



# **An Outcomes Strategy for Chronic Obstructive Pulmonary Disease (COPD) and Asthma in England**

*Assessment of the Impact on Equalities (AIE)*



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# 1. What do we mean by equality and diversity?

- 1.1 Equality is essentially about creating a fairer society where everyone can participate and has the opportunity to fulfil their potential. It is underpinned by legislation designed to address unfair discrimination (past, present or potential) that is based on membership of a particular group. In some circumstances, positive action is encouraged to address discrimination. It is often summarised in terms of:
  - equal access
  - equal treatment
  - equal outcomes
  - equality of opportunity
- 1.2 Diversity is about the recognition and valuing of difference in its broadest sense, and creating a working culture and practices that recognise, respect, value and harness difference for the benefit of the organisation and the individual. The term describes the range of visible and non-visible differences that exist between people. Managing diversity harnesses these differences to create a productive environment in which everybody feels valued, where talents are fully utilised and in which organisational goals are met.
- 1.3 Equality and diversity are not interchangeable but are interdependent. There is no advancement of equality if difference is not recognised and valued. Chapter 3 of the Outcomes Strategy for COPD and Asthma summarises actions on equality.

## Public Sector Duty

- 1.4 The general equality duty is underpinned by specific duties, to help public bodies meet the general duty. The public sector equality duty is a specific duty, which came into effect in April 2011. The public sector equality duty covers all of the protected characteristics and all public organisations are required to create equality objectives and publish information which enables the public to monitor the organisation's ability to promote equality, foster good relations and eliminate discrimination.

## Human Rights

- 1.5 Human Rights and equality are inextricably linked, deriving as they do from the same fundamental principles: equal respect for the dignity of every person. A Human Rights approach treats the individual as a whole person and seeks to address their requirements holistically. At the heart of human rights is the belief that everybody should have autonomy, be treated fairly and with dignity – no matter what their circumstances.
- 1.6 The Equality and Human Rights Commission identifies 15 rights protected by the Human Rights Act 1998. These can be summarised as follows:
  - being treated fairly and with dignity;
  - taking part in the community;

- living the life you choose; and
- being safe and protected from harm.

1.7 In summary, this legislation places a requirement on public bodies to assess their current provision, identify the needs of their 'customer' base and then work with those people to develop the right services, anticipating needs and differentiating the interventions in order to achieve equity of access, experience and outcome.

1.8 The Outcomes Strategy for COPD and Asthma is focused on improving quality of life and care outcomes for people with those conditions. The purpose of the consultation exercise on the draft strategy, which was held from February to April 2010, was to invite feedback on service proposals that will affect people with the disease. Our aim is to give people dignity and choice in the way they interact with the healthcare system and we rely on feedback to get these services right for as many people as possible. We are also aiming to improve the choices everyone makes about how they live their lives to prevent ill health.

## 2. An Outcomes Strategy for COPD and Asthma: Assessing the impact on equalities

- 2.1 The Department of Health (DH) recognises that equality analysis is an essential part of identifying and assessing relevant evidence on policies and helps it to meet its duties in relation to equality legislation and regulations. The Equality Act 2010 requires analysis to consider the following 'protected characteristics': age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation. The Department uses equality analysis to identify opportunities to advance equality of opportunity as well as identify and address potential negative impact.
- 2.2 This AIE has been developed with input from a high-level advisory board of patients, clinicians, charities and other respiratory disease experts that was established to develop the Outcomes Strategy for COPD and asthma. Working groups were established as part of the work of the board to look at specific aspects of COPD and asthma, such as patient awareness and experience.
- 2.3 Department officials have also attended a number of outside meetings and conferences to help inform this AIE. Meetings and discussions have also been held with specialists in the equality areas that helped inform and shape our strategy. This includes a meeting in Tower Hamlets with Bangladeshi men, presenting at the British Lung Foundation (BLF) patient conferences attended by a broad range of people including those from BME groups and older people with both COPD and asthma, and commissioning the Picker Institute to engage with a range of BME groups (see paragraph 4.13).
- 2.4 This assessment is also based on the responses we received to the formal consultation on the draft strategy which ended in April 2010. The consultation included specific questions on tackling inequalities.
- 2.5 Our vision is to ensure that everyone diagnosed with COPD and/or asthma receives equitable, responsive, high quality and effective health and social care services from the right person, at the right time, and in the right place.
- 2.6 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 interventions need to be targeted at those in the most deprived communities.
- 2.7 Our ongoing commitment is to ensure that all communities can expect better prevention strategies for COPD, 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.

# 3. An Outcomes Strategy for COPD and Asthma: Objectives

3.1 The strategy sets out the outcomes that need to be achieved in COPD and asthma to deliver on the Government's commitment to improve health outcomes and reduce inequalities.

**Objective 1: To improve the respiratory health and well-being of all communities and minimise inequalities between communities.**

**Objective 2: To reduce the number of people who develop COPD by ensuring they are aware of the importance of good lung health and well-being, with risk factors understood, avoided or minimised, and proactively address health inequalities.**

**Objective 3: To reduce the number of people with COPD who die prematurely through a proactive approach to early identification, diagnosis and intervention, and proactive care and management at all stages of the disease, with a particular focus on the disadvantaged groups and areas with high prevalence.**

**Objective 4: To enhance quality of life for people with COPD, across all social groups, with a positive, enabling, experience of care and support right through to the end of life.**

**Objective 5: To ensure that people with COPD, across all social groups, receive safe and effective care, which minimises progression, enhances recovery and promotes independence.**

**Objective 6: To ensure that people with asthma, across all social groups, are free of symptoms because of prompt and accurate diagnosis, shared decision making regarding treatment, and on-going support as they self manage their own condition and to reduce need for unscheduled health care and risk of death.**

## COPD

3.2 COPD is a disease of the lungs that is characterised by airflow obstruction or limitation. It is now the most widely used term by clinicians for the conditions in patients with airflow obstruction who were previously diagnosed as having chronic bronchitis or emphysema or chronic unremitting asthma. 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 markedly slow decline in lung function and hence lengthen the period in which a patient can enjoy an active life.

3.3 Smoking is the leading cause of COPD, responsible for over 85% of COPD cases. However, 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.

- 3.4 COPD kills about 25,000 people a year in England and Wales.<sup>1</sup> Recent figures showed that COPD accounted for 4.8% of all deaths in England between 2007 and 2009.<sup>2</sup> It is the fifth biggest killer disease in the UK. Numbers of deaths from COPD increase with age, as the lungs become more obstructed over time. In the UK, deaths from COPD are very low in the age range 0-40 (less than 500 per year) but much higher in the 75+ age range for both males and females (about 20,000 per year).<sup>3</sup> There are around 835,000 people currently diagnosed with COPD in the UK and an estimated 2,200,000 people with COPD who remain undiagnosed.<sup>4</sup>
- 3.5 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, in a cold snap, 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, two-thirds were unable to take a holiday because of their disease and one-third had disabling breathlessness.
- 3.6 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.
- 3.7 Lung damage starts before symptoms are evident. People 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.
- 3.8 Many healthcare practitioners in England tend not to be aware of COPD and tend to focus effort only on smoking cessation. The Outcomes Strategy seeks to rebalance this focus.

## Asthma

- 3.9 The prevalence of asthma in England is among the highest in the world. The Quality and Outcomes Framework 2008 prevalence figures suggest that approximately 5.9% of the English population have asthma, and estimates of prevalence range from 3-5.4 million being affected by asthma. Deaths from asthma have plateaued at between 1000 and 1200 deaths a year since 2000, yet it is estimated that 90% of deaths are associated with preventable factors. Almost 40% of these deaths are in the under 75 age group. Asthma is responsible for large numbers of attendances to emergency departments, and hospital admissions, the majority of which are emergency admissions.
- 3.10 Asthma is a long-term condition that affects the airways in the lungs. Classic symptoms include breathlessness, tightness in the chest, coughing and wheezing. The goal of treatment is for patients to be free of symptoms, and able to lead a normal, active life. This is not a condition involving gradual deterioration over time, so the aim is to achieve this goal in as many patients as possible. The causes of asthma are not well understood, so prevention of asthma is not currently possible. Patients with asthma have different triggers for symptoms, and need to get to know what will provoke their asthma and cause deterioration in their control. Managing asthma involves a

combination of clinical skills and supporting the patient to manage their own condition and to know what action to take if they start to deteriorate. There is considerable evidence that a partnership approach between clinician and patient will achieve the best outcomes.

## The Outcomes Strategy

- 3.11 For those reasons, we have developed, in partnership with key stakeholders, including the NHS, professionals, charities and patients and carers, an Outcomes Strategy to ensure a coordinated approach to quality improvement across the wider care landscape, and to act as the fundamental reference point for improvement effort as it develops nationally and locally.
- 3.12 If the Outcomes Strategy for COPD and Asthma was successfully implemented, improvements in the whole population, across all social groups, would be seen, including:
- an initial increase in the numbers of people diagnosed with COPD
  - over time an overall reduction in the number of people with COPD;
  - a reduction in the number of mortalities 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 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 of COPD; and
  - the identification of, and actions to minimise, the barriers that exist which disadvantage any group to achieve the above objectives.

## 4. Impact of COPD on diverse groups

4.1 Certain sections of the population are more likely to develop COPD than others. For this reason, the Outcomes Strategy is aimed at promoting behaviour change amongst priority groups. Eight priority audience segments most at risk of lung disease were identified through research commissioned by the Department. They are: Routine and Manual Men and Women, Older Smokers and Ex-Smokers, Parents who Smoke, Pregnant Women, Tweens (children aged 7-12), and Bangladeshi Men. The research will be published shortly.

4.2 Based on the research on priority groups, NHS Improvement has created a 'Prevention and Early Identification toolkit' which will shortly be available on the NHS Improvement website for local commissioners to use. It should be noted that priority audiences will vary due to local demographic variation, and should be refined using local needs assessments.

### i. Race

4.3 Black and minority ethnic (BME) groups include many different groups with very different cultural backgrounds, socio-economic status and experiences in wider society. People from BME groups often have different presentations of problems and different relationships with health services. The rates of COPD in particular migrant groups, and subsequent generations, are also sometimes higher.

4.4 People from all ethnic groups are affected by COPD. Whilst there are no reliable estimates for the number of people with COPD in minority ethnic groups, given that 85% of COPD is related to smoking, Health Survey England 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 (21%), or Indian (20%).<sup>5</sup>

4.5 Amongst women, the figures are high for Irish (26%) and Black Caribbean (24%) women, dropping significantly for Black African (10%), Chinese (8%), Indian and Pakistani (5%) and Bangladeshi (2%) women.<sup>6</sup> However, the overall number of people from ethnic minorities with COPD, and their proportion as a whole, is expected to rise with the aging of ethnic minority populations.

4.6 It is important to note that smoking prevalence in the general population now stands at 21% (men 22%, women 20%) from 2007 data, down by about 3% since 2004,<sup>7</sup> 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 with a further target relating to reducing smoking prevalence amongst routine and manual smokers who make up 44% of the adult smoking population. 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).<sup>8</sup>

4.7 We know that Bangladeshi men, for example, have amongst 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 to biomass fuels in their youth in Asia, the smoke from which is known to be an important factor in developing COPD.

- 4.8 There is also an issue as to whether current services for people with COPD and their family 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, or in people's willingness to seek help.
- 4.9 To help assess the impact of ethnicity on COPD we held some focus groups with Bangladeshi men in Tower Hamlets and we commissioned the report from the Picker Institute.<sup>9</sup> 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 BME populations with high smoking rates, virtually the entire caseload for NHS doctors and nurses, or the membership for charities, was not from the BME population.
- 4.10 Other findings were that some female patients from South Asian backgrounds were not engaging with services such as pulmonary rehabilitation, or 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, and
  - women seeing exercise as undignified and failing to understand the role of exercise in COPD
  - that millions of people, not just those in ethnic groups, do not recognise that their shortness of breath is actually a disability, and therefore do not consider seeing their doctor for an assessment.
- 4.11 With ethnic groups in particular, language is very important, and materials may need to be translated. Whilst written documents help, uptake of services can be enhanced by also having advocates within communities.
- 4.12 The British Lung Foundation has recently set up a working group to look at access to services for BME communities and will report in early 2012.
- 4.13 In January 2008 the Department commissioned the Picker Institute to prepare a report 'Exploring the experience of seldom heard people affected by Chronic Obstructive Pulmonary Disorder'. The Picker Institute works with patients, professionals and policy makers to promote understanding of the patient's perspective at all levels of healthcare policy and practice. During the late part of 2007 the Picker Institute undertook research with COPD patients (and their carers) across England on behalf of the Department of Health.
- 4.14 Firstly, a range of minority ethnic patients were interviewed in order to examine whether their experience and understanding of their condition was markedly different to that of the majority white population. Secondly, some of the major themes and issues in the consultation document were discussed by focus groups in order to seek the opinions of

people affected by COPD about those emerging themes. The full report can be found on [www.pickereurope.org](http://www.pickereurope.org).

- 4.15 One of their main findings was the fact that they found so few patients with a diagnosis of COPD from minority ethnic communities. They spoke to dozens of professionals working in various roles with people affected by COPD across England, many working in areas with very high BME populations with high smoking rates but we were consistently told that virtually their entire case load/membership was white. This may be for cultural, sociological, practical or even physiological reasons and there may be an issue with older Asian women or people with poor spoken English that can be overcome with additional support.
- 4.16 Whilst 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 tenant in both access and activity. They are closely monitored on this at a local level with each service conducting an equality audit each year. In addition, statistics relating to the number of clients using the services by age, gender, ethnicity, socioeconomic classification and during pregnancy are published quarterly on the NHS Information website. Healthy Lives, Healthy People A Tobacco Control Plan for England, published in March, set out the Government's efforts to maximise efforts to reduce tobacco use over the next five years.
- 4.17 Services for people with COPD 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. Training for healthcare professionals should also 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 PCT translation services to ensure that they can communicate and understand the elements of their regular review. Access to such translation services should already be established in local services, and is an important factor in ensuring that local healthcare services are tailored to the needs of their local populations.
- 4.18 The Outcomes Strategy also recommends that Bangladeshi men and women in particular are a target audience for prevention and awareness raising campaigns.
- 4.19 For some services such as pulmonary rehabilitation, where there appear to be lower than expected referral of women from ethnic communities, pilot programmes exclusively for men, or women, or, for example, Bengali women from areas of high ethnicity such as East London could be implemented.
- 4.20 The Outcomes Strategy for COPD and Asthma highlights that support for these groups that will rely on:
- local collection and monitoring of information on race and culture;
  - better use of these data to inform commissioning and provision in health and social care;
  - a focus on outcomes that work for individuals and communities;
  - monitoring and evaluating effectiveness of service delivery, especially around equality needs; and

- establishing mechanisms that allow local user groups to engage with providers and commissioners, and that empower and support them so that they can engage effectively.

4.21 This will be underpinned by the new statutory responsibilities of the NHS Commissioning Board and clinical commissioning groups. In addition, Department of Health research and analytical staff will continue to make best use of research in developing effective approaches for reducing race inequality in respiratory disease.

## ii. Religion or belief

4.22 Inequalities arise in respiratory services in relation to religion or belief in three main ways:

- the relationship with other aspects of identity (for some cultures ethnicity and religion are virtually inseparable). Service data show that more people from BME backgrounds identify themselves as religious. By failing to address religion and culture, services disproportionately affect people from BME backgrounds.
- potential for people who hold religious or other beliefs to have poorer experiences of services because core aspects of their identity are overlooked or they have no means of religious expression (for example, prayer rooms). This may cause anxiety and prove detrimental to their recovery
- potential for religious and cultural beliefs and needs to be overlooked in end of life and bereavement care causing stress and anxiety for the dying individual and families and carers.

4.23 Services will need to incorporate religion and belief as well as cultural requirements into the assessment of individuals. Local services will achieve better outcomes if they make resources and facilities available for people to express their religion or belief, and if they respect and provide for both their religious or beliefs and cultural needs. In the Outcomes Strategy, we have emphasised the importance of local decision-making to ensure that services must fit the needs of the local population.

## iii. Disability

4.24 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.

4.25 We have identified that:

- the Equality Act 2010 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.

- 4.26 There are two main aspects to the consideration of the outcomes for disabled people with respiratory disease:
- people with respiratory disease meet the criteria within legislation for the disabled; and
  - disabled people with respiratory disease may face barriers, either barriers to physical access or communication barriers.
- 4.27 The Outcomes Strategy recommends that commissioners and service providers continue to ensure that services are accessible to all disabled people.
- 4.28 The strategy also highlights two important aspects to the improvement of respiratory services for people with learning disabilities and autism:
- inclusivity of mainstream services for people with learning disabilities; and
  - provision of appropriate skills (e.g. sign language).
- 4.29 A long-standing problem has been the lack of support of people with autism, who often do not fit into mainstream services. The autism strategy, 'Fulfilling and rewarding lives', and the recent statutory guidance 'Implementing Fulfilling and rewarding lives: Statutory guidance for local authorities and NHS organisations' to support implementation of the autism strategy outlined priorities for improvement, including:
- the development of diagnostic services and pathways to care and support;
  - the availability of services for people with autism, where appropriate; and
  - greater awareness of autism among healthcare and social care professionals.
- 4.30 People with mental health difficulties meet the criteria for being disabled under legislation. We know that physical and mental health are inter-related. People with mental health problems are more likely to develop COPD because they are more likely to smoke than the rest of the population.<sup>10</sup> People who are diagnosed with COPD are also prone to mental health problems such as depression and anxiety because of their diagnosis.<sup>11</sup>
- 4.31 People with mental health problems smoke much more than the rest of the population, consuming 42% of all cigarettes smoked in England.<sup>12</sup> Smoking usually starts before adulthood; almost half of smokers under the age of 17 have either emotional or conduct disorder; and smoking is six times more common in those with conduct disorder.
- 4.32 Various studies have shown that a significant proportion of people with COPD also have depression and/or anxiety disorder.<sup>13,14</sup>
- 4.33 The Outcomes Strategy highlights the NICE guidelines on depression, which explain how people with a co-morbid long-term physical health conditions and depression should be treated, including the provision of therapy in a stepped care model. These guidelines inform the way Improving Access to Psychological Therapy services are looking to take forward the work with people with co-morbid long term physical health conditions and depression, which are likely to include many people with COPD.
- 4.34 The strategy also highlights the mental health outcomes strategy, 'No Health Without Mental Health', and states that it will be vital for COPD teams to work across professional disciplines to ensure their people access care in a holistic way.

#### iv. Age

- 4.35 COPD is a progressive disease, linked to smoking in around 80% of cases, and the older you are, and the more you have smoked, the worse your COPD will become. It primarily affects people over the age of 45. 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.
- 4.36 The British Thoracic Society's 2006 Report looked at prevalence (percentage) of respiratory illness (which would include COPD) by age from 1995 to 2004,<sup>15</sup> and gave the following figures, based on the Office of National Statistics General Household Survey:<sup>16</sup>

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

- 4.37 The table broadly shows that there has been an increase in prevalence between 1995 and 2004 for all ages groups except those younger than 45.
- 4.38 The National End of Life Care Intelligence Network report on the deaths from respiratory diseases showed that 7% of all deaths in England were caused by chronic lung disease (predominantly COPD) in the 65 – 84 age group, compared to only just under 5% of all deaths in the total population.<sup>17</sup>
- 4.39 The British Lung Foundation's report 'Invisible Lives' showed who is at most risk from COPD. They used Experian's Mosaic lifestyle segmentation and identified five Mosaic groups that are likely to live in the high-risk areas. Three 'lifestyle types' were identified as being at highest risk of hospital admission with COPD. These were:
- older people living in crowded apartments in high-density social housing. This group is nearly four times more likely to be admitted to hospital with COPD than the UK average. It describes people who live in small inner city flats and maisonettes occupied by low-income couples and pensioners whose children are now independent. They tend to be located in areas of large cities that have experienced many generations of economic deprivation where many older residents now live an impoverished existence.
  - older people, many in poor health from work in heavy industry, in low-rise social housing. This group is nearly three times more likely to be admitted to hospital with COPD than the UK average. It describes people who live in parts of declining industrial areas whose population consists of older people towards the end of their working lives or in retirement. They tend to live in communities that have been traditionally reliant on employment in mining, shipbuilding and other heavy industries. Because of long histories of employment in dangerous occupations, there are high numbers of people in poor health or who are permanently unable to work because of sickness.
  - older couples mostly in small towns, who now own houses once rented from the council. This group is twice as likely to be admitted to hospital with COPD as the UK average. It describes people of older working age (from 45 upwards), working in

manufacturing industries and living in mixed areas of older social housing and owner-occupied terraces. These neighbourhoods tend to be areas that have traditionally relied on a mixture of mining and large-scale industrial plants, such as power stations and steelworks, for their employment and are set in towns that have been relatively unsuccessful in developing modern middle class suburbs.

- 4.40 These broad 'lifestyle types' represent people living in deprived inner city areas on low incomes: people in former industrial regions who worked in factories, dockyards or mines etc and those in semi-skilled jobs or unemployed. Many are smokers who will have severe lung damage caused by their habit before the dangers were known.
- 4.41 Many of these people are in their 60s, 70s and 80s and are already retired. However, a fair proportion are younger and thinking about retirement but find themselves with a future disabled with COPD if it is not diagnosed and treated. A lack of awareness of COPD amongst the public and health professionals, together with the stigma attached to a smoking-related lung disease has led to COPD being neglected by health service planners.
- 4.42 Awareness-raising, smoking cessation services, diagnosis, treatment and care are all recommendations highlighted in the Outcomes Strategy as being vital for reducing inequalities. Indeed, 'older smokers' were also identified as one of the priority 'at risk' by research commissioned by the Department. Local prevention and early identification plans should take this into consideration.

## v. Sex

- 4.43 There are differences in the incidence of COPD according to sex. COPD has, certainly until recent years, disproportionately affected men (because of sex differences in smoking and employment in industries that may expose the individual to risk, such as coal mining).
- 4.44 In the UK, the rate of lung disease has been increasing nearly three times faster amongst women than men.<sup>18</sup> Women are more susceptible to developing lung disease than men, also because their lung function worsens with lesser duration of smoking or intensity of smoking than that of men.<sup>19</sup>
- 4.45 Recent figures show that chronic lung disease (predominantly COPD) is the primary cause of death for a higher proportion of men than women. It accounts for almost 5.5% of all deaths in men, and just over 4.5% in women.<sup>20</sup>

## vi. Sexual orientation

- 4.46 There is some evidence that smoking rates are high among lesbian and gay people,<sup>21</sup> which is significant since smoking is the primary cause of COPD. Healthy Lives, Healthy People A Tobacco Control Plan for England, published in March, set out the Government's efforts to maximise efforts to reduce tobacco use over the next five years. The Outcomes Strategy for COPD and Asthma recognises that targeted action to tackling inequalities in tobacco use will be a key component in achieving the ambitions set out in that Plan.

4.47 We are not aware, however, of any obvious differentiation in the care given to people once diagnosed with COPD based on their sexual orientation. Monitoring of sexual orientation by public services is very patchy and inconsistent, making it difficult to develop a national response. A priority action, along with all equality issues, for securing improved outcomes is to institute a system of routine local monitoring of access to services, experience and outcome. Much of the care experience of minority groups relies on the training and education of healthcare professionals and the Outcomes Strategy takes this into consideration.

## vii. Genetic predisposition

4.48 Alpha-1-antitrypsin deficiency was discovered in 1963. It 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.

4.49 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>22</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.

4.50 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>23</sup>

4.51 In 1997, the World Health Organisation (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>24</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. NICE recommends that a genetic test is undertaken if the COPD is early in onset where there is minimal smoking history or family history.

4.52 We therefore recommend that the NICE 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.

### viii. Gender reassignment

4.53 We are not aware of any obvious impact of gender reassignment on COPD. Monitoring of gender reassignment by public services is very patchy and inconsistent, making it difficult to develop a national response. A priority action, along with all equality issues, for securing improved outcomes is to institute a system of routine local monitoring of access to services, experience and outcome.

### ix. Marriage and civil partnership

4.54 Again, we are not aware of any obvious impact of marriage and civil partnership on COPD.

### x. Pregnancy and maternity

4.55 We are not aware of any obvious impact of pregnancy and maternity on COPD.

# 5. Impact of asthma on diverse groups

5.1 Commissioners and providers should plan and provide local services based on the needs of their population. About asthma, the Outcomes Strategy highlights that stratifying a GP practice population of people with asthma according to their risk of loss of control enables a practice to support the people most in need of proactive care. As a national overview, we list below some of the current evidence about the impact of asthma on diverse groups, but we also highlight the need for local monitoring of equalities and inequalities issues to ensure that outcomes are improved across all populations.

## i. Race

5.2 Asthma UK undertook a detailed survey of 600 people with asthma from BME groups in 2008, the results of which they published in their 'Speaking Up' report.<sup>25</sup> This showed clearly what other research has also suggested, that compared with the white population, BME groups have poorer outcomes, less access to information about their condition, and poor access to services. There were considerable differences between the groups surveyed, which comprised African, Bangladeshi, Caribbean, Chinese, Indian, Irish, Polish and Pakistani people with asthma, for example:

- only 64% of people from BME communities think they get high quality asthma treatment – substantially lower than 82% of the general asthma population – with less than 50% of Bangladeshi and Polish groups citing good quality care
- having an asthma action plan is associated with improved outcomes, yet 17% of the BME groups who had a plan said they could not read or understand their plan
- only 9% of Chinese people were aware that they could get information about asthma and local services
- almost a third said that their asthma had held them back at work and almost half, that it restricted their social lives

5.3 Access to services may be impacted by ethnicity. Around one in 20 either had no doctor or did not know whether they were registered with a local surgery. Even those who were registered reported difficulties in registering, difficulties getting convenient appointments and having to travel for more than half an hour to reach their surgery. Other research indicates that poor access to and use of primary care may be associated with higher death rates in asthma.<sup>26</sup>

5.4 Ethnicity may have an even greater impact on hospitalisation than socio-economic status.<sup>27</sup> Previous research has already shown that compared with the white population, South Asian people are three times more likely to require an emergency hospital admission for their asthma, with black people twice as likely.<sup>28</sup> The 'Speaking up' report found that more than two thirds of people did not have symptoms under control, with 58% reporting that their asthma had limited their activities in the last month. Poor control of symptoms is closely associated with acute admissions.

5.5 There is a particularly high rate of asthma in black Caribbean children under 16 years old.<sup>29,30</sup>

## ii. Religion or belief

5.6 We are not aware of any data on the impact of religion or belief. Monitoring of this by public services is very patchy and inconsistent, making it difficult to develop an appropriate response. A priority action, along with all equality issues, for securing improved outcomes is to institute a system of routine local monitoring of access to services, experience and outcome.

## iii. Disability

5.7 Again, we are not aware of any data on disability and asthma, but we highlight the need for monitoring of this area to improve outcomes.

## iv. Age

5.8 More than half the deaths from asthma are in the over 80 age group, although asthma impacts people of all ages.<sup>31</sup>

## v. Sex

5.9 We know that twice as many females die from asthma as males.<sup>32</sup> However, prevalence of asthma in children tends to be higher in boys than girls.<sup>33</sup>

## vi. Sexual orientation

5.10 We are not aware of any data on sexual orientation and asthma, but we highlight the need for monitoring of this area to improve outcomes.

## vii. Socio-economic deprivation

5.11 Living in poverty is associated with poor asthma outcomes, so is likely to impact any ethnic groups suffering deprivation – particularly Bangladeshi and Pakistani groups.<sup>34,35</sup> One study reported that the experience of poverty at various times in early childhood increases the risk of asthma attacks and chronic illness in the fourth year of life.<sup>36</sup>

5.12 People with asthma from lower socio-economic groups are more likely to smoke than those from higher socio-economic groups.<sup>37</sup>

5.13 96% of people with asthma from the highest socio-economic groups report that their asthma is under control, compared with 86% from the lowest socio-economic groups. More people from lower socioeconomic groups also tended to believe that there was nothing they could do to limit their asthma symptoms compared to those from higher groups (32% vs 16%).<sup>38</sup>

5.14 45% of the lowest socio-economic group said that asthma impacted their daily activities compared with those from the highest group (25%).<sup>39</sup>

## 6. The Government's role in reducing health inequalities

- 6.1 The Department of Health has made tackling health inequalities a priority. It is under a legal obligation to promote equality across the characteristics protected in the Equality Act 2010. Subject to Parliamentary approval, the new NHS Commissioning Board and clinical commissioning groups will be under a duty around reducing inequalities access to, and the outcomes of, healthcare.
- 6.2 The NHS Outcomes Framework will help the NHS Commissioning Board to play its full part in promoting equality in line with the Equality Act 2010. One of the principles that the Secretary of State for Health and the NHS Commissioning Board will use to set levels of ambition, will take into account the variation and inequalities of health outcome indicators, taking into account equality characteristics, socio-economic group and area deprivation. Furthermore, active consideration has been given to how outcome indicators can be analysed by equalities and inequalities dimensions. In addition to the legally protected characteristics (age, race, religion or belief, sex, disability and sexual orientation) particular consideration has been given to socio-economic groups and area deprivation, as these are drivers of poor health outcomes.
- 6.3 The Department of Health has created an Equality and Diversity Council, chaired by the NHS Chief Executive, to raise the profile of equality and diversity issues across the NHS and to support the NHS in implementing the Equality Act 2010. The Council reports to the NHS Management Board and is working to develop and deliver change to make the NHS more personal, fair and diverse. Goals include creating a framework that encourages NHS organisations and staff to work closely with the communities they serve and ensuring that managers consider equality and diversity issues and champion good practice.
- 6.4 The question of equality in respiratory diseases raises highly complex issues. The Department of Health will continue to work with people affected, carers, families, communities and relevant agencies in order to refine its understanding of the issues.

# 7. Monitoring and Research

- 7.1 The National COPD Audit, undertaken by consortium led by the Royal College of Physicians, is the most effective method that has been developed to date that monitors the provision and effectiveness of services for people with COPD. The RCP has just applied for funding to run the audit again from 2012/13. If successful, the Department will work with colleagues undertaking the audit to ensure as much equalities data as possible is collected.
- 7.2 In response to the consultation we heard that 82% of respondents felt that the strategy would help everyone with COPD or asthma to get the best care regardless of their age, sex, ethnicity, religion and beliefs, disability or sexual orientation. However, seventeen people disagreed; the comments were mostly around consideration of social class/income as an equality issue for COPD. In more deprived areas there is a danger of COPD being given low priority by clinicians overwhelmed by other health needs. There were also comments on that fact that access to lung transplants is restricted in the over 65s – although lung transplants are not a common solution to COPD. It was also noted that BME groups need literature in other languages. 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.

# Notes

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- <sup>6</sup> Data from Health Survey England 2004, available from [www.dh.gov.uk/en/Publicationsandstatistics/PublishedSurvey/HealthSurveyForEngland//Healthsurveyresults/index.htm](http://www.dh.gov.uk/en/Publicationsandstatistics/PublishedSurvey/HealthSurveyForEngland//Healthsurveyresults/index.htm)
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- <sup>19</sup> See BLF's "20 years of BLF research" document available from [www.lunguk.org/media-and-campaigning/special-reports/](http://www.lunguk.org/media-and-campaigning/special-reports/)
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