered through a tube inserted either into the lungs (endotracheal tube) or via a tracheostomy tube.

#### **Joint Strategic Needs Assessment**

This is a process that will identify the current and future health and well-being needs of a local population, informing the priorities

and targets set by Local Area Agreements and leading to agreed commissioning priorities that will improve outcomes and reduce health inequalities. It is usually carried out between a PCT and a local authority.

### **Long-term oxygen therapy (LTOT)**

LTOT refers to the provision of oxygen therapy for continuous use at home for people with chronic hypoxaemia (PaO<sub>2</sub> at or below 7.3kPa (55mmHg)). The oxygen flow rate must be sufficient to raise the waking oxygen tension above 8kPa (60mmHg). Once started, this therapy is likely to continue for the rest of that person's life. LTOT is usually given for at least 15 hours daily, to include the night time in view of the presence of worsening arterial hypoxaemia during sleep. LTOT is usually provided with an oxygen concentrator.

### **Lung volume reduction**

A procedure that removes approximately 20–35% of the poorly functioning, space-occupying lung tissue from each lung in people with COPD. By reducing the lung size, the remaining lung and surrounding muscles (intercostals and diaphragm) are able to work more efficiently. This results in reduced dyspnoea and improved exercise tolerance.

### **Medical Research Council (MRC) dyspnoea scale**

The MRC dyspnoea scale grades the degree of a person's breathlessness. The five grades are as follows:

- Not troubled by breathlessness, except during strenuous exercise.

- Short of breath when hurrying or walking up a slight hill
- Walks slower than contemporaries on the level because of breathlessness, or has to stop for breath when walking at own pace.
- Stops for breath after about 100m or after a few minutes on the level.
- Too breathless to leave the house, or breathless when dressing or undressing.

### **Nebuliser**

A device that causes a liquid to be converted into an aerosol (spray) or a vapour. Nebulisers are used in drug administration by inhalation in a person with COPD.

### **Nicotine replacement therapy (NRT)**

NRT is used by smokers to replace nicotine going into the bloodstream in order to help reduce cravings when stopping smoking. There are six NRT products: gum, patches, inhalator, microtab, lozenges and nasal spray.

### **Non-invasive ventilation (NIV)**

The delivery of ventilatory support by a mask held firmly to the face, usually over the nasal area, without the need for an invasive artificial airway. Such ventilation has a role in the management of acute or chronic respiratory failure in many people with COPD, and may have a role for some people with heart failure.

**Oximeter**

A photoelectric device that measures the amount of oxygen in blood and other fluids, usually from a finger probe.

**Oxygen alert card**

An alert card that ensures that doctors or ambulance staff are made aware of a person's special needs regarding oxygen therapy and the presence of hypercapnia.

**Pulmonary rehabilitation**

Pulmonary rehabilitation is an evidence-based, multidisciplinary and comprehensive intervention for people with chronic respiratory diseases who are symptomatic and who often have decreased daily life activities. Integrated into the individualised treatment of the person, pulmonary rehabilitation is designed to reduce symptoms, optimise functional status, increase participation and reduce healthcare costs through stabilising or reversing systemic manifestations of the disease.

**Respiratory failure**

A term used to describe inadequate gas exchange by the respiratory system, with the result that arterial oxygen and/or carbon dioxide levels cannot be maintained within their normal ranges. A drop in blood oxygenation is known as hypoxaemia; a rise in arterial carbon dioxide levels is called hypercapnia. Type 1 respiratory failure is defined as hypoxaemia without hypercapnia. Type 2 respiratory failure is caused by increased airway resistance, and both oxygen and carbon dioxide are affected.

**Self-management plan**

Used to teach people to independently complete tasks and take an active role in monitoring and reinforcing their own behaviour.

**Spirometry**

Spirometry is a physiological test that measures how an individual inhales or exhales volumes of air as a function of time. The primary measure in spirometry may be of volume or flow.

It includes, but is not limited to, the measurement of forced vital capacity, forced expiratory volume in one second (FEV1) and other forced expiratory flow measurements. In addition, spirometry may include the measurement of slow vital capacity, maximal voluntary ventilation and inspiratory flow measurements. Spirometry also should include a printed, graphic representation of the expiratory and, if applicable, the inspiratory manoeuvre.

**Telemedicine**

Delivery of health services via remote telecommunications. This includes interactive consultative and diagnostic services.

**Tracheostomy tube**

A tube that is inserted into an incision in the trachea (tracheostomy) to relieve upper airway obstruction or facilitate invasive ventilation.

# Appendix 6. Pilots

1. The NHS Improvement methodology includes:
  - selecting clinical areas to focus on;
  - advertising for expressions of interest in selected areas;
  - applying selection criteria which include:
    - high-level support in an organisation;
    - clinical leadership; and
    - whole-team involvement.
2. Pilot sites include those already providing an exemplary service, those that wish to improve an existing service and those that wish to implement a new service.
3. Organisations are supported by an improvement methodology such as Lean and agree data requirements and measures of success.
4. Measures are developed under the headings of delivery, quality/safety, cost, staff/patient morale and satisfaction, sustainability plus a locally defined measure.

## Evaluation

5. Robust evaluation will be needed so that the clinical and cost effectiveness of the models can be tested. Evaluation should be based both on quantitative methods that can determine impact and outcomes and on qualitative methods to identify barriers to and facilitators of successful implementation.

## Focus of pilots

6. We have focused on six substantive areas to pilot:
  - accurate diagnosis;
  - chronic care;
  - acute care;
  - end of life care;
  - self-management; and
  - improving home oxygen services.

# Appendix 7. References

- † Ministers have agreed to conduct a shorter consultation of six weeks. In the last four year developing the Strategy there has been extensive consultation with over 40 stakeholder organisations, and the last few months have been spent actively engaging with patients and carers throughout England. We have received feedback on the Strategy from around 450 people with COPD and asthma in five locations across the country in December and plan to engage with around 1,000 health and social care professionals, commissioners and managers in March 2010.
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# Appendix 8. Consultation questions

We encourage responses from anyone interested in the issues raised in this consultation document.

During the consultation period, the Department of Health will be engaged in a range of activities designed to receive feedback on the questions in this document. This invitation to comment is part of that process.

Please reply to as many of these questions as possible. If you have a friend, family member or colleague who may also want to respond please let them know about our consultation.

You can complete this form:

- **online** – this is our preferred way for you to respond as it helps us to analyse what you have said more easily and quickly, and prevents any problems with responses being lost or delayed in the post. The form can be filled in online on the Department of Health website (you do not need to download anything):

[www.dh.gov.uk/en/Consultation/DH\\_659](http://www.dh.gov.uk/en/Consultation/DH_659)

- **by hand** – if you would prefer to fill in this form by hand, please write clearly in BLOCK CAPITALS, and if you need more room to answer any of the questions, please continue on a separate sheet, clearly marking the question number. Once you have completed the form, please return to the following address, remembering to add the correct postage:

Kevin Holton  
Department of Health  
415 Wellington House  
133–155 Waterloo Road  
London SE1 8UG

The closing date for response to this consultation is 6 April 2010.



## Consultation questions

### Section 1: Questions on COPD

1. Do you believe this strategy will improve the lives of people with COPD?

Strongly Agree     Agree     Disagree     Strongly Disagree

If you have selected Disagree, or Strongly Disagree, please explain why.

2. Do you feel the specific recommendations are the best way to make this positive difference?

Page	Recommendation	Strongly Agree	Agree	Disagree	Strongly Disagree
<b>Chapter 2: Prevention and identification</b>					
35	1: Identifying prevalence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36	2: Importance of lung health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37	3: Consequences of exposure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40	4: Lung age tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40	5: Minimise workforce exposure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Chapter 3: Finding the 'missing millions'</b>					
44	6: COPD risk factors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44	7: Alpha-1-antitrypsin assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
51	8: Confirmation by spirometry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
55	9: Regular severity assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
57	10: Accurate disease registers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
59	11: Information at diagnosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Chapter 4: High-quality care and support</b>					
66	12: Chronic disease management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
71	13: Evidence-based treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
75	14: Hypoxia clinical assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
77	15: Moderate exercise advised	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Page	Recommendation	Strongly Agree	Agree	Disagree	Strongly Disagree
79	16: Self-management encouraged	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
83	17: Improved exacerbation management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
84	18: Oxygen alert cards	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
85	19: Specialist respiratory review	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
88	20: Non-invasive ventilation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Chapter 5: End-of-life care</b>					
92	21: Improved care access	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
94	22: Bereavement information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Chapter 6: Asthma</b>					
98	23: Recognise similarities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
98	24: Evidence-based guidelines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

For any for which you have selected Disagree, or Strongly Disagree, please explain why.

3. What one thing would you most want **to change** about the current provision of **health and social care services** for people with COPD?

4. What one thing would you most want **to keep** about the current provision of **health and social care services** for people with COPD?

### Section 2: Questions on asthma

5. Do you have confidence that this strategy will make a positive difference for people with asthma?

Strongly Agree [ ]

Agree [ ]

Disagree [ ]

Strongly Disagree [ ]

If you have selected Disagree, or Strongly Disagree, please explain why.

6. What one thing would you most want **to change** about the current provision of **health and social care services** for people with asthma?

7. What one thing would you most want **to keep** about the current provision of **health and social care services** for people with asthma?



**Section 3: General questions**

8. Do you feel this strategy will help everyone with COPD or asthma to get the best care regardless of their age, sex, ethnicity, religion and beliefs, disability or sexual orientation?

Strongly Agree [ ]      Agree [ ]      Disagree [ ]      Strongly Disagree [ ]

9. Is there anything more that should be done to improve the strategy's effect on the equality and diversity issues of age, sex, ethnicity, religion and beliefs, disability and sexual orientation?

10. What more could be done to increase the benefits and/or decrease the costs of the recommendations in the strategy?

11. Do you feel we have identified the main similarities and differences between COPD and adult asthma?

Strongly Agree [ ]      Agree [ ]      Disagree [ ]      Strongly Disagree [ ]

If not, what do you feel we have missed?



12. Is there anything you, or your organisation, could do to help us implement the strategy?

13. Are there gaps in the knowledge about how to diagnose and manage COPD and asthma that could be filled by research in order to deliver better services?

14. Is there anything else you think would improve the quality and productivity of services for people with COPD and asthma?

15. Do you have any other comments?



We may want to publish material from some of the responses we receive.

Are you happy for us to do this with the contents of your response?

Yes  No

We will not publish your name other than in the list of people who responded to the consultation.

Would you like your name to be listed as a contributor to the consultation?

Yes  No

#### **Section 4: Background information about you**

You do not have to complete the following sections about your personal background if you prefer not to. However, the information is confidential and will only be used to assess whether the responses we receive represent a balanced cross-section of views from across society.

#### **Freedom of information**

We manage the information you provide in response to this consultation in accordance with the Department of Health's **Information Charter**.

Information provided in response to this consultation, including personal information, may be published or disclosed in accordance with the access to information regimes. The relevant legislation in this context is the Freedom of Information Act 2000 (FOIA) and the Data Protection Act 1998 (DPA).

If you want the information that you provide to be treated as confidential, please be aware that, under the FOIA, there is a statutory Code of Practice with which public authorities must comply and which deals, among other things, with obligations of confidence. In view of this, it would be helpful if you could explain to us why you regard the information you have provided as confidential. If we receive a request for disclosure of the information we will take full account of your explanation, but we cannot give an assurance that confidentiality can be maintained in all circumstances. An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department of Health.

The Department of Health will process your personal data in accordance with the DPA and in most circumstances this will mean that your personal data will not be disclosed to third parties. However, the information you send us may need to be passed on to colleagues within the UK Health Departments and/or published in a summary of responses to this consultation.

I do **not** wish my response to be passed to other UK Health Departments.

**Questions about you**

Do you have asthma or COPD?

Yes – asthma     Yes – COPD     Yes – both     No 

Which sex are you?

Female     Male     Transgendered     Rather not say 

How old are you?

Under 18     18–24     25–34     35–44     45–54     55–64 65–74     Over 75     Rather not say 

Which ethnicity are you?

Asian/Asian British – Indian	<input type="checkbox"/>	White – British	<input type="checkbox"/>
Asian/Asian British – Pakistani	<input type="checkbox"/>	White – Irish	<input type="checkbox"/>
Asian/Asian British – Bangladeshi	<input type="checkbox"/>	White – Other	<input type="checkbox"/>
Asian/Asian British – Other	<input type="checkbox"/>	Mixed – White and Black Caribbean	<input type="checkbox"/>
Black/Black British – Caribbean	<input type="checkbox"/>	Mixed – White and Black African	<input type="checkbox"/>
Black/Black British – African	<input type="checkbox"/>	Mixed – White and Asian	<input type="checkbox"/>
Black/Black British – Other	<input type="checkbox"/>	Mixed – Other	<input type="checkbox"/>
Chinese	<input type="checkbox"/>	Other	<input type="checkbox"/>

If you have selected 'Other' please specify below:



Do you consider yourself as a person with a disability?

Yes  No  If Yes, please specify below:

Where do you live?

North East	<input type="checkbox"/>	East of England	<input type="checkbox"/>
North West	<input type="checkbox"/>	South West	<input type="checkbox"/>
South East	<input type="checkbox"/>	London	<input type="checkbox"/>
Yorkshire and the Humber	<input type="checkbox"/>	Wales	<input type="checkbox"/>
West Midlands	<input type="checkbox"/>	Outside England and Wales	<input type="checkbox"/>
East Midlands	<input type="checkbox"/>	Rather not say	<input type="checkbox"/>

If you live outside England and Wales, please specify where:

Name:



If you are responding on behalf of an organisation or interest group, please indicate the name of the organisation:

Your role within the organisation:

Thank you for your help with our consultation.

**What happens next?**

Once we have finished the consultation, we will look at all the comments received and see how we can further improve the strategy. We plan to publish a final version of the strategy by summer 2010.



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