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

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Relevant documents (to be published separately)

NHS response to Outcomes Strategy for Chronic Obstructive Pulmonary Disease (COPD) and Asthma (Autumn 2011)

An Outcomes Strategy for Chronic Obstructive Pulmonary Disease (COPD) and Asthma: Assessment of the Impact on Equalities

Prevention and Early Identification toolkit (NHS Improvement - Autumn 2011)

A Good Practice Guide for Home Oxygen (Primary Care Commissioning)

NHS Commissioning Toolkit for COPD pathway (Autumn 2011)

Good Practice Guide for Adults with Asthma (Primary Care Commissioning - Autumn 2011)

Good Practice Guide for Children with Asthma (Primary Care Commissioning - Autumn 2011)

Foreword

The common purpose of government and the National Health Service (NHS) in England is to deliver health outcomes that are among the best in the world. However, for some conditions and diseases, we know our performance falls short of this aspiration, and we deliver health outcomes that fall some way behind those achieved by the best-performing countries, or the outcomes public health specialists and clinicians tell us are achievable. The reasons for this are often complex, and sometimes we know improving health outcomes for a particular patient group will take concerted and strategic effort by all those active in the field of health and social care, and the Marmot review makes clear that such improvements also require action across the social determinants of health. When this is the case, it is appropriate to develop an Outcomes Strategy to ensure a coordinated approach to quality improvement and innovation across the wider care landscape, and to act as the fundamental reference point for improvement effort as it develops nationally and locally. No one wants to deliver poor services, but sometimes problems occur in access, safety and outcomes for particular conditions or diseases that need coordinated and sustained effort to address.

We commend this Outcomes Strategy to people working with those who have Chronic Obstructive Pulmonary Disease (COPD). The case for the strategy for COPD is clear, and our hopes are high for achieving a significant improvement in outcomes for the estimated three million people in England who live with this condition, often unknowingly. Separate attention is given to asthma within this strategy because of the magnitude of the burden of that condition.

Premature mortality from COPD in the UK was almost twice as high as the European (EU-15) average in 2008 and premature mortality for asthma was over 1.5 times higher. We want to close that gap, and believe we can see outcomes for COPD and asthma reach standards comparable with the best in the world. At present, COPD is the second most common cause of emergency admission to hospital and is one of the most costly diseases in terms of acute hospital care in England. Asthma also poses clear resource pressures on the NHS.   The more that we can keep people with COPD and asthma well and at home, the more resource is released to benefit other people.

Our clear aim is to ensure decisions are taken locally, with more flexibility for local people to make decisions based on local needs. We want clinicians on the frontline to be supported to deliver what matters to people with COPD and asthma and their carers, high-quality care and improving outcomes.

Our changes to the health service are aimed to help reverse the gap that currently exists between the best and the rest, and ensure high-quality care for all. One-size-fits all state provision can actually entrench disadvantage and deepen the disparities in service between regions, classes and racial groups in our society. With our plans, people will have the power to drive change in the NHS in their area through transparency, choice and competition. With GPs in control of their budgets, they can decide the best possible care for their patients and design health services that suit their locality.

The NHS Commissioning Board will oversee commissioning on behalf of the Secretary of State. One organisation, working to one mandate, and responsible for delivering a clear set of outcomes across the country, providing the support to local commissioners, and carrying out

commissioning themselves, where necessary. Our plans will now mean a genuine National Health Service, underpinned by clear, national standards that deliver high quality care for all. Whatever happens people want care that is joined up, so that they do not have to put up with the frustrations they have today - with different appointments in different places, with different people, with different messages, all to discuss the same thing. That is why the new commissioning arrangements for healthcare will integrate both the NHS and Social Care. For people with COPD and asthma this is vital if services are to be delivered differently, and in the way people want and expect.

This is particularly important because COPD is often associated with other conditions that also need assessment and effective interventions in a holistic care approach. For example, about 40% of people with COPD also have heart disease, and significant numbers have depression and/or anxiety disorder. It is important that both the physical and mental health of people with COPD and asthma are assessed and addressed to ensure that people access care in a holistic way.

Hospital doctors and nurses will be involved in clinical commissioning. We will also introduce clinical senates, where groups of doctors and healthcare professionals come together to take an overview of the integration of care across a wide area.

Action is needed right across government to make progress against the objectives in this strategy, in areas such as reducing environmental risk factors associated with COPD. However the ambitions cannot be delivered by government alone. We need to rely also on employers, local authorities, industry and the voluntary and community sector. We all have a part to play to meet the social and economic challenge that is posed by those with COPD, and to improve the wellbeing of the population.

It is therefore appropriate that we take this opportunity to thank the many people who have contributed to the development of this strategy. Dame Helena Shovelton, Chief Executive of the British Lung Foundation, has shown an unwavering commitment to supporting people with respiratory disease. Asthma UK has also engaged fully in the development of this strategy, as have many clinical professional societies. The joint National Clinical Directors Professor Sue Hill and Dr Robert Winter have led the development programme for the strategy, with the support of many healthcare professionals, from both primary and secondary cares, who have given their considerable expertise and time in supporting the programme.

In particular, we are grateful to the many people with COPD and asthma and their carers who have given their time and support to the programme, in particular Chris Cox, and to those who sadly lost their lives whilst the strategy was in development, Dennis Ramshaw, Sue Matthews, and Ron Poulson.

Rt Hon Simon Burns MP
Minister of State for Health

Paul Burstow MP
Minister of State for Care Services

1. Introduction and Executive Summary

About outcomes strategies

1.1   This is an outcomes strategy. The purpose of an outcomes strategy is to set out the ways in which we will meet our aim of delivering healthcare outcomes as good as anywhere in the world. Outcomes strategies are developed following extensive engagement with all those with a commitment to improving outcomes in a particular service area.

1.2   Outcomes strategies set out, for a particular service area:
- our vision of the quality of services we want to make available to patients and service users, and to their carers and families;
- the support, information and choices which patients and service users, and their carers and families, will receive to make best use of these high-quality services;
- the ways in which these services will be held to account for the outcomes they deliver through the National Health Service (NHS), social care and public health outcomes frameworks;
- the support which the Government will provide to assist these services meet the outcomes for which they are accountable; and
- the work that the Government will lead in partnership the voluntary and independent sectors to help shape services that meet the needs of patients and service users.

1.3   Outcomes strategies set out how the NHS, public health and social care services will contribute to the ambitions for progress agreed with the Secretary of State in each of the high-level outcomes frameworks:
- where only the NHS needs to be involved in improving outcomes in a particular area, the relevant outcomes strategy will be initiated and its development led by the NHS Commissioning Board.
- where integrated action is required across any combination of the NHS, public health and social care services to improve outcomes in a particular area, the relevant outcomes strategy will be initiated and its development led by the Department of Health, in conjunction with Public Health England and the NHS Commissioning Board as appropriate.

1.4   During the transition to the new structures, the Department of Health will lead on the development of all outcomes strategies, taking account of the NHS Commissioning Board's and Public Health England's input as they emerge in shadow form. Primary Care Trusts (PCTs) will continue to take responsibility for delivering on improved outcomes for their patients until they are abolished, and their functions in the relevant area transferred to consortia, local authorities and the NHS Commissioning Board.

1.5   Outcomes strategies reject the top-down approach of the past that has stifled innovation and creativity. Instead, they focus on how patients and service users can best be empowered to make the right care decisions themselves, and on how clinicians on the

frontline can best be supported to deliver what matters to patients and service users: high quality and improving outcomes.

1.6   Outcomes strategies recognise that the Government can achieve more by working in partnership with others than it can alone. They establish and build on the platforms of joint working that exist across central government – and between government, local organisations, and patient and professional groups – to harness the creativity and innovation which exist across our society in pursuit of our ambitions for the health and social care services.

1.7   We will be preparing a NHS-facing document, for publication when the NHS Commissioning Board is operating in shadow form, that will support the NHS in 2011/12 and 2012/13 in delivering the respiratory specific elements of both the NHS Operating and NHS Outcomes Frameworks and the high-level objectives set out in this strategy.

Chronic Obstructive Pulmonary Disease (COPD)

1.8   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.

1.9   COPD kills about 25,000 people a year in England and Wales.[1] Recent figures showed that COPD accounted for 4.8% of all deaths in England between 2007 and 2009.[2] 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).[3] 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, which is equivalent to 13% of the population of England aged 35 and over.[4]

1.10   Data from the World Health Organisation (WHO) shows that premature mortality from COPD was almost twice as high in the UK as in the rest of Europe (EU-15) in 2008 and premature mortality for asthma was over 1.5 times higher. Premature mortality for COPD and asthma has decreased in the last decades in parallel with the European (EU-15) average for both men and women but the gap between the UK and the European (EU-15) average has not changed.[5] 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.[6]

Asthma

1.11   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.

1.12   The prevalence of asthma in England is among the highest in the world. The Quality and Outcomes Framework (QoF) prevalence figures suggest that approximately 5.9% of the English population have asthma (2008), 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 admissions, the majority of which are emergency admissions.

1.13   Given integrated action is required across the NHS, public health and social care services to improve outcomes to those people with COPD and asthma, this outcomes strategy was initiated and developed by the Department of Health, in partnership with a range of stakeholders representing all interests.

Objectives

1.14   Six shared objectives are set out in the strategy:

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.

1.15   Ultimately, success in delivery of these objectives is dependent on the widespread use of appropriate preventative strategies, and on integrated services being planned and

delivered around the needs of individuals across the whole life course from maintaining health and well-being to diagnosis of disease and proactive management of symptoms and episodes of worsening and eventually to end of life.

1.16   Success will also depend on a pro-active approach to tackling health inequalities since there is a social gradient in the prevalence of COPD and asthma and its risk factors. The approach to care will need to be personalised and take account of any circumstances that might affect the outcomes of care or disease prevention.

1.17   Achieving the COPD and asthma objectives set out in this strategy will help the NHS Commissioning Board and clinical commissioning groups improve against the higher-level measures in the NHS Outcomes Framework and the Commissioning Outcomes Framework.

1.18   It is up to the NHS, working with local authorities, voluntary organisations, business, 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, innovative models of care and scientific and technological advances, and harnessing expertise.

1.19   This strategy is being published at a time of transition in local government and in health and social care. Where this document refers to the new structures, these are the Government's current intentions for those bodies, subject to Parliamentary approval.

1.20   This Outcomes Strategy describes:
- the ambitions expressed by the public, people with COPD and their carers, and clinicians who helped develop the Outcomes Strategy
- the determination to tackle health inequalities and address equalities issues
- acknowledgement of the role environmental factors can have in causing or exacerbating conditions and the need for authorities to work in partnership to tackle these.
- system management support and incentives for delivery of the Outcomes Strategy
- cross government delivery effort and how work with partner organisations can help shape policies, approaches and services to meet the needs of the COPD population
- the similar experiences of people living with COPD and with other long term conditions, as well as the special challenges faced by people with COPD
- the challenges of COPD for the public and employers, and advice on how to meet them
- a call to action in the form of **REACT** to galvanise the collective efforts of the health system, professionals , people with COPD and the public to fundamentally change the burden of COPD through a focus on **R**espiratory health and good lung health, **E**arly accurate diagnosis, **A**ctive partnership between healthcare professionals and people with COPD, **C**hronic disease management (or control of symptoms) and **T**ailored evidence-based treatment for the individual
- the challenge of poor lung health for the public health service, and what materials can be used to help deliver the necessary improvements in COPD prevention, through raising awareness of symptoms and encouraging people to secure early diagnoses of COPD and asthma
- the outcomes the Government expects the NHS to pursue, and the information resources it expects the NHS Commissioning Board to draw on to drive

improvements in the quality of NHS commissioning. This includes, but is not limited to the National Institute for Health and Clinical Excellence (NICE) clinical guideline for COPD and the NICE Quality Standard for COPD.

- the similarities and differences between asthma and COPD and what can be done by Government, the NHS, healthcare professionals, public health, and individuals themselves to improve quality and outcomes for people with asthma
- the information, support and choices people need to make the best use of high-quality services and be active partners in care
- the challenge for community and social care services in supporting people with COPD and asthma in an integrated approach with the NHS, and how these care and support services need to contribute.

Making best use of our resources

1.21 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 improving outcomes for people with COPD and asthma. We need a focus on three things to make this possible. First, improving quality whilst 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, including in variation of provision and inequalities, and manage the change. Third, to act now, for the long term.

1.22 The development of this Outcomes Strategy takes place within the context of the tighter financial environment ahead. The Government has protected the NHS in England in the Spending Review settlement, with cash funding growth of £11.5bn (over 10%) by 2014/15. By comparison with other departments, this is a comparatively good settlement, though by NHS historical standards still extremely challenging. Over the next spending period (2011/12 – 2014/15) the NHS will face significant additional demand for services arising from the age and lifestyle of the population as well as the need to fund new technologies and drugs.

1.23 In order to meet this challenge, and continue to drive up the quality and outcomes achieved by NHS services, the NHS needs to deliver up to £20 billion of recurrent efficiency savings by April 2015. The QIPP programme has been created to enable the NHS to make these savings, which will be reinvested in frontline services.

1.24 Many of the measures outlined in this strategy are designed to support the NHS to meet the QIPP challenge, by demonstrating how they can improve quality, whilst simultaneously reducing cost, either by identifying where resources might be released or by improving understanding of the key interventions that have greatest effect.

1.25 Appropriate management of those with moderate and severe COPD will mean ensuring that those people already diagnosed have a correct diagnosis, including of severity and co-morbid conditions, and are managed proactively in a chronic disease management model according to the most cost-effective and evidence-based interventions. This will mean following the care model that recognises that the greatest increases are in the number of people living with multiple conditions. Therefore, we must recognise those common components of good long-term condition management that include risk

profiling, integrated care teams and self-care (see section 5). This includes engaging people in personalised care planning discussions, agreeing a way forward and ensuring people have the information they need to be effective self-managers of their conditions. For those living in the population with symptoms and undiagnosed COPD, and where lung damage will have already occurred, (with an impact on their functional ability) this will mean ensuring that they are identified and diagnosed early, they receive effective evidence based interventions to prevent further progression and are supported to manage their condition.

2. What the public, people with COPD and asthma their carers and clinicians want

2.1   The ambition of this Outcomes Strategy is to determine how people at risk from, or having COPD and asthma, can best be empowered to lead the lives they want to lead and to keep themselves and their families healthy; and on how practitioners on the front line can best be supported to deliver what matters to people with respiratory disease.

2.2   In the course of developing the Outcomes Strategy we listened to the public and concluded that their needs are for:
- information and advice on how to reduce their risk of respiratory disease
- timely access to services (eg stopping smoking services) which can help them reduce their risk of respiratory disease or of making it worse
- information on the symptoms and signs of respiratory disease, so that they can seek help early
- the reassurance that if they or their relatives do develop respiratory disease they will have rapid access to high quality services which deliver outcomes which are amongst the best in the world.

2.3   People with COPD and asthma and their carers told us specifically that they want:
- timely access to comprehensive quality assured assessment and diagnostic services
- information related to their condition and how it is managed to be available to all practitioners involved in their care irrespective of the setting
- access to reliable information about their condition which sets out all the options so that they can make choices which are appropriate for them
- easy access to comprehensive information about the services available to them and the outcomes achieved by these services
- to be empowered to make choices about their care where these are clinically appropriate and to be supported in decision making to the extent that they wish
- to know that they will receive the support they need whilst living with their condition and to be supported to remain in work and play an active role in society and local communities
- to be treated as a whole person, often with a range of other conditions
- to know that everyone involved in their care has the necessary skills, training and expertise and be reassured that everyone involved in their care will work effectively together, so that their care will feel seamless even when delivered in different locations
- to be able to access specialist services without delay should they need to do so; and to be assisted where necessary to remain at home
- to know that if they are approaching the end of life their preferences for care will be discussed with them and every effort will be made to meet their needs and their preferences
- to be treated as a whole to enable them to fully undertake activities of daily living and for the care providers to act as one team.

2.4   Health and social care professionals told us specifically that they want:

- the training, support and information they need to deliver high quality care and deliver good outcomes
- to work in a service which is well managed, so that their time is used effectively and so that care is streamlined for people with COPD and asthma
- to be able to compare the outcomes they achieve with those achieved elsewhere in this country and in other countries
- to be free to make the choices which they feel will benefit their patients the most
- to be recognised for the specialist skills and knowledge that they possess and for this to be fully utilised to deliver better outcomes for people
- to be able to work across traditional boundaries of care and to be supported to be innovative and to deliver care differently
- to have information about the people they care for, that is shared and easily accessible across the whole health system
- to be supported in creating the evidence on which models of care needs to be based.

3. Tackling health inequalities and addressing equalities issues

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

Introduction

3.1 Tackling health inequalities in England is essential to improving outcomes and achieving mortality rates that match the best performing countries in the world. *Equity and Excellence: Liberating the NHS* makes clear the Government's ambition to reduce health inequalities and improve the health of those with the poorest outcomes.

3.2 As the Marmot Review demonstrated, the social gradient in many health outcomes for people in disadvantaged groups and areas is a major contributor to England's poorer health outcomes in comparison with other similar countries. The review also showed that action on the social determinants of health - the conditions in which people live, work and grow - is needed to achieve sustainable improvements in health outcomes.[7]

Box 1 - The Marmot Review

The Marmot Review (2010) set out the different and interacting factors that shape health and well-being. These include: material circumstances, the social environment, psychosocial factors, behaviours, and biological factors. In turn, these factors are influenced by social position, itself shaped by education, occupation, income, gender, ethnicity and race. All these influences are affected by the socio-political and cultural and social context in which they sit.

3.3 Aspects of people's identity and their experiences of inequality interact with each other. For example, people from black and minority ethnic (BME) groups are more likely to live in deprived areas and have negative experiences, both because of their ethnic identity and because of their socio-economic status and living environment. Incidence and mortality rates from respiratory disease are higher in disadvantaged groups and areas, leading to worse outcomes and lowering our overall performance.

3.4 Our estimates suggest that the Routine and Manual (R&M) occupational group represents almost half of the people with diagnosed or undiagnosed COPD in England. Men aged 20-64 employed in unskilled manual occupations in England and Wales are around fourteen 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.[8]

3.5 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%.[9] COPD represents an enormous challenge – and opportunity - for the

Government's strategic objectives of reducing health inequalities amongst these groups. External factors such as air pollution can also exacerbate conditions.

3.6   As with many health conditions, there is a range of inequalities in the outcomes and experience of people with respiratory disease. These can occur at every stage of the patient pathway, from prevention right through to end of life. They can also affect a range of groups in society, including socio-economically disadvantaged groups and areas, Black and Minority Ethnic groups, older or younger people, men or women, people with disabilities, people from particular religions or with particular beliefs and the lesbian, gay, bisexual and transgender (LGBT) community.

3.7   The Equality Act 2010 replaced the three existing public sector equality duties pertaining to disability, race and gender with a new Equality Duty. It covers nine protected characteristics, and there is a public sector duty to advance equality and reduce inequality for people with these protected characteristics, which are:
- age
- disability
- gender reassignment
- marriage and civil partnership
- pregnancy and maternity
- race
- religion or belief
- sex
- sexual orientation.

3.8   The Analysis of the Impact on Equalities (AIE) (formerly called an Equality Impact Assessment (EqIA)) which accompanies this strategy, sets out in more detail the evidence of the differential impact of these characteristics and sets out an action plan to address these issues. The AIE also sets out actions for promoting equality.

The role of government in reducing inequalities

3.9   The Department of Health has made tackling health inequalities a priority and, subject to Parliamentary approval, has proposed in the Health and Social Care Bill that there should be new duties on health inequalities for the Secretary of State for Health, the NHS Commissioning Board and clinical commissioning consortia. For the NHS these duties would apply to access to, and the outcomes from, healthcare. This priority was also highlighted in the *Healthy Lives, Healthy People* white paper and the Department is working with other government departments through the Cabinet Sub Committee on Public Health to address the inequalities resulting from the social determinants of health.

3.10   The Department is also under a legal obligation to promote equality across the characteristics protected in the Equality Act 2010.

3.11   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.

3.12   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.

3.13   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 particular consideration has been given to socio-economic groups and area deprivation, as these are drivers of poor health outcomes.

3.14   The question of equality in respiratory disease raises highly complex issues. The Department of Health and other partners, including the British Lung Foundation and Asthma UK will continue to work with people affected, carers, families, communities and relevant agencies in order to refine our understanding of the issues.

4. Prevention

Improving public health outcomes and narrowing health inequalities

4.1   *Healthy Lives, Healthy People* sets a clear vision for public health and disease prevention focused on improving the healthy life expectancy of the population and improving the health of the poorest fastest. It introduces three key shifts:
- public health will be locally led, with local, ring-fenced budgets and powers
- public health will be unified, focused on outcomes, and will do what works, and
- responsibility and partnership will be strengthened at every level.

4.2   To drive improvements in public health, *Healthy Lives, Healthy People: Transparency in Outcomes* sets proposed high level ambitions for health improvement, protection and the prevention of ill health. It will be for those working at a local level to decide how best to deliver improvements against these high-level outcomes articulated following a local needs assessments and the involvement through local Health and Well Being Boards of the NHS, the Public Health service and Social Care.

4.3   A number of key indicators spanning several of the proposed domains will drive efforts to prevent respiratory disease.

4.4   The changes required to deliver on this outcome are complex as it takes time to bring about change, particularly the cultural change required so that people are encouraged to reduce risky behaviours and present early to their GP when they have signs and symptoms.

4.5   To improve outcomes the NHS and Public Health England will need to work together, offering integrated advice and care to the public and people with COPD. There are clear areas of shared accountability between the outcomes frameworks to recognise the responsibilities of the NHS and PHE in delivering improvements. For example, the NHS Outcomes Framework 2011/12 includes reducing mortality for people under 75 with a respiratory disease as an improvement area, and proposes that it should also be an improvement area in Healthy Lives, Healthy People: Transparency in Outcomes.

Public Health England (PHE)

4.6   A range of services will in future be the responsibility of PHE, including:
- public health intelligence;
- primary prevention interventions;
- vaccination services;
- screening programmes, including screening quality assurance (QA); and
- targeted campaigns to raise public awareness of disease and early symptoms and to encourage early presentation.

4.7   The new approach to public health delivery means that local areas will decide on their own priorities and ways of improving health in their communities, with Health and Wellbeing Boards making a full and independent assessment of needs based on the local population. This strategy will help commissioners and providers to then design

and target the most appropriate services for their local area. For local authorities it should also help local areas to develop and support strategies to tackle environmental factors that affect COPD such as air pollution.

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 pro-actively address health inequalities.

Prevention of COPD

4.8   Changes to the quality and cost of healthcare for those with COPD depend on fewer people developing the disease.   Keeping people healthy will help improve productivity, ensuring, for example, that those in the working population remain able to make their full contribution.   In developed regions, 25% of Disability Adjusted Life Years (DALYS) are attributable to risk factors common to respiratory disease. We believe action can be taken to minimise the risk of contracting COPD either by not starting, or stopping smoking, avoiding and controlling risks in the environment and workplace.

4.9   The areas for action are:
- developing prevention strategies for respiratory disease
- raising awareness of good lung health
- persuading the public to take lung health seriously
- ensuring employers (particularly those in 'at risk' environment) are doing all they can to protect staff and encourage good lung health
- empowering partners/communities to support the process of encouraging prevention

Who is at risk?

4.10   Current and ex-smokers are most at risk of contracting COPD. We can add to the group people who have been exposed to inhaled dusts and gases in the workplace or those who have an inherited genetic problem that leads to the early onset of emphysema or those who may have previously been diagnosed with asthma. Occasionally COPD may be the result of inadequate lung development in childhood that can be trans-generational, or damage caused by infections in childhood that affect lung growth and development.

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Box 2 - Key facts

In England:
- The Department of Health estimates that over 3 million people have COPD, but only about 835,000, mainly those with severe disease, are registered with the NHS as having COPD
- Deprived populations have the highest prevalence and the highest under-diagnosis of COPD
- There are ethnic disparities with Black men in deprived urban areas having particularly high risk
- COPD accounts for a large proportion of the gap in life expectancy between the areas with the worst health and deprivation and the average – around 8% of the gap for men and 12% of the gap for women
- Lung disease and particularly that associated with COPD costs business 24 million working days in sick leave and £3.8 billion in direct costs from lost productivity.[i]
- Around 15% of COPD may be caused or made worse by exposure to dusts and gases at work.[ii]
- 40% of people with lung disease are below retirement age (1.4 million based on 3.5 million cases nationally) and a quarter of those below retirement age are unable to work at all (400,000 people unable to work).

[i] *British Thoracic Society. Burden of lung disease, 2nd edition. BTS, 2006*
[ii] *Trupin L, Earnest G, San Pedro M et al. The occupational burden of chronic obstructive pulmonary disease. European Respiratory Journal 2003; 22: 462–469*

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Tobacco control

4.11   Smoking is the primary cause of preventable morbidity and premature death, accounting for over 80,000 deaths in England in 2009, and kills about half of all lifetime users. If current smoker' patterns continue, tobacco will kill about 10 million people worldwide every year by 2020[10]. Whilst smoking rates have fallen considerably since the 1960s, over 8 million people in England still smoke.[11] Smoking is the major preventable risk factor for COPD. Dissuading people from starting to smoke and helping people to quit remain critical. We have published a tobacco control plan that will set out more detail on how the Coalition Government proposes to reduce smoking prevalence.

4.12   Whilst tobacco dependence should decrease in Europe in the next decade, there will be no decrease in smoking-related respiratory diseases as the damage to the lungs will have already happened, cannot be reversed, and in many becomes progressive.

4.13   *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.

4.14   Whilst the Public Health Outcomes Framework will provide the key source of information about the progress on reducing tobacco use, the Government has set three national ambitions to focus tobacco control work across the whole system:

- reduce smoking prevalence among adults in England: to reduce adult smoking prevalence in England to 18.5% or less by the end of 2015, meaning around 210,000 fewer smokers a year
- reduce smoking prevalence among young people in England: to reduce rates of regular smoking among 15 year olds in England to 12 per cent or less by the end of 2015
- reduce smoking during pregnancy in England: to reduce rates of smoking throughout pregnancy to 11 per cent or less by the end of 2015

4.15   Targeting action to tackling inequalities in tobacco use will be a key component in achieving these ambitions. In some communities smoking prevalence remains much higher than the average and is associated with a higher incidence of respiratory disease, and particularly COPD. Very specific action will be required at a local level to tackle the problem and to introduce sustainable improvements for the future. While smokers in more disadvantaged groups often find it harder to quite for a variety of reasons, some smoking cessation services have been very successful in achieving excellent quit rates in disadvantaged areas. Considering both smoking prevalence and COPD prevalence with enable concerted and targeted action to be taken.

Employment and COPD

4.16   Large numbers of people in the workforce are affected by lung disease or are at serious risk of developing a respiratory condition and 24 million working days are lost each year costing around £3.8 billion due to reduced productivity.

4.17   Employers can:
- provide top level support and commitment
- ensure people work in a safe environment
- promote healthy lifestyles
- provide support to stop smoking
- help identify people who may have lung disease
- provide support for employees during disease flare-ups
- support individuals with chronic conditions to remain in work.

4.18   The majority of those who develop COPD in England will have done so from smoking. Many will be diagnosed while they are still employed. Where exposure to a substance encountered at work can have an adverse effect on health, there are specific obligations under health and safety law 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 e.g. occupational heath advice, taking due note of the need to consult with the person and gain consent before taking any action.

4.19   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 and robust monitoring is to be put in place.

4.20   Minimising inhalational exposure amongst the workforce will help at-risk people to 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 wellbeing of staff.

4.21   The Public Health Responsibility Deal sets out the actions that industry, the voluntary sector, NGOs and local government will take to help people make healthier choices. In line with the Responsibility Deal, we have published the Chronic Conditions guides for both employers and employees and are developing a collective pledge around lung health.[12]

Prevention and lung health risk modelling

4.22   In the vast majority of cases our lifestyle choices affect our risk of developing COPD. Respiratory disease could largely be prevented by changes in lifestyle behaviours. *Healthy Lives, Healthy People* recognises the need for a new approach to improving the public's health, which will support prevention.

4.23   At a local level, Directors of Public Health will provide strategic leadership on public health across the local health economy along with a public health budget that is ring-fenced to ensure it is used to tackle preventable causes of ill health.

4.24   Little is understood by the public about lung disease due to lack of clear and consistent messaging:
   - there is stigmatisation of lung disease as 'self-inflicted' (from smoking) – a barrier which needs to be overcome amongst healthcare professionals and the public
   - COPD is usually identified too late to achieve significant quality of life improvements or to slow progression
   - there is an over-representation of those 'at risk' in lower socio-demographic groups.

4.25   A quick reference risk-model to help employers, planners and commissioners has been developed to help understand an approach to both message development and service intervention. As an individual progresses through the spectrum of risk – from those currently not exposed to risk, to people who are exposed and have symptoms, but are undiagnosed – different interventions will be required in order to deliver different changes in behaviour. The model is set out in the toolkit to be published on the NHS Improvement website (http://www.improvement.nhs.uk)

4.26   The key to the successful prevention and treatment of the disease 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 behavioural change by ensuring people take action to avoid the causes and exacerbating factors of COPD, such as cigarette smoke, or workplace dusts and gases. Action on the social determinants of health, such as the local environment, is also important.

4.27   The Marmot Review noted that proximity to green space reduced disease prevalence. The Review found that people with lower education levels living close to green space had lower annual prevalence rates of COPD than those living further away.[13]

4.28 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 amongst a diverse range of audiences. A toolkit setting out this information will shortly be published on the NHS Improvement website.

4.29 Those working in healthcare delivery, from commissioners to providers, private companies to voluntary and community organisations, need to work together to deliver these overall objectives in an appropriate way, to fit local circumstances.

4.30 We know that the public does not universally understand complex clinical terms like COPD. For this reason, we suggest adopting messages built around the concepts of lung health, lung disease and lung age (lung age is the age predicted estimation of 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). Our work suggests that these concepts have resonance and meaning for the public.

4.31 In the longer term, 'lung health' should be incorporated into more general health initiatives and messaging. Only limited behaviour change can be achieved solely through mass communication campaigns. In addition, lung disease affects some communities disproportionately, so generic, nationwide campaigns may be ineffective in delivering lasting behaviour change. The prevention strategy is therefore to support local and regional approaches that:
- 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
- enables appropriate co-operation or collaboration with voluntary and community organisations and commercial organisations to help find people and engage them with appropriate messages.

4.32 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 we are trying to reach have traditionally been difficult to engage in the past, so the involvement of local communities in the design, evaluation and continual improvement of interventions measured against outcomes will be key for their success.

4.33 Certain sections of the population are more likely to develop COPD than others. For this reason, this strategy is aimed at promoting behaviour change amongst priority groups, helping to address health inequalities.   Eight priority audience segments most 'at risk' of lung disease have been identified and are set out in the toolkit.

4.34 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' which will shortly be available on the NHS Improvement website.

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5. Improving quality and outcomes for people with COPD

> **Box 3 - Key COPD statistics**
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> In England:
>
> - COPD is the fifth biggest killer with more than 30,000 deaths a year.
> - Data from the World Health Organisation shows that death rates from respiratory disease are almost double the EU average
> - COPD is the second most common cause of emergency admissions to hospital and one of the most costly inpatient conditions to be treated by the NHS
> - COPD is often associated with other long-term conditions. For example, 40% of people with COPD also have heart disease, and significant numbers have depression and/or anxiety disorder
> - There is a 50 fold difference is costs between mild and very severe COPD
> - 15% of those admitted to hospital die within three months
> - 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

Introduction

5.1   This chapter looks at what the Coalition Government's reforms will mean for improving outcomes for people with COPD in general, and how improvements can be made in the quality of care people receive and the outcomes that can be delivered.

5.2   The primary purpose of the NHS is to improve health outcomes for all: to deliver care that is safe, effective and provides the best possible experience for everyone.

5.3   In common with many other long-term conditions, COPD is a progressive disease. It is characterised by airflow obstruction and inflammatory mediated lung tissue damage, because of genetic or lifestyle or environmental factors. It is disease with no beginning and associated with the slow insidious onset of symptoms and loss of lung function.

5.4   3.2 million people have COPD but 2.2 million are undiagnosed. Many of these interact with the health system on a regular basis but remain undiagnosed because:
   - people do not recognise the symptoms as they develop gradually over a long period of time
   - many people think it is normal to have a cough and to be short of breath
   - people often put the symptoms down to smoking and think nothing can be done
   - doctors often treat the symptoms but fail to diagnose the underlying lung disease.

5.5 This leads to poor outcomes for people when they are diagnosed, with reduced survival and a significantly impaired quality of life.

5.6 People with COPD need to be recognised as having lung damage that will be progressive. The disease will, over time, result in further lung function impairment, disability, and for some, death. Data suggest that the vast majority of admissions for COPD are unscheduled and present a high burden on the NHS.

5.7 However, with the right care and treatment there is the potential to slow down or modify the progressive nature of this disease. This should be supported by the three key elements that will improve care for all people living with long-term conditions:
- risk profiling to identify and manage those at most risk
- integrated care which moves away from the largely reactive models of care that exist today into proactive, multidisciplinary teams, and
- self care that recognises the need for a partnership approach between the person with COPD, their carer, and the healthcare professional in ensuring there is a care planning approach, with regular reviews, adherence and compliance to treatment and good communication and exchange of information to support effective self management.

5.8 The current model of care in respiratory disease largely waits for people to develop illness, then focuses only on the management of conditions.

5.9 A more proactive approach to care in the future should focus on:
- personalised prevention: targeting public health and education messages at individuals to make it personal in an attempt to prevent the behaviour that leads to illness)
- delay of onset: some people will already have undertaken risky behaviours and will develop an illness, the aim here would be to change behaviour to delay the onset of that condition for as long as possible or to intervene early to prevent further deterioration)
- management post-diagnosis: involving people in their own care, using the generic long-term conditions model (outlined later in the chapter), so that conditions are managed well, using good practice in disease pathways and, where possible, incorporating assistive technology.

5.10 These three areas would not be mutually exclusive as people with one condition are at a higher risk of developing a second further condition, so it is important to identify the possibility of preventing or delaying the onset of multiple co-morbidities as well.

A Big Society approach to tackling COPD

5.11 In our Big Society, we will reframe our approach to COPD, rebalancing the relationship between people with COPD and healthcare professionals, and between people with COPD and the public services they use, to ensure that people are empowered and at the centre of decisions about their health and care. This is best expressed through our commitment to 'no decision about me without me'.

5.12 Optimal care for people with COPD requires a partnership approach between the person with COPD and their carer. The healthcare professional should ensure this by

taking a care planning approach, with regular reviews, adherence and compliance with treatment and good communication and exchange of information to support effective self-management.

5.13   A partnership approach is also required from the NHS, public health and social care services. All services need to work effectively together to ensure that people with COPD experience seamless and holistic care.

5.14   Working together with other organisations and individuals we can make an even bigger difference. The state, as the funder of NHS services, will always have a significant role to play, however:
- charities like the British Lung Foundation and Asthma UK raise awareness of COPD and asthma, raise money to fund research, deliver some services, provide information, and campaign for change
- academic institutions and professional organisations already undertake research into all aspects of respiratory disease
- commercial companies develop new tests and treatments for COPD and asthma;
- independent hospices support those nearing the end of their life, and
- thousands of people with COPD and asthma support each other both informally and through support groups such as the British Lung Foundation's (BLF's) local Breathe Easy Groups.

The Coalition Government's reforms and COPD

NHS Commissioning Board

5.15   *Equity and excellence: Liberating the NHS* sets out the Government's long-term vision for the NHS. The Government will, subject to Parliamentary approval, create an autonomous NHS Commissioning Board, accountable to the Secretary of State, but free from political interference. One of its responsibilities will be to secure improvements in the delivery of health outcomes. The Board is intended to provide leadership for quality improvement through commissioning guidance and hold clinical commissioning groups to account for their performance and quality of services.

5.16   The NHS Commissioning Board is expected to begin its work in shadow form from the autumn of 2011.Subject to Parliamentary approval, it will be formally established as an executive non-departmental public body in 2012 to start to authorise clinical commissioning groups, and will take on its full statutory responsibilities from April 2013. It is intended to:
- support continuous improvements in quality and outcomes of NHS funded services
- promote choice and patient and public engagement
- establish and support clinical commissioning groups and hold them to account
- directly commissioning services including primary medical care, other family health services, specialised commissioning, offender and some military health
- allocate and account for NHS resources
- reduce inequalities in access to outcomes and healthcare
- oversee planning for emergency resilience and lead NHS operational response to significant emergencies.

5.17   The Secretary of State for Health will set a formal mandate for the NHS
        Commissioning Board. This will be subject to consultation and Parliamentary scrutiny,
        including scrutiny by the Health Select Committee. The NHS Outcomes Framework will
        form part of this broader mandate.

NHS Outcomes Framework

5.18   The NHS Outcomes Framework 2011/12 signals the direction of travel for the NHS in
        focusing on outcomes. It sets out the high-level national outcome goals covering the
        majority of treatment activity for which the NHS is responsible for delivering. It aims to
        provide a national-level overview of how well the NHS is performing, to act as an
        accountability mechanism between the Secretary of State and the NHS Commissioning
        Board and to act as a catalyst for driving quality improvement and outcome
        measurement throughout the NHS.

5.19   The NHS Outcomes Framework sets out national outcomes goals. The NHS
        Commissioning Board will decide how best to deliver improvements on the ground and
        translate the national outcomes into outcomes and indicators that are meaningful at
        local level in the Commissioning Outcomes Framework. The shadow NHS
        Commissioning Board will take forward work on developing the Commissioning
        Outcomes Framework, with the support of NICE.

Box 4: The NHS Outcomes Framework

The five domains in the NHS Outcomes Framework 2011/12 are:

Domain 1: Preventing people from dying prematurely
Domain 2 : Enhancing quality of life for people with long-term conditions
Domain 3: Helping people to recover from episodes of ill health or following injury
Domain 4: Ensuring people have a positive experience of care, and
Domain 5: Treating and caring for people in a safe environment and protecting them
from avoidable harm.

5.20   In Domain 1, respiratory disease is captured under the improvement area' Reducing
        premature mortality from the major causes of death'. The indicator 'under 75 mortality
        rate from respiratory disease will be used, and will be a shared responsibility between
        the NHS Commissioning Board and the Secretary of State for Health through Public
        Health England.

5.21   In Domain 2 `Enhancing quality of life for people with long-term conditions' also relates
        to COPD outcomes. This domain seeks to capture how successfully the NHS is
        supporting people with long-term conditions to live as normal a life as possible and
        where appropriate remain in employment. The overarching indicator 'health-related
        quality of life for people with long-term conditions' allows the Secretary of State for
        Health to understand whether health-related quality of life is improving over time for the
        population with long-term conditions. The domain does not take a condition specific
        approach, but focuses on the generic outcomes that matter most to people with long-
        term conditions.

5.22 However, action needs to be taken across all five domains to ensure quality outcomes for people with respiratory disease are achieved. This action will be outlined in the companion document to be published over the summer, as will propose outcome indicators to measure progress against the strategy's objectives.

5.23 The NHS Commissioning Board will set out more detailed measures as part of its Commissioning Outcomes Framework, which it will use to hold clinical commissioning groups to account for securing improvements in outcomes.

5.24 The Board will drive service improvement through commissioning guidance, based on Quality Standards developed by NICE, along with evidence of best practice from other sources, such as this Outcomes Strategy.

5.25 Achieving the specific COPD and asthma outcomes set out in this strategy will help the NHS to improve against the measures in the NHS Outcomes Framework and the Commissioning Outcomes Framework. Driving improvements in the quality of NHS services will be a primary objective of the NHS Commissioning Board, alongside other duties such as tackling inequalities, promoting public involvement, promoting equality, research and innovation and supporting the QIPP challenge.

Clinical commissioning groups (CCG's)

5.26 In place of the current system, we will hand responsibility for commissioning to clinical commissioning groups. CCG's will be well placed to commission health services to meet the real needs of people for whom they are responsible. Through these groups, General Practitioners (GPs) and other clinicians will have new opportunities to shape the way that health services are designed and delivered. Taking into account the increasing range of NICE Quality Standards and other commissioning guidance, CCG's will work closely with secondary care and other healthcare professionals, and with community partners, to design joined-up services, and optimal care pathways, that make sense to patients, families and the public.

5.27 CCG's will have flexibility to seek commissioning support and enter into collaborative or joint commissioning arrangements, including with other clinical commissioning groups, local authorities and charities, particularly for services that cross boundaries.

5.28 The shadow NHS Commissioning Board, working with Strategic Health Authorities and Primary Care Trusts, will ensure that CCG's have the support to prepare for their statutory establishment. The Department is already working with the professional societies, voluntary organisations and other to develop guidance and support for CCG's in commissioning effective COPD services.

5.29 Doctors, nurses and other professionals will come together in 'clinical senates' to give expert advice, which we expect clinical commissioning groups to follow, on how to make patient care fit together seamlessly in each area of the country. To support the better integration of services, they should include public health specialists and adult and child social care experts. Clinical senates will have a formal role in the authorisation of clinical commissioning groups. In addition they will have a key role in advising the NHS Commissioning Board on whether commissioning plans are clinically robust and on

major service changes. The 'clinical senates' will be hosted by the NHS Commissioning Board.

The Quality and Outcomes Framework

5.30   The Quality and Outcomes Framework (QOF) is a framework for rewarding GP practices for systematically providing high quality care for their patients. QOF guidance is available through the NHS Employers website http://www.nhsemployers.org. QOF achievement data is published annually by the NHS Information Centre on its website http://www.ic.nhs.uk/.

5.31   NICE are considering two new indicators for QOF in relation to COPD:

- the percentage of patients with COPD and Medical Research Council (MRC) Dyspnoea Scale ≥3 at any time in the preceding 15 months, with a record of oxygen saturation value within the preceding 15 months
- the percentage of patients with COPD and Medical Research Council (MRC) Dyspnoea Scale ≥3 at any time in the preceding 15 months, with a record of a referral to a pulmonary rehabilitation programme (excluding patients on the palliative care register)

Further details of indicators in development and the NICE process for reviewing QOF indicators are on the NICE website at http://www.nice.org.uk/aboutnice/qof/qof.jsp

NICE Quality Standards

5.32   A suite of NICE Quality Standards will support the delivery of outcomes, including those relevant to COPD. Quality Standards are designed to provide an authoritative definition of what high-quality care looks like across a particular part of a care pathway or service.

5.33   Quality Standards are developed by NICE, working in partnership with patients, clinicians, social care professionals, commissioners, leading experts and healthcare specialists in that particular field. At present Quality Standards focus on NHS service provision, but subject to Parliamentary approval, NICE will also have responsibility for providing Quality Standards and other guidance in the field of social care.

5.34   The Department of Health currently commissions NICE to produce these standards. Subject to the successful passage of the Health Bill, this commissioning function pertaining to Quality Standards for the NHS will transfer to the NHS Commissioning Board (and, for social care and any public health Quality Standards, will remain with the Secretary of State for Health).

5.35   The Secretary of State for Health and the NHS Commissioning Board will be under a duty to have regard to Quality Standards in carrying out their functions, particularly their new statutory duty to improve service quality. The Board will also use Quality Standards in developing the commissioning guidance that commissioning groups will have to follow.

5.36   NICE is producing a quality standard for COPD covering management and treatment as part of its work programme for 2011 and intends to publish this shortly.

5.37   The COPD Quality Standard aims to provide a set of clear statements describing high quality care, with associated measures, within the scope it has adopted. In this case, the scope of the Quality Standard will focus on management and treatment of diagnosed COPD, and it will be framed explicitly as addressing this territory. Its content is based on the NICE existing clinical guideline and reflects acknowledged good clinical practice. On the issues it covers is consistent with this strategy. However, not all those with COPD are receiving services that meet these standards, and the Quality Standard will be valuable in supporting improved quality of care for this group of people.

5.38   This strategy has a far broader scope, from prevention, through early detection and diagnosis to treatment and end of life care. This Outcomes Strategy sets out a vision for a future service that is likely to require a significant shift in emphasis for Public Health and NHS services. It is intended to drive up the quality of care for all those with the condition, from mild to severe disease.

5.39   Both the Quality Standard and the strategy will inform practical guidance for commissioners on how to leverage improvements in the full spectrum of COPD services. Commissioning guidance issued by the NHS Commissioning Board will provide Clinical Commissioning Groups with practical information and advice to allow them to address issues around poor quality care and ensure that quality care becomes standard.

5.40   NICE will put in place a process to review its Quality Standards once they are published. It will explicitly keep the developing evidence base under careful review, with a view to developing a revised standard with a broader focus at the appropriate juncture. A vehicle for this might be the scheduled review of NICE's COPD Clinical Guideline in 2013. NICE would, with DH or NHSCB agreement, be able to include prevention and population-based interventions, and to take into consideration any newer evidence about the benefits of different models of care.

Box 5 - NICE Quality Standards

NICE 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, along with its partners and service users

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Co-ordinating, promoting and supporting research

5.41   There will be a new duty for the Secretary of State to promote research and for Clinical Commissioning Groups to promote research and innovation and the use of research evidence, in line with the current proposed duty on the NHS Commissioning Board.

5.42   Clinical Commissioning Groups and the NHS Commissioning Board will ensure that treatment costs for patients who are taking part in research funded by Government and

research charity partner organisations are funded through normal arrangements for commissioning patient care, as set out in existing guidance.

5.43   High-quality research is vital to improving our understanding of the causes of COPD and the treatment and care of those with the condition. Research in the UK is supported by a wide range of organisations from the private, charity and public sectors. The Department of Health through the National Institute for Health Research (NIHR) and Policy Research Programme has invested in research for respiratory disease and will continue to support high quality programmes. The NIHR will also continue to work with research councils and other funders and where appropriate co-ordinate research efforts.

5.44   We are working with the UK Respiratory Research Collaborative chaired by Professor Stephen Holgate to bring together the main research bodies in respiratory disease and key researchers to facilitate discussion on the main research priorities going forward.

5.45   Areas that have been identified in the development of this Outcomes Strategy include:
- the effectiveness and cost effectiveness of models of care provision
- lung health epidemiology
- effective and cost approaches to case finding and treatment
- impact of variation in clinical care on patient outcomes and cost in primary and secondary care
- patient education and supported self-management
- physical activity and exercise and effectiveness of interventions
- effective models of changing clinical behaviour (improving diagnosis and management)
- effectiveness of Home Oxygen.

5.46   Research in these all these areas should look to address inequalities issues.

Actions across government

5.47   Most government departments have plans of action that will improve outcomes for people with respiratory disease.

5.48   The Department for Work and Pensions is reforming the Welfare to Work programme, ensuring that work always pays by replacing existing means-tested working-age benefits with a single Universal Credit. Existing support will be consolidated into a new integrated Work Programme to provide help for people to move into work. It will operate a differential funding model that will provide additional support for people who have traditionally been harder to help – including mandatory Employment and Support Allowance claimants, and claimants who were recently in receipt of Incapacity Benefit.

5.49   Cross-government action is also helping people to stay in work. Evidence shows that work in generally good for individual's health and wellbeing and it is important that employees, should they develop a chronic condition, do not leave employment prematurely. The Government's innovative Fit for Work Service pilots are multi-disciplinary projects delivered by local providers, focusing on early intervention and designed to get workers on sickness absence back to work faster and to keep them in

work. The programme is being evaluated and the results will enable us to determine what works and in what circumstances.

5.50   The Health and Safety Executive (HSE) is working closely in partnership with employers and others in industries where risk to lung health are higher to ensure measures and behaviours reduce exposure. The Department for Environment, Food and Rural Affairs works cross Government to reduce environmental risks factors such as from air pollution, which is known to exacerbate COPD symptoms and also through providing access to advice when air pollution might present a risk to people with COPD. Local authorities will also be free to work with public health bodies to deliver strategies and plans to manage air quality locally and reduce health risks.

High quality care for people with COPD

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.

5.51   An estimated 3.2 million people have COPD, yet only 835,000, mainly with severe disease, have been diagnosed. Both recorded and expected prevalence of COPD varies widely between areas. In a recent study, the ratio of diagnosed to expected prevalence varied from 0.20 to 0.95, with a mean of 0.52. Under-diagnosis was more pronounced in urban areas, and is particularly severe in London.[14] Late diagnosis has a substantial impact on symptom control, quality of life, clinical outcome and cost because undiagnosed people receive inappropriate or inadequate treatment.

5.52   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 disease severity

5.53   Failing to diagnose accurately and assess disease severity can overestimate the prevalence and severity of COPD and thus lead to wasted resources or underestimate the severity of the disease and interventions that could be beneficial in controlling symptoms and progression. Inaccuracies in assessing lung function can also affect the type of treatment that people receive.

5.54   People with COPD need to be recognised as having lung damage that will be progressive and even with optimal care and management will over time, result in further lung function impairment, disability, and for some, death. However, with the right care and treatment there is the potential to slow down or modify the progressive nature of this disease.

5.55 Furthermore COPD is often associated with other conditions that also require-assessment and effective interventions in a holistic care approach. For example, about 40% have heart disease, about 10% have diabetes, and significant numbers have high blood pressure, and osteoporosis. However most people with COPD report breathlessness as being the major disabling symptom that interferes with everyday activities.

5.56 Various studies have shown that a significant proportion of people with COPD also have depression and/or anxiety disorder.[15,16] It is important that both the physical and mental health of people with COPD are assessed and addressed to ensure their people access care in a holistic way.

5.57 It is mainly through early and quality assured diagnosis, a more comprehensive assessment of severity, effective proactive disease management and evidence based treatment interventions that lives from COPD will be saved and the burden on the resources of the NHS will be reduced. The modelling work on how many lives per year we think we can save and the cost associated with that will be outlined in a subsequent NHS companion document to be published over the summer.

5.58 All of the above is why this outcome strategy signals a 'call to action' to the whole health and social care system, to professionals, people with COPD, the voluntary sector and the public to REACT which will be key feature of our national effort. This coming together around a simple acronym has been demonstrated to be successful in the Stroke strategy.

R is for Respiratory health and the importance of good lung health and greater awareness of the symptoms of respiratory disease

E is for early accurate diagnosis and assessment of severity to ensure late diagnosis is minimised, risks are reduced through better-informed people, effective interventions can begin and late diagnosis is minimised

A is for Active partnership between healthcare professionals and people with COPD to be partners in care, to self manage their condition and to exercise choice in the treatment they receive and where it is delivered

C is for Chronic disease management and proactive management of all disease severities and any co-morbid conditions and responsive episodic care provided around the needs of the patient

T is for Tailored evidence-based treatment for the individual and the evidence based use of all pharmacological and non-pharmacological interventions tailored to individual choice and benefit and linked to regular review

COPD and mental health

5.59 The Mental Health Outcomes Strategy *'No Health Without Mental Health'* describes the Government's ambitious aim to mainstream mental health in England and to achieve parity of esteem between mental and physical health services. We know that COPD and mental health are interrelated and it will be important that both this Outcomes Strategy for COPD and the Mental Health Outcomes Strategy are considered by the NHS and others when commissioning and providing COPD services.

5.60   COPD and mental health impact on each other in two ways. Firstly, people with mental health problems are more likely to develop COPD because they are more likely to smoke than the rest of the population[17], and secondly, people who are diagnosed with COPD are prone to mental health problems such as depression and anxiety because of their diagnosis.[18]

5.61   We know that people with mental health problems smoke much more than the rest of the population, consuming 42% of all cigarettes smoked in England.[19] 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.

5.62   Various studies have shown that a significant proportion of people with COPD have depression and/or anxiety disorder.[20,21]

5.63   Recognising and addressing these issues is an important aspect of COPD care. Taking a pro-active approach to managing both the physical and psychological impacts of COPD could help to improve an individual's ability to manage their illness and shortness of breath, improve independence, reduce hospital stays, and improve their quality of life. Mental health problems can be treated by a range of pharmacological and non-pharmacological treatment, alongside and together with treatments for the physical effects of COPD.

5.64   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. There are clear merits and benefits from the inclusion of someone with accredited skills and experience within a multidisciplinary team to provide input where necessary for people with severe anxiety and depression and guidance to improving the mental health and well being all those with COPD.[22]

5.65   The NICE guidelines on depression 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.

5.66   It will be vital for commissioning to be undertaken across physical and mental health in a way that will allow COPD teams to work across professional disciplines to ensure their people access care in a holistic way.

5.67   There are examples of good practice around the country of mental and physical health services being offered to people with COPD in a joined-up and holistic way. Good practice examples are available on the NHS Lung Improvement website.[23]   A specific example is given in Box 6.

5.68   Psychological conditions such as anxiety and depression are also more common in people with asthma in than the general population. This is covered in paragraphs 6.20 to 6.22.

Box 6 – Case study: Newcastle Upon Tyne Hospitals NHS Trust

Cognitive Behavioural Therapy (CBT) and COPD

A pilot service using CBT was developed for COPD patients found to be anxious or depressed.

Patients accessing the COPD service at the Trust were assessed using the Hospital Anxiety and Depression Questionnaire. Those who had significant levels of anxiety or depression were offered a CBT intervention by an experienced respiratory nurse consultant who had undertaken the relevant training.

Hospital admissions were noted six months before and after the CBT intervention. The findings showed clinical and statistically significant improvements in anxiety and depression scores and a statistically significant reduction in hospital admissions.

The CBT service was achieved without additional funding. Following their own training, the Nurse Consultant developed a short course in CBT skills to enable other staff to learn basic skills in CBT. This course is funded by offering staff from outside the Trust places at a small fee. This has enabled three other members of staff at the Trust to assist in providing the service.

## Management of those with Long Term Conditions, including COPD

5.69   People with long-term conditions such as COPD, often live with more than one condition. The growth of multiple co-morbidities will be the defining issue of how the health and social care system manages long-term conditions. To do this effectively, services will need to be developed and commissioned in a manner that places the patient at the centre of decision making about the care required.

5.70   International evidence and best practice shows us that there are several key principles that provide the common spine for treatment and care of all people with long-term conditions:[24,25,26,27,28]

Risk profiling - Using risk-profiling tools to ensure that commissioners understand the needs of their population and manage those at risk. This will assist in preventing disease progression and will allow interventions to be targeted and prioritised.

Integrated Care Teams - All health and social care services work together at a local level with both primary and secondary care expertise and input to provide joined up and personalised services. These teams pull in specialist services when necessary, but treat a person holistically, regardless of their condition(s). There is somebody within each team who co-ordinates the individual's care and acts as the point of contact for them.

Self Care - There needs to be a systematic transfer of knowledge and power to people with long-term conditions to empower them to maximise self-management and choice. This includes ensuring that; people engage in shared decision making in order to co-produce a care plan, that both they and their carers have access to the appropriate information about how to manage their condition and that there is 'no decision about me without me' as they are active participants in all decisions about their care. This will require a cultural shift for both people with long-term conditions and clinicians whereby the importance and value of self-care and education are truly understood and where shared decision-making and supported self-care are seen as an integral elements of LTC management.

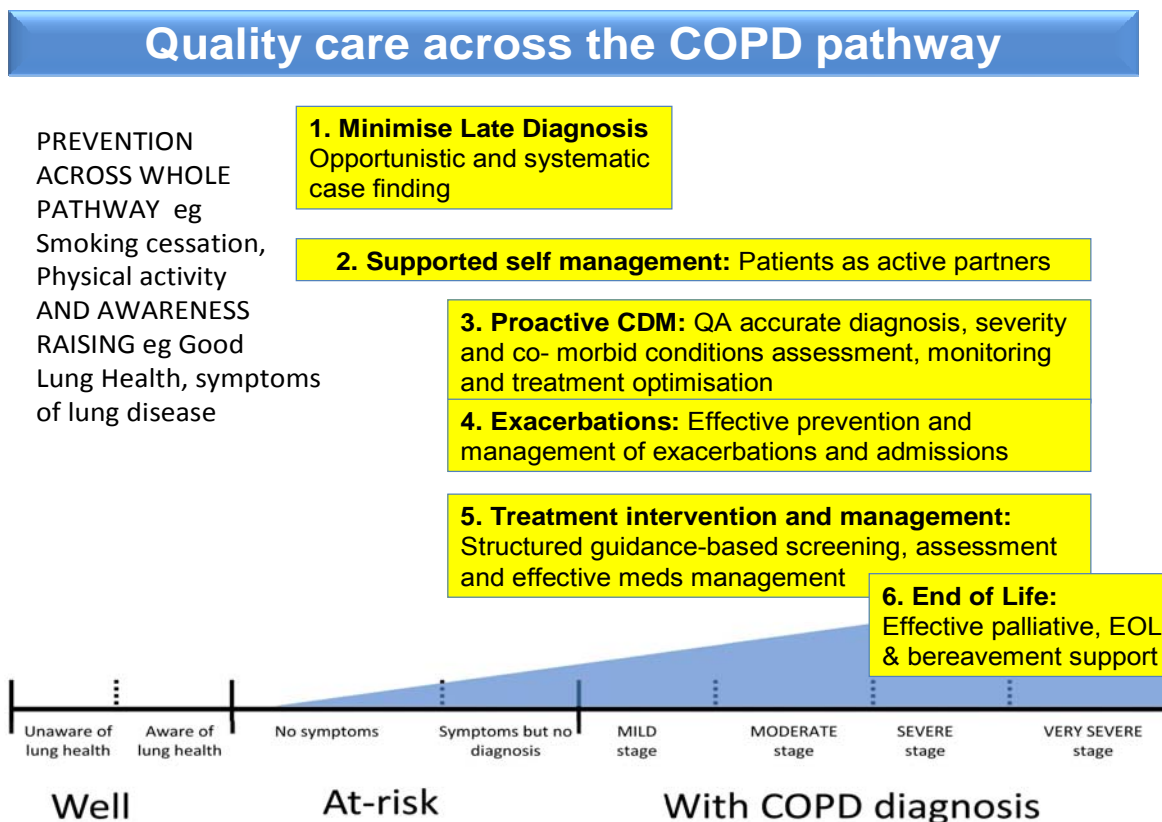The fourth element in this process is the need to implement all of the three elements.
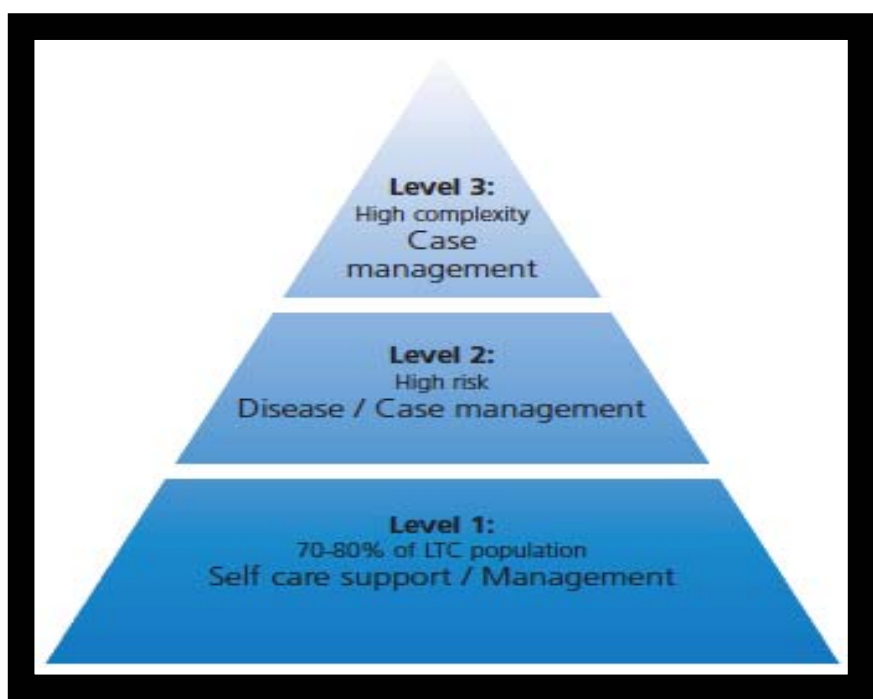
5.71   This approach is effectively demonstrated in the long-term conditions model developed for the NHS since 2005. By effectively stratifying the population using risk assessment tools, the population with long-term conditions can be identified on the care pyramid shown above. This demonstrates that approximately 70 to 80% of the population will have one or more less limiting long-term conditions that can be managed appropriately by providing relevant information, engaging people in care planning and supporting them to self-care. A smaller percentage of people will be living with more complex conditions, which require more intensive one-to-one interventions, using a case management approach. All will benefit from personalised care planning which will engage the person with the long term condition in an open discussion about the care that person needs to meet personal goals and health ambitions.

5.72   By following this approach we will achieve better management (including self-management) of people with COPD[29]. Better management of COPD would result in; slower disease progression, as exacerbations can be minimised by identifying complications early, fewer planned and unplanned acute episodes and shorter lengths

of stay. Services will be more responsive and accessible and will inform and empower people to manage their own condition.

COPD and models of care

5.73   Evidence suggests that delivery of services for people with COPD are effective where an integrated care model is developed using multidisciplinary teams.[30,31] These teams will promote the model that recognises the common spine of all LTCs and is based on the knowledge that the greatest increases we will see are in the numbers of people living with co-morbidities.

Quality care across the COPD pathway

PREVENTION ACROSS WHOLE PATHWAY eg Smoking cessation, Physical activity AND AWARENESS RAISING eg Good Lung Health, symptoms of lung disease

1. Minimise Late Diagnosis Opportunistic and systematic case finding

2. Supported self management: Patients as active partners

3. Proactive CDM: QA accurate diagnosis, severity and co- morbid conditions assessment, monitoring and treatment optimisation

4. Exacerbations: Effective prevention and management of exacerbations and admissions

5. Treatment intervention and management: Structured guidance-based screening, assessment and effective meds management

6. End of Life: Effective palliative, EOL & bereavement support

| Unaware of lung health | Aware of lung health | No symptoms | Symptoms but no diagnosis | MILD stage | MODERATE stage | SEVERE stage | VERY SEVERE stage |

Well   At-risk   With COPD diagnosis

5.74   The key features are:
- early recognition of disease to minimise late diagnosis through opportunistic and systematic case finding and better recognition of signs and symptoms by healthcare professionals especially those in primary care and by the population itself
- personalised care and support for self management, with people with COPD and carers receiving disease specific education and training to become active partners in a systematic approach to care planning and management which provides opportunity for problem based learning and a shared understanding of risks and issues
- proactive management by healthcare professionals starting with an accurate diagnosis and a disease register, monitoring and assessment of severity, co-morbid conditions and impact of disease, regular review with specialist input depending on severity of condition, and early and specialist rehabilitation and social services support to prevent disability and improve quality of life and community equipment

and other support to promote independent living and activities of daily living and re-ablement

- effective prevention and management of acute episodes with prompt identification and treatment (where possible in the community) in a care model which facilitates admission avoidance, early supported discharge and structured hospital admission with structured admission/specialist intervention, proactive follow up post exacerbation for treatment review and optimisation
- treatment intervention using evidence based pharmacological and non pharmacological treatments and regular review to ensure optimisation as well as community provision of specialist interventions/devices to support treatment and monitoring of signs and symptoms
- effective and equitable end of life care including palliation of symptoms, end of life care management, bereavement care and support for relatives.

Box 7 - Palliative Care Funding Review

Extract from funding the Right Care and support for everyone (Thomas Hughes-Hallett, July 2011)

We want to ensure everyone is able to live well until they die. Like birth, death is a part of life - something no one can avoid. But, unlike the beginning of life where it is clear what the state will provide, the evolution of palliative care has led to a lack of transparency about how the state funds a good, safe death.

5.75   Overall these features will ensure that outcomes are improved such that there is:
- improved survival and reduced mortality
- improved diagnosis rates and severity states
- improved Quality of Life and social functioning
- slower disease progression
- reduced exacerbation rate
- reduced admission/readmission rates
- high quality end of life care

6. Improving quality and outcomes for people with asthma

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.

Box 8 - Key asthma statistics

- The prevalence of asthma in England is among the highest in the world, with approximately 5.9% of the English population having asthma
- Premature mortality from asthma was 1.5 times as high in the UK than in the rest of Europe (EU-15) in 2008.
- Estimates of prevalence range from 3 to 5.4 million being affected by asthma.
- There are around 1000 deaths from asthma in England per year.
- 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 admissions, the majority of which are emergency admissions, and 70% of which may have been preventable with appropriate early interventions.

Improving outcomes for people with asthma

6.1 Like COPD, asthma is a common long-term condition. While the primary focus of this Outcomes Strategy is COPD, asthma has been included because:
- it is a common respiratory condition that poses a significant burden on both the NHS and individuals
- there is considerable variation in outcomes across England, and the Atlas of Variation highlights that there may be a 5-fold difference between PCT areas in the number of emergency admissions in adults, and a 6-fold difference for under 18 year olds
- despite the UK leading the world in guidelines for asthma they have been poorly implemented and people with asthma do not receive evidence-based interventions or individual action plans, which are known to impact positively on outcomes
- many people report that their asthma is poorly controlled, impacting their ability to undertake normal activities of daily life, and sometimes resulting in emergency care in hospitals
- deaths from asthma appear to have reached a plateau and are not reducing
- there is the opportunity to benefit people with asthma while addressing improvements in services for people with COPD.

6.2 There are both differences and similarities between asthma and COPD. It is not always easy to differentiate between these conditions in adults, but a wrong diagnosis will result

in the patient not getting the care that they need. Understanding the key differences and similarities between asthma and COPD is critical.

The goal of asthma care

6.3   The goal of asthma care 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. Therefore, what people need access to a service that facilitates prompt and accurate diagnosis, a treatment plan which is discussed and agreed with the person with asthma, and which provides ongoing support as the person controls his or her own condition in such a manner that the need for unscheduled healthcare is a rare event.

Outcomes Frameworks and asthma

6.4   As stated earlier the NHS Outcomes Framework 2011/12 sets out the five high-level outcome domains and highlights that respiratory disease features strongly in Domain 1: Preventing people from dying prematurely. This is very relevant to asthma since over 90% of deaths are believed to have preventable features, so asthma deaths are considered 'amenable to healthcare intervention'. Whereas COPD is largely a disease-affecting people over 45, asthma can affect people of all ages, and deaths occur throughout the age range.

6.5   Domain 2 `Enhancing quality of life for people with long-term conditions' addresses the functional ability of people with long-term conditions. Rather than taking a condition specific focus to outcomes, this domain focuses on generic outcomes that matter to people with any long-term condition. This is highly appropriate for asthma where the goal of management is to be free of symptoms, enabling people with asthma to continue with the normal activities of daily life. People with asthma and healthcare professionals need to work together to ensure that people with asthma are helped to remain active in the workplace and at school wherever possible. This requires good quality medical care, and good understanding, on the part of individuals, of how asthma affects them as an individual.

6.6   Domain 2 also includes an improvement area, which aims to reduce emergency admissions of people with conditions that should normally be managed successfully without the need for hospitalisation. An emergency visit to hospital for asthma is highly distressing for individuals and their families. Any such breakdown in the control of a patient's asthma should be followed up to establish why it happened and to make changes in care to avoid future occurrences.

6.7   Reducing emergency admissions of people with asthma who are under 19 receives specific mention in Domain 2 as an area for improvement. Asthma is responsible for a significant number of emergency admissions in young people, so the NHS needs to pay particular attention to exploring why these admissions are necessary and finding ways to avoid them.

6.8   In this context, the Department of Health has asked NICE to develop a Quality Standard for asthma that will support the NHS in delivering the outcomes in the NHS Outcomes Framework. This will set some clear markers about high quality care, which can be used

by commissioners and providers to ensure that a range of appropriate services is provided to people with asthma.

6.9   In asthma as with COPD the principle of putting the patient at the centre of decision making about how to manage their condition is paramount. By adopting approaches such as risk stratification of asthma registers, integrated multidisciplinary care teams, care planning and supported self-care people will receive care that will support independence, improved outcomes and fewer admissions.

6.10   The better people understand their condition and its treatment, the more value they will derive from their medical care. There is good evidence that care planning that helps people understand their treatment monitor their symptoms and what to do when the control of their asthma is worsening are an effective part of asthma care. This approach has been recommended in evidence based clinical guidelines using self-management plans for over 20 years. However, it is estimated that only a quarter of people with asthma in the UK have a self-management plan.[32] Yet people with asthma without one are four times more likely to have an asthma attack needing emergency care in hospital.[33]

6.11   Stratifying a GP practice population of people with asthma according to their risk of loss of control in line with the long-term conditions model outlined at paragraph 5.58 enables a practice to support the people most in need of proactive care. The range of severity in asthma is considerable, and while many people have well-controlled asthma, those with the most brittle and difficult asthma often lack the services they need because they are a relatively small group. Yet there are as many as a quarter of a million people in this category – or 5% of the total asthma population.[34] These people consume a disproportionate share of the expenditure on asthma care due to the high cost of hospital treatment. These individuals may need help to stay in employment, help getting access to benefits and disability allowance and need to be identified within a practice in order that they have access to the services they need. This group of people tell us that they face stigma in the workplace and school, widespread ignorance in the general population and sometimes lack of recognition by health services too.[35] Addressing the needs of this group alongside people with asthma that is well controlled, is challenging, but necessary in order that appropriate care is available for these people, and NHS resources are used effectively.

What is being done to improve asthma care

6.12   The Department of Health has been working with two multidisciplinary groups comprising people with asthma, parents, voluntary sector, hospital doctors, nurses and GPs to examine what needs to be done to improve asthma care in England. Building on the excellent British Asthma Guidelines from Scottish Intercollegiate Guidelines Network (SIGN) and the British Thoracic Society (BTS), the Asthma Steering Group is developing a Good Practice Guide for adults with asthma, which will describe what a good service for people with asthma looks like. This work is designed to provide anyone involved in commissioning or providing services with a description of the kind of services they should be making available, in order that people are able to achieve the goal of asthma care, which is freedom from symptoms.

6.13   We also recognise that asthma is a significant and common long-term condition affecting children. We believe that any improvements in the care of asthma in adults may also affect children. We are therefore developing a specific Good Practice Guide for Children with Asthma, which will set out what good care for children with asthma looks like, this will help to address the specific needs of children.

6.14   A National Review of Asthma Deaths, run by a consortium led by the Royal College of Physicians, will look into the circumstances surrounding deaths from asthma. It is not clear why the number of deaths from asthma in England has not reduced significantly from around 1000 for many years, even though it is widely accepted that there are preventable factors in 90% of deaths. For a twelve-month period starting in 2012/13, every death from asthma will be investigated systematically in order to explore the circumstances surrounding death – the medical care received, the environmental conditions, the involvement of workplace and school. We are expecting this to build on previous confidential enquiries into asthma deaths in regions of the UK and to provide a more robust body of evidence on which to build our understanding of how life-threatening situations arise and how they can be avoided in future. The learning from this study will be fed back into clinical practice so that people receive higher quality care and we can reduce deaths from asthma in time, in line with the outcome on reducing mortality from respiratory diseases in the NHS Outcomes Framework 2011/12.

6.15   A series of improvement projects started in May 2011, which are designed to trial discrete changes in care in order to learn about what models of care are of greatest benefit to people with asthma. Under the leadership of NHS Improvement, seven NHS organisations will undertake initiatives over a 12-month period to address specific points in the care pathway, and explore how improvements may be made. These range from training pharmacists to support people with asthma in understanding and using their medication through to better communication between hospitals and the community following a hospitalisation for asthma. The learning from these projects will be fed back into mainstream services in order to deliver better care for people with asthma across the country.

6.16   NICE is also currently considering revisions to QOF indicators for asthma.

For potential inclusion on the menu for the 2012/13 QOF, NICE is considering the following indicators:
- the percentage of patients with asthma 14 years of age and over who have had an asthma review in the previous 15 months that includes a record of a structured asthma educational discussion that includes a written asthma personal action plan
- the percentage of patients with asthma 14 years of age and over who in the previous 15 months have a record of a structured asthma educational discussion that includes a written asthma personal action plan.

NICE is also currently considering indicators for inclusion in the menu for the 2013/14 QOF. For asthma, these are:
- the percentage of patients, 5 years and over, newly diagnosed as having asthma from 1 April 2011 in whom there is a record that the diagnosis of asthma has been made supported by the current BTS-SIGN guidelines
- the percentage of children reaching the age of 5 years after or on 1 April 2011 with an existing diagnosis of asthma in whom there is a record that the diagnosis of

asthma has been reviewed and confirmed (supported by the current BTS-SIGN guidelines) within 15 months of becoming 5 years

NICE is also working on an indicator that will be more specific about the content of the asthma review:

- the percentage of patients with asthma who have had an asthma review in the previous 15 months that include an assessment of asthma control using the RCP 3 questions

Further details of indicators in development and the process for reviewing QOF indicators are on the NICE website at http://www.nice.org.uk/aboutnice/qof/qof.jsp

6.17　Public Health England and local authorities can work with employers to eliminate occupational factors that may cause or exacerbate asthma.

6.18　Employers can:
- raise awareness of asthma in the workplace
- ensure people with asthma are not discriminated against
- recognise that people with severe asthma have a disability
- be tolerant about the unpredictability of asthma attacks
- be aware that workplace pollutants may cause or exacerbate asthma and take steps to remove them
- provide employees with support and advice to help them remain in employment

6.19　Asthma places a considerable burden on the NHS and people's lives, particularly if it is poorly controlled. The need to focus on asthma has been recognised in the Outcomes Frameworks, and government-led initiatives will help to address the challenges that poor asthma care presents. This needs to be complemented by concerted action at a local level to implement the evidence based recommendations in clinical guidelines for individuals, and in designing services for people with asthma that support shared decision-making and maintain good symptom control.

Asthma and mental health

6.20　Psychological conditions such as anxiety and depression may be up to six times more common in people with asthma than in the general population.[36] Depression may be present in between 14 to 41% of those with asthma. It is particularly common in people with severe and difficult-to-control asthma, and this is emphasised in the British Asthma Guidelines.[37]

6.21　Those with asthma who also have depression or anxiety experience more asthma symptoms and have worse outcomes in terms of higher use of healthcare resources, increased healthcare costs, less successful emergency treatment and increased hospitalisation. Psychological problems may be responsible for some of the at-risk behaviours of people with asthma, such as not taking their medication and smoking.

6.22　Mental health problems can go unrecognised by clinicians.   Whilst routine assessment of psychological and emotional well-being is accepted practice for conditions such as COPD, it is not currently a standard part of community based asthma care. More

research is needed to build the evidence base in this area, and to establish the benefit of routine assessment for all people with asthma.

7. Information and choice

Introduction

7.1   High quality services depend on having accurate, relevant, contextualised, timely and accessible information. In the future, the Health and Social Care Information Centre (HSCIC) will have a key role in publishing raw data that will be available for a range of different organisations to use. Information will be central to the drive for better outcomes and support for commissioning and patient choice.

7.2   Information will also be central to helping the public to make the right decisions for their care. We are committed to creating a presumption of choice, including choice of treatment and qualified provider across many NHS-funded services.

Information on COPD and asthma

7.3   *Liberating the NHS: An Information Revolution* set a vision for care where:
* people with COPD and asthma must have the information they need to make the right choices about their health and treatment
* the NHS and social care commissioners and providers must have the information they need, appropriately analysed by protected equality groups and health inequalities dimensions such as socio-economic group and area deprivation, to enable them to make the right decisions around commissioning and providing quality services; and
* the public must have the information they need to make the right choices about healthy lifestyles.

7.4   To be effective, all of these different groups of people need to be able to access and use information that is:
* informing, so that they know it is comprehensive and can be trusted
* engaging, so that they are willing and able to use it, and
* empowering, so that they know how it can make a difference.

7.5   Knowledge empowers people to manage their own health if their information needs are addressed from the person's own perspective and delivered in a format that the person can understand.

7.6   During stakeholder workshops with people with COPD and asthma and their carers. A number of key topics were identified. These were:
* education about the disease
* management of breathlessness
* pharmacological treatments
* management of exacerbations
* psychological support.

7.7   As a routine part of their practice, care professionals should support and encourage self-care, signposting people to reputable information sources such as information

prescriptions and other resources such as patient decision aids, and information on the air quality index. They should encourage people to explore such resources in their own time and, if they wish, with their family. Information prescriptions are an important means of providing this information.[38]

7.8 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 help develop standardised material in conjunction with people with COPD and asthma, their representatives, and healthcare professionals and use this to inform the following ways of supporting service providers and people through information:
- information available via the internet (including NHS Choices)[39]
- the Expert Patient programme
- information prescriptions

NHS Choices

7.9 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.

7.10 ince 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. It provides information about all stages of COPD and asthma from diagnosis and treatment options, through to information about living with these conditions. It also hosts the country's biggest health website blog on COPD. Videos have been developed for NHS Choices on areas such as pulmonary rehabilitation, the correct use of inhalers and spacers and COPD walking groups. All information on asthma has recently been updated. We will be discussing with them other areas, including recognition of exacerbations and preparation and instructions for spirometry.

Expert Patients Programme

7.11 The Department of Health published *'The expert patient: A new approach to chronic disease management for the 21st century in 2001'*.[40] This promoted the concept of user-led self-management programmes. The programme offers courses to help people with long-term conditions to manage their condition better on a day-to-day basis.

7.12 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.[41]

Information prescriptions

7.13 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.

7.14 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. 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.

7.15 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

7.16 Other national resources to assist implementation include NHS Choices, where the Information Prescription Service (www.nhs.uk/ips) can be used to generate IPs for a number of long-term conditions. This tool allows professionals to create more tailored prescriptions, pulling together national content, information from key voluntary and community organisations and locally uploaded information, along with a facility to write personal notes specific to the patient.

7.17 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.

Expanding patient choice

7.18 *Liberating the NHS: greater choice and control* is based on individuals being at the heart of decision-making in the NHS. No decision about me without me should be a guiding principle in the delivery of all treatment.. In COPD, a range of different forms of choice are relevant, including:
- where to have treatmen;
- which organisation delivers treatment and care
- which team delivers the treatment, and
- what form of clinically appropriate treatment to have.

7.19 We would envisage that the guiding principles in relation to COPD will be the same as for most other NHS services – people will be able to elect to receive care from any organisation in England that offers a service that is clinically appropriate for them, meets

the essential levels of safety and quality expected from providers of NHS-funded services and can deliver services within NHS prices.

7.20 For people with COPD nearing the end of their life, it is important that they are given a choice about where they are cared for, and die. Most deaths occur in hospital, but, when asked, most people say they would like to die at home in familiar surroundings, close to family and friends. Changing this will require improving the support that is available in the community. As set out in *'Equity and Excellence: Liberating the NHS'*, a national choice offer will be established for those people who choose to die at home (including a care home) to receive the support that they need. A review will be undertaken in 2013 to determine when this offer should be introduced.

The patient voice

7.21 As well as extending choice, it is important that patients and the public have a voice in how services develop. *Liberating the NHS: Equity and Excellence* set out proposals to establish HealthWatch as a national and local consumer voice championing the views and experiences of patients. The Government's response to the consultation on these proposals, *Liberating the NHS: Legislative Framework and Next Steps*, recognised the importance of HealthWatch England having a stronger identity to strengthen the patient voice.

7.22 Following the NHS listening exercise, Monitor will also now have a duty to carry out appropriate public and patient involvement in the exercise of its functions, and commissioners will have an explicit duty to involve patient and carers in their own care. This will of course be relevant for all people with COPD.

7.23 Many respiratory charities have also developed programmes to encourage greater patient involvement in the development and delivery of NHS services.

Local HealthWatch

7.24 Local HealthWatch will be commissioned by local authorities to provide an independent voice for patients, service users and carers of all ages throughout the commissioning cycle. It will be able to provide advocacy services on behalf of service users, including those in disadvantaged groups, particularly those that are seldom seen or heard, such as offenders, gypsies and travellers.

Improving quality: Quality Accounts

7.25 Quality Accounts are public reports produced by NHS organisations about the quality of healthcare services they provide. The reports provide a mechanism for helping providers to identify and focus on the issues that will make the biggest difference to quality of care. They can also be used to explain to commissioners, patients and the public which issues have been prioritised and how the organisation will address them.

7.26 Quality Accounts provide a mechanism to help providers identify and focus on the issues that will make the biggest difference to the quality of care they provide, as well as providing an opportunity to explain to commissioners, patients and the public which

issues have been prioritised and how the organisation will set about addressing them. In June 2010, acute providers published the first Quality Accounts. Following evaluation the lessons learned are that Quality Accounts have been an effective tool for raising the profile of quality improvement and engaging Boards. As organisations gain experience in this type of reporting, their Quality Accounts will be more effective at explaining to patients how key services such as respiratory disease are being improved.

Carers

7.27   Carers, family and friends play a critical role in supporting many people with COPD. Improving the support for people living with COPD also requires improved support for carers. The Carers Strategy set out four priority areas for improved support, which apply to people caring for people with COPD as much as for any other condition:
- supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages
- enabling those with caring responsibilities to fulfil their educational and employment potential
- Personalised support both for carers and those they support, enabling them to have a family and community life, and
- Supporting carers to remain mentally and physically well.

Community pharmacy services

7.28   Many community pharmacies already provide locally commissioned services that can support people with COPD and asthma, such as stop smoking services and medicines use reviews. These are available to people close to home and at times convenient to them.

7.29   New services, delivered through community pharmacies, are expected to be introduced from October 2011 including:
- the introduction of a New Medicine Service (NMS) to help improve medicines adherence for people with long-term conditions newly prescribed a medicine. Patients with COPD and asthma will be one of the areas the service will initially focus on;
- the introduction of national target patient groups for Medicines Use Reviews (MURs) to ensure they are provided to those who will benefit the most. One of the national target groups will be patients with respiratory disease.

7.30   Both of these services should benefit patients with COPD and asthma, in supporting them to take their medicines as intended and helping to improve their lifestyles, in particular stopping smoking.

7.31   The 'healthy living pharmacy' concept, initially piloted in Portsmouth has shown it can make a real difference to the health and well-being of the local population. The experience in Portsmouth has been that healthy living pharmacies can produce better outcomes and offer higher-quality services. For example, 27% of the people with COPD or asthma who had a medicines review with their pharmacist were smokers; 75% of

these accepted help to stop smoking. 44% went on to quit smoking and 48% showed improvement of asthma or COPD symptom control on return to the pharmacy six months later. Other PCTs are now following suit or have shown an interest.

8. Social care services

Social Care Outcomes Framework

8.1   *Transparency in outcomes: a framework for adult social care 2011/12* was published earlier this year.[42] It aims to ensure the best outcomes are achieved for those needing social care, their families and carers, and the wider local community, by improving the quality of services and supporting transparent local accountability. The Framework contains a set of outcome measures for this purpose, many of which have particular relevance for people with COPD and their carers who use social care services. As the number of people living with COPD increases, so it will become ever more important to ensure quality of life is maximised.

8.2   People with COPD and other long-term conditions want to have and control their own support and engage socially to help avoid loneliness and isolation. They also want to know what choices are available to them locally and what they are entitled to and who to contact when they need help. The social care sector, including children's services, employment services, leisure and housing, for instance, will want to consider how these goals can be delivered. Social Care services will also need to understand how these common goals support local services to work together to improve outcomes for their local population and that the detail of different frameworks or organisations do not place barriers in the way of partnerships.

8.3   In working together, the NHS and social care can ensure there is a supported discharge arrangement in place and with re-ablement or intermediate care services, help reduce repeat emergency admissions and support carers in care planning arrangements.

8.4   Working with public health, social care will play a key role in ensuring those with COPD maintain good health and wellbeing and in preventing avoidable ill health through re-ablement or intermediate care services and early intervention. Health and Wellbeing Boards will identify local health and wellbeing issues through Joint Strategic Needs Assessments (JSNA) and commissioning priorities aimed at addressing those needs will be agreed in a joint health and wellbeing strategy. JSNA's identify local health and social care needs and joint health and wellbeing strategies will identify areas for priority action; help commissioners specify outcomes that encourage local innovation; and help providers shape services to address local needs. Health and wellbeing boards will have a duty to involve users and the public in the JSNA and joint health and wellbeing strategy; this could include a range of stakeholders such as providers from the public, private and voluntary and community sectors and members of the local community.

9. Conclusion

9.1   This strategy spells out the Coalition Government's commitment to improving services for people with COPD and asthma, and to narrow health inequalities.

9.2   To achieve this, the Government has agreed six high-level objectives to improve outcomes for people with COPD and asthma. This strategy sets out how public health, the NHS and social care can achieve these improvements in outcomes by empowering people to ensure effective planning and commissioning of services that meet local needs and by coming together through the REACT 'call to action' which embraces the concepts of prevention and long term condition management.

9.3   Accountability is a key driver of the current reforms. The public sector, including the public health, the NHS and social care organisations, has a responsibility to the public and users of services to deliver on these outcomes.

9.4   The public and service users will play an active part in decisions about how priorities are determined, how public money is spent and how discriminatory attitudes can be challenged.

9.5   Local action will be supported by a sustained, cross-government approach. The Department of Health has established a Respiratory Programme Board, which will work in partnership with stakeholders to provide help and advice to realise this strategy. The Board brings together professional bodies, commissioners, provider organisations, the voluntary and community sector and the views of people with COPD and asthma and their carers.

9.6   Between 2011 and 2013, while the NHS Commissioning Board and Public Health England are being fully established, this Programme Board will bring partners together to help drive forward implementation of this strategy. The Department will review the function of the Programme Board for 2013 onwards, once the NHS Commissioning Board and Public Health England are fully established.

9.7   Action at local and national levels to implement this strategy will only be effective if there is sustained partnership working across all sectors, and by addressing the wider social determinants of health.

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