

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

Draft Equality Impact Assessment

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DH INFORMATION READER BOX

Policy HR/Workforce Management Planning/ Clinical	Estates Commissioning IM&T Finance Social care/partnership working
Document purpose	Consultation/discussion on best practice
Gateway reference	11943
Title	Consultation on a Strategy for Services for Chronic Obstructive Pulmonary Disease (COPD) in England: Draft Equality Impact Assessment
Author	DH/Medical Directorate/Respiratory Team
Publication date	February 2010
Target audience	PCT CEs, PCT Chairs, NHS Trust CEs, NHS Trust Board Chairs, SHA CEs, Special HA CEs, Care Trust CEs, Directors of HR, Foundation Trust CEs, Directors of Finance, Medical Directors, Allied Health Professionals, Directors of PH, GPs, Directors of Nursing, Communications Leads, Local Authority CEs, Emergency Care Leads, Directors of Adults' SSs, PCT PEC Chairs
Circulation list	Voluntary organisations/NDPBs
Description	The Department of Health is developing a strategy for COPD services. This consultation draws on evidence from a wide range of reports and stakeholders and the recommendations of an external reference group. It invites everyone to give their views on ideas set out in the document, as well as contribute new ideas to the debate. This draft Equality Impact Assessment is part of the consultation.
Cross reference	N/A
Superseded documents	N/A
Action required	N/A
Timing	Responses should be submitted by the closing date
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Consultation on a Strategy for Services for Chronic Obstructive Pulmonary Disease (COPD) in England

Draft Equality Impact Assessment

Please read this document along with *Consultation on a Strategy for Services for Chronic Obstructive Pulmonary Disease (COPD) in England*.

We would welcome your comments.

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Summary

This draft Equality Impact Assessment (EqIA) considers the possible impact of the draft Strategy for Services for COPD in England ('the strategy') on people according to their race, disability, gender, age, religion or belief and sexual orientation. The draft EqIA aims to:

- identify any potential issues in the strategy on any of these groups;
- ensure that development of the strategy takes account of the potential issues and informs continuing development to reduce inequality; and
- inform the eventual full EqIA for the strategy, due to be published in 2010.

Introduction

Chronic obstructive pulmonary disease (COPD) is a disease of the lungs that is characterised by airflow obstruction or limitation. The airflow obstruction is usually progressive, not fully reversible (unlike asthma) and does not change markedly over several months. It is treatable, but not curable: early diagnosis and treatment can, however, markedly slow decline in lung function and hence lengthen the period in which a patient can enjoy an active life.

Smoking is the leading cause of COPD, responsible for over 85% of COPD cases. But it can also be caused by long-term inhalation of polluted air, for example by miners working in mines and inhaling coal dust. A small number of people have a genetic predisposition to lung damage, where they have a defective gene that does not produce enough of a protein that helps keep the lungs clear.

COPD is now the term most widely used by clinicians for the conditions in patients with airflow obstruction who were previously diagnosed as having chronic bronchitis or emphysema or chronic unremitting asthma.

Our vision 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.

Our ongoing commitment is to ensure that all communities can expect better prevention strategies for COPD and quicker identification for those at greatest risk, as well as clear standards of care and treatment that ensure dignity and respect are at the heart of the patient journey.

This draft EqIA is based on proposals in the consultation document and will be finalised once the results of the consultation have been determined. If you would like to comment on this draft EqIA as part of the consultation process, we would welcome your views. Please see the last few pages of the consultation document for the full list of consultation questions.

Why do we need a national strategy for COPD?

Respiratory disease, which includes COPD, is the second leading cause of death in the UK, accounting for 20% of deaths, not far behind cancer at 21%.¹ Death rates from respiratory diseases are particularly high compared with the majority of developed countries, apart from Ireland. At about 75 deaths per 100,000 population, this is about 65% higher than the European Union (EU) average of about 45 deaths per 100,000. COPD accounts for a significant proportion of these deaths. Furthermore:

- COPD is ranked fifth among killer diseases in the UK and is on course to become the third leading cause of death by 2030.
- Even though COPD is a large and growing cause of death and disability, most people in England know nothing about it, what causes it, or the consequences of contracting it.
- Lung damage starts before symptoms are evident. Patients who experience shortness of breath may already be in the advanced stages of the disease, when a large proportion of lung function has already been lost.
- Many healthcare practitioners in the UK tend not to be aware of COPD and tend to focus effort only on smoking cessation.
- Many people think, incorrectly, that the lungs can repair themselves.
- The Department of Health estimates that over 3 million people have COPD, but only about 835,000 are registered with the NHS as having COPD. Many of the ‘missing millions’ are not aware they have a lung disease, due to the mildness of early symptoms, and do not therefore do anything to look after their lungs and prevent future ill health. A key part of the strategy is about identifying these ‘missing millions’.

Strategy objectives

The objectives of the strategy are focused on four key themes:

1. **Prevention and awareness:** Improving public understanding of lung health, of potential risks to lung health, and raising awareness of the signs and symptoms of COPD and other respiratory conditions, including asthma.
2. **Identification and diagnosis:** Accurate early diagnosis and identification of the ‘missing millions’ of people who are unaware they have COPD. This will help people access services that fully assess the severity of disease together with any other coexisting conditions and also the impact on everyday living activities. This assessment can then be used to inform a treatment developed in partnership with healthcare professionals, which sets out an understanding of risk factors and how the risk factors can be minimised.
3. **Acute and chronic care:** Introducing a proactive chronic disease management model. This should look at all disease severities (mild, moderate, severe), and be based on regular assessment and reviews. Where appropriate, people should be offered evidence-based treatment such as pulmonary

rehabilitation, as well as exercise and self-management planning so they can receive the most appropriate treatment. Thought should be given to the accessibility of the intervention, and it should be delivered in a way that encourages compliance and adherence. Overall, it should be an integrated approach, which focuses on early identification of exacerbations and treatment close to home. If the person needs hospital treatment then it should be provided in a structured manner, with improved access to non-invasive nasal ventilation technologies.

4. **End-of-life care:** People who are identified as being in the end-of-life care stage should be managed according to best practice guidelines (including access to a range of options for palliative care). Any bereavement support needs of carers should be identified and provided.

The strategy also looks at the similarities and differences between COPD and asthma.

Lung disease is a major contributor to health inequalities, with those in the lowest social groups up to 14 times more likely to have the disease than those from the highest. To meet health inequalities targets, lung health and lung disease care need to be targeted at those in the most deprived communities.

Following the launch of the draft strategy a formal consultation will take place. The final version of the strategy and its implementation plan is then due to be published in 2010.

What is the draft strategy intended to address?

COPD kills about 25,000 people a year in England and Wales. COPD is the fifth biggest killer disease in the UK, claiming almost as many lives as cancer. Numbers of deaths from COPD increase with age, as the lungs become more obstructed over time. In the UK, deaths from COPD are low in the age range 0-40 (less than 500 per year) but much higher in the 75 and over age range for both males and females (about 20,000 per year).² There are about 835,000 people currently diagnosed with COPD in England and an estimated 2 million people with COPD who remain undiagnosed, which is equivalent to 13% of the population of England aged 35 and over.³

COPD is a disabling illness. Although it affects people in different ways, those with COPD often have attacks of breathlessness, a bad cough and repeated chest infections. They produce a lot of sputum and can be affected both in the winter when it is cold, and in the summer when air pollution can be high. Quality of life for people with advanced COPD is also affected. There are problems with restricted mobility and these are compounded by social isolation and poor self-esteem. 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.

COPD is expensive. The direct cost of COPD to the UK healthcare system is estimated to be between £810 million and £930 million a year. This is due to the high prevalence of COPD and high burden of treatment taking place in secondary care. Hospital admissions make up a significant part of the direct costs, despite only a small proportion of people with COPD being admitted to hospital. Costs are much higher for those with severe COPD than with mild COPD.

As the cost of provision of services to diagnose and treat COPD is a key element in assessing the affordability of each recommendation within the strategy, we have produced a separate draft economic impact assessment that looks at this in detail. This document is also available from the Department of Health website consultation pages.

The strategy recommendations

A full list of all the recommendation in the draft strategy is given below.

Chapter 2: Prevention and identification

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.

Chapter 3: Finding the 'missing millions'

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 World Health Organization (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.

Chapter 4: High-quality care and support

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 in 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.

Chapter 5: 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.

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

Chapter 6: Asthma

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.

What we want to achieve

A successful outcome from the implementation of the national strategy for COPD would see equal improvements across the whole of the population of England regardless of population group. The specific outcomes involved are:

- a reduction in the number of people with COPD;
- a reduction in the number of deaths and the severity of disabilities from COPD;
- fair access to services and health improvement;
- the provision of better quality treatment and care throughout the whole of treatment and care and in all aspects of life;
- a greater understanding by the public and all the health and social care professions involved of the factors that contribute to the risk of COPD and recognising the symptoms COPD; and
- the removal of barriers which disadvantage any group in achieving the above outcomes.

Evidence

We estimate there are around 835,000 people currently diagnosed with COPD in England and an estimated 2 million people with COPD who remain undiagnosed, which is equivalent to about 13% (or almost one in eight) of the population of England aged 35 and over.

The prevalence of COPD reported to the Department of Health through the Quality and Outcomes Framework (QOF),⁴ was as follows: in 2005/06 COPD prevalence was 1.4% in England,⁵ 1.8% in Scotland,⁶ 1.9% in Wales,⁷ and 1.5% in Northern Ireland.⁸ These figures clearly fall far short of the estimate of around 13% of the population having COPD.

As QOF figures record the activities of GPs, they suggest that GP registers may be significantly under-reporting local prevalence of the condition. In some instances, less than 1% of a practice's population is included on COPD registers, even though the rate of COPD in the population may be as high as 13% of the population aged 35 and over. Across the country, rates of COPD reported by GPs vary from 0% to 7.4%. There are also many people who are on both the asthma and COPD register. For some this may be appropriate, but for many the duplication is likely to be unnecessary. There is also significant misdiagnosis with, in some areas, about 30% on the COPD register who don't have COPD. For these reasons, one of the recommendations included in the consultation document is to improve the accuracy of disease registers so that people diagnosed with COPD can be identified.

Respiratory disease is responsible for one in five deaths in England, which is more than ischaemic heart disease, and greater than in most other European countries. COPD is responsible for a quarter of these deaths. Some 24.9 million working days were lost due to respiratory illness in 2004/05 at an estimated cost of £1,728.5 million.

The Healthcare Commission conducted an Improvement Review on COPD (Clearing the Air – 2006). It found wide variations in care and many people not having access to the services deemed important in existing national guidelines. In primary care there was poor awareness of COPD and considerable under-diagnosis. The report highlighted the need for personalised, structured and integrated care for people with COPD if the disease burden is to be managed more effectively.

During the development of the COPD national strategy, issues that have been identified by the External Reference Group include:

- a lack of awareness of COPD by healthcare professionals and the public;
- little focus on prevention and risk reduction;
- large numbers of people not diagnosed, or inaccurately classified;
- no clear care pathways or models of care provision, including for acute and chronic care, and little proactive management of patients;
- varying access to pulmonary rehabilitation and supportive care; and
- sparse access to specialist services at end of life.

A report by the Health Development Agency in 2004 attributed to smoking the death of 87% of men with COPD and 84% of women with COPD.⁹

Impact of COPD on diverse groups

Race

People from all ethnic groups are affected by COPD. While there are no reliable estimates for the number of people with COPD in minority ethnic groups, given that 80% of COPD is related to smoking, Health Survey England¹⁰ 2004 figures would suggest that Bangladeshi men (40% smoking prevalence) are most at risk, followed by men who are Irish (30%), Pakistani (29%), Black Caribbean (25%), Black African and Chinese (both 21%), or Indian (20%).

Among women, the figures are high for Irish (26%) and Black Caribbean (24%) ethnic groups, dropping significantly for Black African (10%), Chinese (8%), Indian and Pakistani (5%) and Bangladeshi (2%) groups. However, the overall number of people from ethnic minorities with COPD, and their proportion of the population as a whole, is expected to rise with the aging of ethnic minority populations.

It is important to note that smoking prevalence in the general population now stands at 21% (men 22%, women 20%) from 2007 data,¹¹ down by about 3% since 2004, but it is unknown if a similar reduction has occurred in minority ethnic groups since the Health Survey England data of 2004. National smoking targets are focused on achieving an overall drop in smoking prevalence to 21% or less by 2010, with a further target relating to reducing smoking prevalence among smokers in the 'routine and manual' group of workers who make up 44% of the adult smoking population. While NHS stop smoking services provide free support to all smokers, they are also configured to address and improve health inequalities, and therefore have this as a central tenet in both access and activity. They are closely monitored on this at a local level, with each service conducting an equality audit annually. In addition, statistics relating to the number of clients using the services in terms of age, gender, ethnicity, socioeconomic classification and during pregnancy are published quarterly on the NHS Information Centre website.¹²

Looking at one example of race and COPD, we know that Bangladeshi men have among the highest rates of admissions to A&E for lung disease, and a very high smoking prevalence. Due to this very high smoking prevalence, Bangladeshi women are likely to have been heavily exposed to passive smoke, even if they do not smoke themselves. Also, older Bangladeshi women may have been exposed in their youth in Asia to biomass fuels, the smoke from which is known to be an important factor in developing COPD.

There is also an issue as to whether current services for people with COPD, their families and carers adequately take account of cultural differences. Research suggests that ethnicity can be a factor in the extent to which COPD is understood, or acknowledged, and in people's willingness to seek help.

NHS stop smoking services exist across England, providing free, evidence-based support to all smokers who want to stop. While national targets are related to an overall drop in smoking prevalence, services are configured to address and improve health inequalities ensuring the support they offer is accessible by all. Between April 2008 and March 2009, smokers from ethnic minority groups accounted for 7% (45,228) of those who set a quit date, an increase on 6% in 2007/08 (37,734) and 3% in 2001/02 (7,366).¹³ NHS stop smoking services provide for around a quarter of all successful quits per year, but wider, comprehensive tobacco control measures, e.g. smoke-free legislation, are also required to reduce prevalence. The new ten-

year strategy for tobacco, due to be published by the end of 2010, will look in greater detail at further tobacco-control action and specific population groups.

The national strategy for COPD looks to address these issues and seeks the views of everyone with an interest in this condition. It emphasises that services should take account of the fact that the needs of people from minority ethnic groups may be different from those of the majority population and may require specifically tailored interventions. It also suggests that training should enable an understanding of the possible differing needs of people from minority ethnic backgrounds. For those who do not have English as a first language, there may be a need for support through local primary care trust (PCT) translation services to ensure that patients can communicate and understand the elements of their regular review. Access to such translation services should already be established through PCTs, and is an important factor in ensuring that local healthcare services are tailored to the needs of their local populations.

We also recommend that Bangladeshi men and women, in particular, are a target audience for our prevention and awareness-raising campaigns.

To help assess the impact of ethnicity on COPD, we have run some focus groups with Bangladeshi men in Tower Hamlets and also worked with the Picker Institute, who produced a report *Exploring the experience of seldom heard people affected by COPD in January 2008*.¹⁴ The key outcome of this research was that it was hard to find people with COPD from minority ethnic communities, as they tend not to present until they are hospitalised. The report from the Picker Institute consistently found that even in areas with very high black and minority ethnic populations with high smoking rates, virtually the entire case load for NHS doctors and nurses, and the membership for charities, was not from the black and minority ethnic population.

Other findings were that some female patients from South Asian backgrounds were not engaging with services such as pulmonary rehabilitation, nor were they taking an active part in self-management. Some possible reasons put forward for this were:

- lack of transport;
- women not used to joining in open activities;
- women seeing exercise as undignified and failing to understand the role of exercise in COPD;
- a lack of recognition that their shortness of breath is actually a disability that needs a doctor's assessment;
- written materials not translated; and
- a lack of advocates within their community.

For some services, such as pulmonary rehabilitation, where there appear to be lower than expected referral rates of women from ethnic communities, we will consider running some pilot pulmonary rehabilitation programmes exclusively for men, or for women, and recruiting, for example, only Bengali women for advocacy roles in areas of high ethnicity such as East London.

Disability

COPD is a progressively disabling condition that cannot be cured, and in time will lead to death. People with COPD also often have other disabling conditions, such as heart disease, which complicates the nature of the care they require. The strategy acknowledges this. It also emphasises that training of the NHS workforce should enable a better understanding of the differing needs of people with COPD, including those with additional disabilities.

We have identified that:

- the Disability Discrimination Act (DDA) 1995/2005 is important in respect of the obligations it places on employers to make workforce adjustments;
- it is essential that information on COPD should be available in all formats to accommodate individuals' impairments, difficulties or disabilities; and
- there is a need for improved links between the NHS and community services.

Case studies featuring patients with co-morbidities, mental health problems and social difficulties will be helpful, and we will be collecting these during the consultation process.

In developing the final EqIA we will also be working with a range of groups, and we will also be engaging with them during the public consultation.

A large part of the strategy (Chapters 3–6 inclusive) is aimed at improving the lives of people with COPD once they have been diagnosed, right through to end-of-life care, and reducing any associated disability along the way.

Gender (including transgender)

There are differences in the incidence of COPD according to gender. COPD has until recent years disproportionately affected men (as a consequence of gender differences in smoking behaviour and employment in industries that may expose the individual to risk, such as coal mining).

In the UK, the rate of lung disease has been increasing in recent years nearly three times faster among women than among men.¹⁵ Women are also more susceptible to developing lung disease because their lung function worsens with shorter duration or lesser intensity of smoking than men.¹⁶

As smoking prevalence is higher among 'routine and manual' workers, who are predominantly men, this will strongly factor into our calculations when we are producing our communications strategies to accompany the launch of the strategy.

Age

COPD primarily affects people over the age of 45. It is a progressive disease, linked to smoking in about 80% of cases, and the older you are and the more you have smoked, the worse your COPD will become. One of the fundamental aims of the strategy is to proactively identify people with COPD earlier in the course of the disease and ensure they receive structured support and follow-up on a regular basis.

The British Thoracic Society's 2006 report¹⁷ looked at prevalence (%) of respiratory illness (which included COPD) by age from 1995 to 2004, and gave the following figures, based on the Office of National Statistics General Household Survey:¹⁸

Percentage of men and women with respiratory illness, by age

Year	16–44		45–64		65–74		75+		All Ages	
	M	F	M	F	M	F	M	F	M	F
1995	6.5	6.3	5.4	5.9	8.2	8.9	8.5	7.6	6.5	6.6
2004	5.6	5.3	5.5	6.6	10.3	9.1	9.8	8.3	6.3	6.4

The table broadly shows that there has been an increase in prevalence between 1995 and 2004 for all age groups except for those younger than 45.

Religion or belief

As far as we are aware, the only obvious religious or belief aspects in relation to COPD concern palliative and end-of-life care. Religion or belief may affect people's wishes as they approach death. We welcome any views on any other religious issues associated with COPD.

Sexual orientation

We are not aware of any obvious sexual orientation aspects to COPD and its care. As with religion and belief we also welcome any views on any sexual orientation issues associated with COPD.

Further considerations

Human rights

The Human Rights Act 1998 incorporated the European Convention on Human Rights into domestic law to create a new culture of respect for human rights. The aim was to change the culture of rights and responsibilities and to empower the UK population, enabling them to influence the development of services that affect them. All public authorities must respect Convention rights in all that they do.

The COPD strategy is focused on improving quality of life and care outcomes for people diagnosed with COPD, and the purpose of the consultation exercise is to invite feedback on service proposals that will impact on people with the disease. Our aim is to give people dignity and choice in the way they interact with the public healthcare system, and we rely on feedback to get these services right for as many people as possible. We are also proposing to provide information and services developed in consultation with our target audience, i.e. those diagnosed with the condition, and also aiming to improve detection and treatment of COPD while helping people to make informed choices about how they live their lives to prevent ill health.

Monitoring and research

The National COPD Audit 2008, undertaken by the Royal College of Physicians, is the most effective method that has been developed to date to monitor the provision and effectiveness of services for people with COPD.

The consultation document also outlines where there are gaps in knowledge about how to diagnose and manage people with COPD and asthma, where models of care need to be piloted and where further research is required. We are also interested to hear from people about whether there are any gaps that need filling, and have a specific question in the consultation about this.

Have we got it right?

We want to help everyone with COPD in England, and to help prevent people from getting COPD. But to do that well we need your help to ensure that the Department of Health has correctly identified and considered the possible impact of the strategy on people according to their race, disability, gender, age, religion or belief and sexual orientation.

You can help by providing answers to the following questions in the public consultation that has been published alongside this document:

- 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?
- 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?

Summary of action following consultation

The Department of Health will consider all comments received during the consultation process, and will review the strategy to take into account the feedback received. A final version of the strategy is planned for publication by early 2010. We also plan to publish several documents alongside the launch of the strategy. Currently, these are likely to include the following:

- a full Equality Impact Assessment;
- a full Economic Impact Assessment;;
- a summary of the responses received during the consultation;
- a management of medicines document; and
- a workforce strategy.

Action plan and timeline

The strategy outlines a programme of work that will be undertaken by the Department of Health subject to suitable funding being identified. The final strategy will set out a clear action plan for implementation and a timeline for delivery. Other work will include:

- completion of consultation by date given on the consultation website;
- production of all finalised documents (date to be determined post-consultation);
- launch of final strategy and all associated documents (date to be determined); and
- implementation of strategy (dates to be determined).

Additional information

This document can also be downloaded from www.dh.gov.uk/en/consultations/index.htm

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- ² British Thoracic Society *Burden of lung disease*. BTS report 2nd edition BTS, 2006.
- ³ Shahab L, Jarvis, MJ, Britton J, West R. Chronic obstructive pulmonary disease: Prevalence, diagnosis and relation to tobacco dependence of chronic obstructive pulmonary disease in a nationally representative population sample. *Thorax* 2006; 61: 1043–1047.
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- ⁵ England QOF data available from www.ic.nhs.uk/statistics-and-data-collections/audits-and-performance/the-quality-and-outcomes-framework
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