

# An Outcomes Strategy for COPD and Asthma:

### NHS Companion Document



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# An Outcomes Strategy for COPD and Asthma:

NHS Companion Document

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# Foreword

We are in the final year of transition to the new commissioning and management system for the NHS. It is vital that in this year we continue to uphold the highest standards of care and quality and take bold, long-term measures to secure sustainable change.

The case for taking action to improve outcomes for Chronic Obstructive Pulmonary Disease (COPD) and asthma is clear. Premature mortality from COPD in the UK was almost twice as high as the European average and premature mortality for asthma was over 1.5 times higher. Around 90% of deaths from asthma each year could have been prevented. And of the estimated three million people living with COPD in England, only 900,000 have received a clear and accurate diagnosis and are getting appropriate treatment to improve their quality of life and clinical outcomes.

We need to change our approach to COPD from one that is reactive and waits until people have severe symptoms - which costs more for the NHS and results in poorer outcomes for individuals - to one which is proactive, preventing disease, diagnosing earlier and treating and managing the condition from its early stages. In asthma, we can work harder to prevent people unnecessarily dying each year, and support people to reach the ultimate and achievable goal of freedom from their symptoms.

The Outcomes Strategy for COPD and Asthma was published in July last year. It set out the high-level vision for all parts of the system - the NHS, public health, social care, other national and local government departments, and the private and voluntary sectors - for achieving this change in approach. To support the NHS as we transition to the new NHS architecture I am now publishing this *NHS Companion Document*, which sets out best practice to achieve improved outcomes for COPD and asthma.

The NHS will be judged on its performance in reducing deaths from respiratory disease through the NHS Outcomes Framework. This *Companion Document* provides support and guidance to the NHS to achieve fewer deaths year on year. I want to see the NHS rival any healthcare system in the world for its quality and outcomes for COPD and asthma. We can save money, reduce deaths and improve the quality of life of those with COPD and asthma by changing our approach and by working with people with COPD and asthma as equal partners in their care.

Sir David Nicholson Chief Executive – Designate NHS Commissioning Board

# Preface

The Outcomes Strategy for COPD and Asthma showed the Government's commitment to improving services for people with respiratory disease, as well as providing high-quality care that is safe, effective and responsive to the needs of individuals in streamlined services delivered closer to home.

This *NHS Companion Document* is a key part of the suite of tools and resources planned to help support different parts of the system implement the *Outcomes Strategy*.

The NHS will be working towards improving outcomes across all five domain of the NHS Outcomes Framework. This *Companion Document* work through each of the five domains, detailing the actions and interventions the NHS can take to make improvements in outcomes for those conditions.

We would like to thank everybody who has been involved in developing the *Outcomes Strategy for COPD and Asthma* and the *NHS Companion Document*. In particular, we would like to thank the British Lung Foundation and Asthma UK who represent patient's interests so effectively and also the many healthcare professionals and their representative bodies who have given their time and expertise freely and willingly.

Meeting the challenge set out in the *Outcomes Strategy for COPD and Asthma* will require all those working in the NHS to break down barriers and be true partners in care.

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

Professor Sue Hill and Dr Robert Winter Joint National Clinical Directors for Respiratory Disease

#### **Chronic Obstructive Pulmonary Disease (COPD)**

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 people 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 someone can enjoy an active life.

#### Asthma

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 people 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 freedom from symptoms in as many people as possible. The causes of asthma are not well understood, so prevention of asthma is not currently possible. People with asthma have different triggers for symptoms, and need to get to know what will provoke their asthma and cause deterioration in their control.

# Why does the NHS need to act to improve quality and outcomes for people with COPD and asthma?

One person dies from COPD every 20 minutes in England - around 23,000 deaths a year. If the whole NHS were to deliver services in line with the best around 7,500 lives could be saved

Death rates from COPD are almost double the EU average. 15% of those admitted to hospital with COPD die within three months and around 25% die within a year of admission

One in eight people over 35 has COPD that has not been properly identified or diagnosed, and over 15% are only diagnosed when they present to hospital as a emergency

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. There is a four-fold variation in non-elective admissions across England, and readmission rates vary by up to five times in different parts of the country.

80% of people with COPD have at least one other long-term condition. COPD is linked with an increased risk of mortality from cardiovascular disease, and having depression and/or an anxiety disorder

Over 50% of people currently diagnosed with COPD are under 65 years of age

24 million working days are lost each year from COPD with £3.8 billion lost through reduced productivity

There are around 1,000 deaths from asthma a year in the UK, the majority of which are preventable

The UK has the highest prevalence of asthma in the world, at around 9-10% of adults

Asthma costs the NHS an estimated £1 billion a year

It is estimated that around 80% of spending on treating those with asthma is spent on the 20% with the severest symptoms

There is a 6 fold variation in admission rates across England for adults with asthma

Many people with asthma are not achieving freedom from symptoms, with a recent large scale survey reporting that around 35% of adults with asthma had had an asthma attack in the previous 12 months ASTHMA

# Introduction

## What can the NHS do to improve quality and outcomes for people with COPD and asthma?

- 1. The NHS is aspiring to excellence and the best possible outcomes for people in a future which is patient-centred, clinically-led and focussed on the needs of the local population.
- 2. For COPD and asthma, this means the NHS working together with the public health and social care systems to meet the six objectives that were set out in the *Outcomes Strategy for COPD and Asthma* published in July 2011.

Box 1: Outcomes Strategy for COPD and Asthma – objectives

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

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

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 of prevalence

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

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

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 to reduce the need for unscheduled health care and risk of death

3. The Outcomes Strategy for COPD and Asthma recognises that these conditions are national priority clinical areas, and that joint working is needed from prevention right through to the end of life. To achieve this, good, strong working relationships are essential - not only within the NHS (between primary, secondary and community care) but also between the NHS and other partners like the public health system, local government and social care, the private sector and voluntary organisations. As a key example, the indicator on mortality from respiratory disease in people under 75 is

shared by both the NHS and the Public Health Outcomes Frameworks - both services will need to work together to achieve improved outcomes in this area.

- 4. This *NHS Companion Document* describes the actions and interventions the NHS specifically can take to help achieve the outcomes relevant to the NHS set out in the *Outcomes Strategy.*
- 5. The *NHS Companion Document* is not mandatory, but rather describes best practice in achieving improved outcomes. It should support the work already started by the NHS in response to the NHS Operating Frameworks 2011/12 and 2012/13, which called on the NHS to implement the recommendations in the *Consultation on a Strategy for Services for COPD in England*<sup>1</sup> and the *Outcomes Strategy for COPD and Asthma*<sup>2</sup> respectively.
- 6. It should also complement work being undertaken to meet the National Institute for Health and Clinical Excellence (NICE) Quality Standard for COPD, published in 2011. The NICE Quality Standard statements describe high quality management and treatment of diagnosed COPD for the parts of the care pathway where evidence was available to meet NICE criteria. These are reflected and drawn upon throughout this document.

#### **Box 2: NICE Quality Standard for COPD**

1 – People with COPD have one or more indicative symptoms recorded, and have the diagnosis confirmed by post-bronchodilator spirometry carried out on calibrated equipment by healthcare professionals competent in its performance and interpretation

2 – People with COPD have a current individualised comprehensive management plan, which includes high-quality information and educational material about the condition and its management, relevant to the stage of disease

3 – People with COPD are offered inhaled and oral therapies, in accordance with NICE guidance, as part of an individualised comprehensive management plan

4 – People with COPD have a comprehensive clinical and psychosocial assessment, at least once a year or more frequently if indicated, which includes degree of breathlessness, frequency of exacerbations, validated measures of health status and prognosis, presence of hypoxaemia and comorbidities

5 – People with COPD who smoke are regularly encouraged to stop and are offered the full range of evidence-based smoking cessation support

6 – People with COPD meeting appropriate criteria are offered an effective, timely and accessible multidisciplinary pulmonary rehabilitation programme

7 – People who have had an exacerbation of COPD are provided with individualised written advice on early recognition of future exacerbations, management strategies (including appropriate provision of antibiotics and corticosteroids for self-treatment at home) and a named contact

8 – People with COPD potentially requiring long-term oxygen therapy are assessed in accordance with NICE guidance by a specialist oxygen service

9 – People with COPD receiving long-term oxygen therapy are reviewed in accordance with NICE guidance, at least annually, by a specialist oxygen service

10 – People with admitted to hospital with an exacerbation of COPD are cared for by a respiratory team, and have access to a specialist early supported-discharge scheme with appropriate community support

11 – People admitted to hospital with an exacerbation of COPD and with persistant acidotic ventilator failure are promptly assessed for, and receive, non-invasive ventilation delivered by appropriately trained staff in a dedicated setting

12 – People admitted to hospital with an exacerbation of COPD are reviewed within 2 weeks of discharge

13 – People with advanced COPD, and their carers, are identified and offered palliative care that addresses physical, social and emotional needs

- 7. This document is intended as guidance to support commissioners and providers during the current transitional period, prior to the NHS Commissioning Board (NHSCB) and clinical commissioning groups (CCGs) taking on their commissioning responsibilities from April 2013 onwards. The NHSCB may choose to publish its own guidance in due course to reflect these new commissioning arrangements.
- 8. This document is intended to be useful for all involved in improving quality and outcomes in the NHS for people with COPD and asthma clinicians, commissioners, providers, and people with those conditions and their carers.

#### How the Companion Document fits with national strategy

- 9. The *NHS Companion Document* is intended to describe for the NHS what it specifically can do to help meet the objectives in the *Outcomes Strategy for COPD and Asthma*, to address the whole care pathway for people with COPD and asthma.
- 10. In the new NHS architecture, the NHS Outcomes Framework will be used 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 NHSCB, and as a catalyst for quality improvement through the NHS. It is structured around five domains, which set out the high-level national outcomes that the NHS should be aiming to improve.
- 11. For clarity for the NHS in how the objectives in the *Outcomes Strategy for COPD and Asthma* link to the NHS Outcomes Framework, this *Companion Document* is also structured according to the five domains.
- 12. Chapter 2 goes through each of the five domains for COPD and Chapter 3 does the same for asthma. The indicators from the NHS Outcomes Framework relevant to COPD and asthma are given for each domain, and the actions and interventions described under it show how the NHS can make improvements in outcomes in that

area. The objectives from the *Outcomes Strategy for COPD and Asthma* are clearly linked to the domains they are relevant to.<sup>i</sup>

- 13. For COPD, the actions and interventions under each domain draw on the NICE Quality Standard statements and the NICE clinical guideline for COPD. For asthma, although the NICE Quality Standard is still in development, evidence-based best practice guidelines are also drawn upon.
- 14. The diagram below shows how the different documents fit together.



## Support for implementation of the *Outcomes Strategy for COPD and Asthma* and the *NHS Companion Document*

15. Until April 2013, there is support for implementation of the Outcomes Strategy for COPD and Asthma and the NHS Companion Document from the joint National Clinical Directors (NCDs), NHS Improvement<sup>ii</sup>, the respiratory leads appointed to each Strategic Health Authority (now cluster)<sup>iii</sup>, and the local respiratory networks that have been established.

<sup>&</sup>lt;sup>i</sup> Objectives 3 – 6 from *An Outcomes Strategy for COPD and Asthma* are drawn upon in this Companion Document as they are specifically relevant to the NHS. Objectives 1 – 2 are primarily relevant to Public Health.

<sup>&</sup>lt;sup>iii</sup> http://www.improvement.nhs.uk/lung/Contacts/SHARespiratoryClinicalLeads/tabid/108/Default.aspx

- 16. The Department and NCDs will work with the respiratory leads to consider how they can best align themselves with the new structures and arrangements during transition to the NHSCB and the new commissioning system. Additionally the Department will work with partner organisations such as the British Thoracic Society (BTS), Primary Care Respiratory Society UK (PCRS-UK), British Lung Foundation (BLF) and Asthma UK and involve them in innovation and improvement, delivery and the provision of expert knowledge, advice and clinical leadership.
- 17. Assessing progress on delivery of this strategy during transition and beyond will be important. As agreed with the respiratory leads locally, they will each publish an annual report at the end of 2012/13 to measure progress on implementation and on improving outcomes so far. The establishment of a national dataset for respiratory disease (INHALE), in conjunction with NHS East of England, will, together with the geographical lead reports, enable national progress reports to be developed.<sup>iv</sup>
- 18. When the NHS Commissioning Board is in place, it may wish to review the arrangements of support for implementation of the *Outcomes Strategy for COPD and Asthma* post April 2013.
- 19. The *Companion Document* will be supported by a COPD Commissioning Toolkit, which will be published shortly. This will set out service specifications and standard contracts for various elements of the COPD care pathway, to help commissioners to commission high-quality care. Again, they will be not be mandatory, but rather describe best practice. The toolkit includes the following elements of the care pathway:
  - Improving diagnosis spirometry and clinical assessment;
  - Pulmonary rehabilitation;
  - Managing acute exacerbations; and
  - Home oxygen assessment and review services.
- 20. Other tools to support implementation of the *Outcomes Strategy for COPD and Asthma* include:
  - A Good Practice Guidance for Home Oxygen (published April 2011 by Primary Care Commissioning)<sup>v</sup>
  - A Good Practice Guide for Adults with Asthma (to be published Spring 2012 by Primary Care Commissioning)
  - A Good Practice Guide for Children with Asthma (to be published Summer 2012 by Primary Care Commissioning)

<sup>&</sup>lt;sup>iv</sup> <u>http://www.inhale.nhs.uk/</u>

<sup>\*</sup> http://www.pcc.nhs.uk/uploads/HOS/2011/08/home\_oxygen\_service\_assessment\_and\_review\_v4.pdf

#### Future commissioning responsibilities

- 21. From April 2013, responsibility for commissioning will be handed to clinical commissioning groups (CCGs). CCGs will be well placed to commission health services to meet the real needs of people for whom they are responsible. Through these groups, 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 commissioning guidance, CCGs 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.
- 22. The consultation document *Liberating the NHS: Commissioning for Patients* proposed that the NHS Commissioning Board, supported by NICE, will develop a Commissioning Outcomes Framework (COF) to hold clinical commissioning groups to account and so that there is clear, publicly available information on the quality of healthcare services they commission. The consultation response *Liberating the NHS: Legislative framework and next steps* showed there was widespread and strong support for such a framework and the NHS Listening Exercise confirmed that there is almost universal support for making improvement in quality and healthcare outcomes the primary purpose of all NHS-funded care.
- 23. The COF will allow the NHS Commissioning Board to identify the contribution of CCGs to achieving the national outcome goals for health improvement in the NHS Outcomes Framework, while also being accountable to patients and local communities. It will also enable clinical commissioning groups to benchmark their performance and identify areas for improvement.
- 24. The COF will become operational from April 2013 as CCGs take on full responsibility for commissioning.
- 25. NICE held a consultation on its list of proposed indicators for the 2013/14 COF which ended on 29 February 2012. Details on the proposed indicators can be found on the NICE website at <a href="http://www.nice.org.uk/aboutnice/cof/cof.jsp">http://www.nice.org.uk/aboutnice/cof/cof.jsp</a> and NICE can be contacted at <a href="http://www.nice.org.uk/aboutnice/cof/cof.jsp">COF@nice.org.uk/aboutnice/cof/cof.jsp</a> and NICE can be contacted at <a href="http://www.nice.org.uk/aboutnice/cof/cof.jsp">COF@nice.org.uk/aboutnice/cof/cof.jsp</a> and NICE can be contacted at <a href="http://www.nice.org.uk/aboutnice/cof/cof.jsp">COF@nice.org.uk/aboutnice/cof/cof.jsp</a> and NICE can be contacted at <a href="http://www.nice.org.uk">COF@nice.org.uk</a> if there are any queries. The results of the consultation and further testing will be provided to their independent Advisory Committee for consideration in June. NICE will then publish their recommendations for the NHSCB to consider in Summer 2012.

# Chapter 1: REACT – a call to action

- 26. The Outcomes Strategy for COPD and Asthma set out six high-level objectives for the NHS, public health and social care services to improve quality and outcomes for people with COPD and asthma. The objectives span prevention, diagnosis, treatment, care and management and end of life.
- 27. The *Outcomes Strategy* brought these objectives together in a 'call to action' to the whole health and social care system, to professionals, people with COPD and asthma, the voluntary sector and the public to **REACT** and change the approach to respiratory disease in England:

REACT		
R	Respiratory health and the importance of good lung health and greater awareness of the symptoms of respiratory disease	
Е	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	
Α	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	
С	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	
т	Tailored evidence-based treatment for the individual and the evidence-based use of all pharmacological and non-pharmacological interventions to individual choice and benefit and linked to regular review	

- 28. This document uses the five domains of the NHS Outcomes Framework to describe what action the NHS can specifically take to help meet those objectives and REACT to improve the lives of people with COPD and asthma. The document clearly shows which are the relevant indicators for COPD and for asthma in each domain of the NHS Outcomes Framework, and describes the key interventions and actions that commissioners and providers can do to improve outcomes in that area.
- 29. For clarity, each activity or intervention is listed under only one domain, but naturally may impact on the outcomes in any or all of the other domains as well, since in reality they do not exist in isolation. It is important that a whole pathway approach to COPD and asthma care is taken and adopted locally by commissioners and providers if they want to see real improvements made to the quality of services and the impact that has on the lives of people with COPD and asthma.
- 30. A summary of the actions and interventions described in the following chapters is given in Annex C.

# Chapter 2: Improving quality and outcomes for people with COPD

# DOMAIN ONE: Preventing people from dying prematurely

- 31. COPD is an umbrella term and includes chronic bronchitis, emphysema and chronic unremitting asthma, which can all co-exist in some people with the disease. It is associated with lung tissue damage and airflow obstruction which leads to the symptoms of breathlessness, reduced exercise tolerance and the production of excess mucus. Significant lung damage may be present before, for example, airflow obstruction is detected or symptoms such as cough and breathlessness are reported.
- 32. The onset of the disease is insidious as people often fail to recognise the symptoms and are therefore diagnosed late, when their COPD has advanced from mild disease and become more moderate or severe in nature. COPD is a progressive disorder the lung damage cannot be reversed but treatment early on in the disease can halt or slow it down, and treatment later on in the disease can delay the onset of disability and prolong survival.
- 33. As COPD progresses and becomes advanced other complications may arise such as respiratory failure, which requires interventions such as long term oxygen therapy to prolong survival and improve quality of life.
- 34. The NHS Outcomes Framework has a specific indicator in Domain One to reduce respiratory mortality in the under 75s. This indicator is also shared with the Public Health Outcomes Framework (see Chapter 4). There is well-established evidence that shows that healthcare interventions reduce mortality in COPD. However, the NHS Atlas of Variation and other data show us that: <sup>3</sup>
  - Care is variable;
  - There is a focus on treating the more severe end of the disease, rather than mild or moderate disease. This is reflected in the focus of the guidelines for evidence-based treatment and intervention;
  - Emerging information from global clinical trials is not always implemented.
- 35. There are three main approaches that the NHS can take to prevent people dying prematurely:
  - i. *Diagnose earlier and accurately* ensuring that people have the right diagnosis, and receive appropriate treatment
  - ii. *Prevent progression -* through evidence-based treatment, prompt and effective management of exacerbations, and interventions such as smoking cessation
  - iii. *Prolong survival ensuring that people with more severe COPD receive interventions such as non-invasive ventilation and long-term oxygen therapy*
- 36. The table below sets out the key actions and interventions the NHS can do to ensure these steps are taken, so that premature deaths from COPD are prevented.

	DOMAIN ONE: Preventing people from dying prematurely				
	NHS Outcomes	HS Outcomes  • Life expectancy at 75 i males ii females amework • Under 75 mortality rate from respiratory disease			
	Outcomes Strategy for COPD and Asthma	Objective 3: To reduce the number of people with COPD who die prematurely through a proactive approach to early identification, diagnosis and intervention			
	NICE Quality Standard for COPD	Statem	ents 1, 3, 5, 7, 8, 9, 10, 11		
	Diagnose earlier an accurately	id	Prevent progression	Prolong survival	
Why does the NHS need to act?	<ul> <li>2.1m people are living with undiagnosed COPD – an estimated 70% of the total number of people with COPD</li> <li>10% of acute admissions for COPD are in people without a prior diagnosis of the condition. Most of these have severe disease and some are in respiratory failure</li> <li>Over 25% of people with a diagnostic label of COPD have been wrongly diagnosed, usually associated with poorly-performed spirometry</li> </ul>		It costs the NHS nearly ten times more to treat severe COPD than mild disease The rate of lung function decline is faster in the earlier stages of	If all PCTs performed as well as the top 25% on COPD treatment and care, 7,800 lives would be saved in England each year Regular moderate or high	
			the disease which can be modified by treatment	physical activity reduces mortality and prolongs survival	
			symptoms are moderate leads to a decline in symptoms similar to that of healthy never smokers and a reduction in cough, phlegm	When non-invasive ventilation (NIV) is used in appropriate people, survival is almost doubled	
			and wheeze in most individuals within the first year	Long-term oxygen therapy can improve survival rates by around 40%. However around 30% of	
	Patients who have COPD and have smoked have a higher incidence of lung cancer and cardiovascular disease		Exacerbations are common in COPD and if not treated promptly and appropriately lead to further lung damage and lung function decline	people currently prescribed oxygen either do not benefit clinically, or do not use the oxygen	
	Identify people whose treatment history and symptoms suggest that COPD may have been missed, and those currently diagnosed with COPD without a clear diagnosis Perform quality-assured diagnostic spirometry on those identified and confirm diagnosis, together with other investigations to assess severity and coexistence of other conditions Assess for the presence of alpha- 1-antitrypsin deficiency and for bronchiectasis in patients with a suggestive history		Ensure people with COPD receive evidence-based treatment	Promote regular physical activity in all people with COPD	
the NHS do to improve outcomes?			Offer appropriate smoking cessation support to people with COPD who smoke	Identify those who may need NIV both in the acute setting and as a long-term domiciliary treatment, and ensure structured assessment of need for NIV is carried out by a respiratory specialist	
			Identify and treat exacerbations promptly		
				Ensure routine pulse oximetry is performed in people with COPD whose FEV1 is lower than 50%	
				predicted to identify those who may need long-term home oxygen therapy and, for those identified, ensure structured assessment of need by a home	
What can	Recognise the link betwee COPD and lung cancer an explore the use of proactiv strategies to diagnose ear	n d /e lier		oxygen assessment and review service	

37. More background and detail on the actions and interventions in Domain One is given below.

#### Diagnose earlier and accurately

What the NHS can do to improve outcomes:

- Identify people whose treatment history and symptoms suggest that COPD may have been missed, and those currently diagnosed with COPD without a clear diagnosis
- Perform quality-assured diagnostic spirometry on those identified and confirm diagnosis, together with other investigations to assess severity and coexistence of other conditions
- Assess for the presence of alpha-1-antitrypsin deficiency and for bronchiectasis in patients with a suggestive history
- Recognise the link between COPD and lung cancer and explore the use of proactive strategies to diagnose earlier

#### Why?

- 38. There are over 2.1 million people in England living with undiagnosed COPD, significantly more than the 900,000 who have been diagnosed.
- 39. Of the undiagnosed population, the majority have mild or moderate disease, but a significant minority have severe COPD. Late or under diagnosis has been shown to have a strong association at practice level with hospital admission for exacerbations. If people remain undiagnosed until they are severely disabled by the condition, or are admitted to hospital as an emergency, the benefits of treatment to the individual are greatly reduced and the costs to the healthcare system greatly increased.
- 40. If diagnosed earlier, people with COPD can take steps to improve the outcome of their disease and prevent its progression, and healthcare providers can focus on helping people to remain well. Evidence from recent global clinical trials shows that the rate of decline in lung function is faster in the earlier stages of the disease where people are less likely to have a diagnosis contrary to previous clinical opinion.<sup>4 5 6 7 8 9</sup>
- 41. Undiagnosed people with moderate or severe COPD have high healthcare costs in the two years before diagnosis.<sup>10</sup> Many people also present with symptoms of COPD for between at least two and 10 years before a diagnosis is made.<sup>11</sup> Preventing people dying prematurely requires a proactive and systematic approach to earlier and more accurate diagnosis.
- 42. It is important that the diagnosis made is accurate and confirmed through qualityassured spirometry and other lung function tests to assess severity and functional ability. Differentiation between COPD and asthma and other lung diseases is essential. An assessment for the presence of bronchiectasis in patients with excess sputum production and difficult-to-treat respiratory exacerbations, is also important.
- 43. Most, but not all COPD, is caused by cigarette smoking, as are many other diseases, such as cardiovascular disease. These diseases therefore may co-exist in someone with COPD and it is important for treatment and disease progression that this is properly

recognised and assessed. This is particularly true in lung cancer where up to 65% of people with lung cancer also have COPD.

44. Ultimately, earlier and accurate diagnosis would reduce the numbers of deaths from COPD, help to prevent progression of the disease, prolong survival and improve quality of life of those diagnosed.

### Identify people whose treatment history and symptoms suggest that COPD may have been missed, and those currently diagnosed with COPD without a clear diagnosis

- 45. It is important that COPD is recognised within the community in a cost-effective and efficient manner. There is also a need to ensure that addressing any COPD underdiagnosis does not increase the burden of COPD misdiagnoses, so it is important that those currently diagnosed with COPD and/or on COPD medication without a clear or accurate diagnosis are also identified.
- 46. Targeted case-finding can be done through auditing GP registers to identify people whose treatment history and symptoms suggest a diagnosis that COPD may have been missed or that COPD has been incorrectly diagnosed. NICE recommends that a diagnosis of COPD should be considered in people over the age of 35 who have a risk factor (generally smoking) and who present with exertional breathlessness, chronic cough, regular sputum production, frequent winter 'bronchitis' or wheeze.<sup>12</sup>
- 47. In order to identify adults with early signs of COPD, there needs to be more use of symptom questionnaires, microspirometry or other measurements as case finding tools. As there is insufficient evidence at present to support the use of these tools, the Department of Health has commissioned a study to examine their effectiveness and cost effectiveness of approaches to case finding before issuing further guidance to the NHS see box below.

#### Box 3: Case finding programme

A 'case finding' approach is being piloted in which individuals are selected for quality-assured diagnostic spirometry on the basis of age, smoking status, symptoms and micro-spirometry. This does not diagnose COPD but helps to rule out those individuals with a low probability of having COPD.

The study population consists of current smokers (aged 35 years or older) registered with practices in York and Hull. Individuals are <u>excluded</u> if they have a cognitive or physical condition that precludes them from completing the questionnaires or undergoing lung function testing.

A number of case finding tools are being tested:

- Symptoms and symptom-based questionnaires
- 'Case finding' micro-spirometry
- Peak flow measurement and wheeze measurement

The study is expected to report in late 2012.

#### Box 4: British Lung Foundation awareness raising campaigns

The British Lung Foundation has run campaigns aimed at raising awareness of good lung health and to encourage the early diagnosis of COPD in conjunction with six Primary Care Trusts in England.

In NHS Hull they ran a campaign in September 2010 to: Increase demand for lung function testing in primary care in Hull Identify those with likely undetected COPD by lung function testing in the community for at risk groups Provide COPD information to at risk groups

The following elements combined to provide a fully integrated awareness-raising campaign:

- Pre-campaign communication with health care outlets to engage support
- Provision and distribution of COPD campaign materials (posters/leaflets/beer
- mats) to GP surgeries, pharmacies, health centres, libraries and other venues. NHS Hull were responsible for the local media campaign
- Awareness stands with free lung testing in targeted community settings

The total number of people tested was 544.

22% of people tested were referred to GP with abnormal lung function

# Perform quality-assured diagnostic spirometry on those identified and confirm diagnosis, together with other investigations to assess severity and coexistence of other conditions

- 48. Making a diagnosis of COPD relies on clinical judgement, based on a confirmation of history, physical examination and confirmation of the presence of airflow obstruction using quality-assured diagnostic spirometry. Spirometry is also critical for evaluating the influence of some co-morbid conditions and in assessing the severity of the disease.
- 49. Spirometry is the test that measures exhaled volume and/or flow against time from a maximum intake of breath. It can detect the presence of airflow obstruction in the lung, as well as the degree of reversibility achieved with bronchodilator treatment.
- 50. However, because of poor quality spirometry, many people are diagnosed as suffering from COPD when they actually have another condition. It is important therefore that quality-assured spirometry that meets national and international guidelines and standards is commissioned and provided so that the results are quality assured and clinically interpreted correctly. The Department of Health will include reference to these guidelines, and specifications for achieving accurate spirometric data, within a guidance document for the NHS to be published alongside the COPD Commissioning Toolkit (which includes a section on diagnosis).

- 51. There will be several benefits in improving quality-assured confirmatory diagnoses. Failing to perform accurate spirometry can overestimate the prevalence and severity of COPD and thus lead to wasted resources in treating people who do not actually have the disease, or a milder form of it. A survey of practices across Devon revealed that 27% of people on GP COPD registers did not meet the diagnostic criteria for COPD.<sup>13</sup>
- 52. It is important that people not only get an accurate, quality-assured diagnosis, but that there is clear differentiation of COPD from asthma and other diseases. This differentiation is critical if there is to be appropriate intervention and management of the condition, the natural course of the disease in an individual is to be modified and the more cost-effective treatment is to be provided. The main differences between COPD and asthma are set out clearly in Annex B.
- 53. Overlooking the possibility of reversible disease can result in significant unnecessary morbidity, and so tests to assess the degree of reversibility of airway obstruction are important before a definitive diagnosis of COPD is made.
- 54. Spirometry is not the only diagnostic test that may be required at the initial diagnosis stage to ensure that the disease and its impact are physiologically fully characterised in an individual and severity is established. For example, the presence of emphysema is not reflected in spirometric measurements and is likely to have a greater impact on measures of gas transfer. Investigations such as radiology using HRCT and a measure of gas transfer or of exercise tolerance may be more informative in the assessment and monitoring of some individuals.<sup>14</sup>
- 55. For those with coexistent heart failure, an assessment of both the lung and cardiac contribution to breathlessness will need to be established through the use of both spirometry and more extensive lung function tests and echocardiography. As a result, it is important that access to these tests is readily available for a comprehensive evaluation at the point of initial diagnosis.
- 56. Diagnostic testing and the services that provide them are subject to Care Quality Commission (CQC) regulatory arrangements. To help providers maintain the quality of their diagnostic services and provide evidence to the CQC, an accreditation programme for respiratory diagnostic testing is being introduced during 2012 as part of the Improving Quality in Physiology Diagnostics (IQIPS) programme.<sup>vi</sup> Although participation in the programme is not mandatory, by taking part providers will help to ensure that people with COPD are accurately diagnosed and receive the correct treatment. Reference will be made to the accreditation process for respiratory diagnostics in the COPD Commissioning Toolkit so that it can be built into any commissioning specifications and contract arrangements, in line with best practice.
- 57. It is very common for people with COPD to have additional long-term conditions. Around 33% have hypertension, 19% have coronary heart disease, 18% have depression, 11% have diabetes and 6% have heart failure. It is important that access to appropriate tests is readily available for a comprehensive evaluation at the point of initial diagnosis, and that there are locally-agreed pathways for referral for treatment of other conditions.

<sup>&</sup>lt;sup>vi</sup> Improving Quality in Physiological diagnostic Services (IQIPS) is a programme hosted by the Accreditation Unit of the Royal College of Physicians with support from the Department of Health.

### Assess for the presence of alpha-1-antitrypsin deficiency and for bronchiectasis in patients with a suggestive history

- 58. At the diagnosis stage, it is also important that arrangements are in place for assessment of alpha-1-antitrypsin deficiency, which can lead to early onset emphysema and premature death. Alpha-1-antitrypsin is an enzyme inhibitor secreted by the liver to protect the lungs from permanent damage. Low levels in the circulation are associated with the development of early onset emphysema and therefore phenotyping and genotyping for those individuals with low circulating levels needs to be provided. Smoking can exacerbate the effect of the low level of inhibitor and lead to severe COPD in young to middle-aged adults.
- 59. The early detection of alpha-1-antitrypsin deficiency results in increased awareness of the dangers of smoking and environmental pollution.<sup>15</sup>
- 60. The World Health Organisation (WHO) have recommended that all people with a diagnosis of COPD and/or a history of adult onset asthma should be assessed for alpha-1-antitrypsin deficiency.<sup>16</sup> Following assessment of individuals for alpha-1-antitrypsin, those identified would have their lung disease assessed more closely and receive appropriate genetic counselling, and their relatives would be offered assessment.
- 61. Some patients with COPD will also develop bronchiectasis, which will range from mild to more severe forms of the disease requiring more complex treatment usually in specialist centres. The BTS has produced best practice guidelines for the assessment and treatment of bronchiectasis which commissioners and providers can refer to.<sup>17</sup>

### Recognise the link between COPD and lung cancer and explore the use of proactive strategies to diagnose earlier

- 62. As well as being a major cause of COPD, cigarette smoking is the main preventable cause of lung cancer. Many studies have also found evidence of a substantially increased risk of lung cancer in people with COPD independent of smoking (twice as common in men and four times as common in women). The estimated prevalence of COPD in people with lung cancer has been shown to be between 50 and 65%. While the three-year survival from diagnosis of lung cancer is already very low, it is considerably lower in those with a prior COPD diagnosis. Lung cancer is more common in people aged 65 and older and among those with a prior diagnosis of COPD, lung cancer is diagnosed at an even later age.
- 63. The Department of Health National Awareness and Early Diagnosis Initiative (NAEDI) currently includes a national campaign to raise public awareness of the symptoms of lung cancer and encourage early presentation to the GP.
- 64. Locally, proactive strategies to recognise the co-existence and to improve the diagnosis of both conditions could be explored.

#### **Prevent progression**

What the NHS can do to improve outcomes:

- Ensure people with COPD receive evidence-based treatment
- Offer appropriate smoking cessation support to people with COPD who smoke
- Identify and treat exacerbations promptly

#### Ensure people with COPD receive evidence-based treatment

65. Evidence-based treatment recommendations for people with COPD form a central part of the NICE clinical guideline for COPD.<sup>18</sup> All people with COPD should receive treatment in accordance with this guideline, which is based on presenting symptoms, and a partnership approach between the person with COPD and their healthcare professionals. In all cases of COPD (irrespective of severity), treatment should be optimised to control and/or minimise symptoms to ensure that people living with the disease can play an active part in everyday life (as outlined in paragraphs 110 – 119 in Domain Two).

#### Offer appropriate smoking cessation support to people with COPD who smoke

- 66. The health gains achieved by stopping smoking are indisputable. For COPD, stopping smoking is of proven benefit in terms of interfering with disease progression and should be recognised as a treatment, not just as a way of preventing disease. Stopping smoking also benefits other conditions such as cancer, cardiovascular disease, diabetes and osteoporosis. Stop smoking services should offer a long-term programme that is flexible enough to deal with an individual's needs. It can take as many as seven or eight attempts for a smoker to quit, therefore programmes need to consider this and have robust systems to follow up those that have used the service and offer further help if needed.
- 67. It is important that there is access to behavioural support and recommended stop smoking pharmacotherapies (e.g. Nicotine Replacement Therapy including combination therapy, varenicline and bupropion) that greatly increase the chances of stopping smoking.
- 68. Evidence-based stop smoking interventions, which combine behavioural support and pharmacotherapy, offer the best chance of stopping smoking, and therefore avoid or significantly reduce the impact of lung disease. NHS Stop Smoking Services are available throughout the country offering free stop smoking support to all smokers through a range of interventions and a variety of access points.
- 69. Stop smoking services should also take into account other smoked substances that may have an impact on lung health, such as cannabis. Links could be made with local drug teams to address this issue.

#### Identify and treat exacerbations promptly

70. Even when a diagnosis is made, and if proactive care measures are in place, it is inevitable that a proportion of people with COPD will experience episodes of acute

exacerbations. COPD exacerbations are associated with worse quality of life, faster disease progression and increased mortality.

- 71. There is good evidence that prompt therapy in exacerbations results in less lung damage, faster recovery and fewer admissions (and subsequent readmissions) to hospital. People should be able to access clinical help early in the course of an exacerbation and, as recommended in the NICE clinical guideline for COPD, should be given a course of antibiotic and corticosteroid tablets to keep at home for use as part of a self-management strategy.<sup>19</sup>
- 72. Some people with COPD are prone to frequent exacerbations, defined as requiring two or more courses of antibiotics and/or corticosteroids in a 12-month period. Prompt treatment at the onset of exacerbation symptoms has been shown to improve outcomes.<sup>20</sup> Thus it is important that people who develop exacerbations, together with their carers, are able to understand and recognise exacerbation symptoms. As outlined in the *Outcomes Strategy for COPD and Asthma*, options and emerging good practice models for access to 24-hour advice for people will be investigated as part of the NHS Improvement Lung work programme so that people receive optimal information and advice about their worsening symptoms and exacerbations. It is important that locally there is a pathway of care which is proactive and supports people with COPD and their carers to identify symptoms earlier.
- 73. Some exacerbations may be mild and self-limiting and only require an increase in regular inhaled medication. However people with more severe exacerbations will require access to specialist care to undergo investigations such as measurement of arterial blood gases, chest radiograph to exclude pneumonia, and assessment of therapeutic requirements including for example intraveneous antibiotics. The severity of an exacerbation is also affected by other pre-existing conditions (co-morbidities) or complications that are commonly found in this group and need to be both recognised and investigated.<sup>21</sup> A severe exacerbation has one or more of the following features:
  - The presence of respiratory failure
  - The presence of pneumonia
  - The presence of co-morbidities requiring active intervention
  - Failure of first line therapy
- 74. Whilst many COPD exacerbations can be assessed and managed in the community, specialist advice, care and investigations will need to be available to many people with moderate to severe disease during exacerbations. Commissioners and providers may find it useful to look at the emerging findings from the work of the NHS Improvement Lung programme and other evidence-based practice such as that available on the Improving and Integrating Respiratory Services in the NHS initiative (IMPRESS) website, which have been evaluated for their impact on reducing hospital admissions or readmissions.<sup>22 23</sup> The COPD Commissioning Toolkit the Department of Health will be publishing shortly will also have a section on managing acute exacerbations.

#### Prolong survival

What the NHS can do to improve outcomes:

- Promote regular physical activity in all people with COPD
- Identify those who may need NIV both in the acute setting and as a long-term domiciliary treatment, and ensure structured assessment of need for NIV is carried out by a respiratory specialist
- Ensure routine pulse oximetry in people with COPD whose FEV1 is lower than 50% predicted to identify those who may need long-term home oxygen therapy and, for those identified, ensure structured assessment of need by a home oxygen assessment and review service

#### Promote regular physical activity in all people with COPD

- 75. People with COPD develop progressive and irreversible narrowing of the airways that is associated with muscle weakness, causing breathlessness and reduced capacity for activity. This results in respiratory disability, especially in those with more severe disease, and a corresponding increase in dependence on health and social care resources.
- 76. People with mild COPD are generally not sufficiently disabled by their condition to warrant participation in formal pulmonary rehabilitation programmes (MRC Dyspnoea Grades 1 or 2). However, people with mild COPD should receive the same physical activity messages from their healthcare professionals as the general population at least 30 minutes of physical activity, five times a week is good for your physical and mental health. This message may need to be tailored to overcome negative expectations about physical activity, including getting out of breath. Positive messages need to underscore the importance of maintaining an ability to carry out activities of daily living. The important message is about volume (150 minutes per week, which can be broken down into chunks of 10 minutes or more). In addition, the meaning of 'moderate' needs explanation (feel warm and breathe more heavily than usual).
- 77. Regular moderate physical activity has been shown to be associated with a 30-50% reduction in risk of both hospital admission and respiratory mortality and with improvements in quality of life measures.<sup>24</sup> The same study demonstrated a median survival difference of seven years between those who take very low levels of physical activity compared with those taking moderate or high levels.

# Identify those who may need NIV both in the acute setting and as a long-term domiciliary treatment, and ensure structured assessment of need for NIV is carried out by a respiratory specialist

78. A proportion of people with COPD will develop hypercapnic respiratory failure either as a primary consequence of their lung disease or as secondary to an acute exacerbation of COPD. NIV has been shown to not only reduce mortality but also reduce the need for invasive tracheal intubation and its associated complications.

- 79. NIV is a method of assisting someone's breathing without using an invasive airway, typically by using a tightly fitting nasal or facial mask that is attached via tubing to a portable ventilator.
- 80. Paragraphs 140 146 in Domain 3 describe the use of acute NIV in the management of respiratory failure. The National COPD Audit 2008 estimated that around 250 lives a year could be saved through the use of acute NIV.<sup>25</sup>
- 81. Long-term domiciliary NIV in appropriate people with COPD has been shown to improve survival, particularly when used in conjunction with long-term oxygen treatment.<sup>26</sup> The initial assessment for home NIV is normally performed in hospital, and people will be established on NIV before their discharge into the community.
- 82. NIV requires specialist respiratory assessment and ongoing review of individuals for compliance and improvement and for maintenance of equipment and provision of consumables.

# Ensure routine pulse oximetry in people with COPD whose FEV1 is lower than 50% predicted to identify those who may need long-term home oxygen therapy and, for those identified, ensure structured assessment of need by a home oxygen assessment and review service

- 83. People with severe COPD need regular assessment for the presence of arterial hypoxaemia. Those who meet the clinical criteria for prescription of home oxygen need specialist assessment with arterial blood gas measurement according to current guidelines. Regular pulse oximetry should be considered in all with severe or very severe disease with referral of those with abnormal saturation for specialist oxygen assessment.
- 84. All those on home oxygen require follow up as their condition may deteriorate with worsening hypoxaemia and higher flow rates may be required. At the same time, the use of ambulatory oxygen may change and the prescription should reflect the current requirements.
- 85. The Department of Health has developed advice in *Home Oxygen Service: Good practice guide for assessment and review*, describing the content of a home oxygen assessment and follow service up for people who might require oxygen therapy.<sup>27</sup>
- 86. The home oxygen service provides around 85,000 people in England with oxygen therapy within their own homes, of which about 60% have COPD. The total cost of the service in England is around £110m. In some areas there is no quality-assured assessment of people being prescribed oxygen, and it is prescribed by a range of healthcare professionals. In PCTs that have introduced a review of their oxygen registers coupled with the introduction of a formal assessment service up to £400,000 has been saved in one year. If the scale of savings were replicated across England, it is estimated that they could amount to between £10-20m of savings a year.

# DOMAIN TWO: Enhancing the quality of life for people with long-term conditions

- 87. COPD is a long-term condition, with lung damage often having occurred before any evidence of airway obstruction can be detected. The lung damage cannot be reversed and in many instances is progressive. This means that even people with mild or moderate disease will decline rapidly without optimal intervention. Currently there is not an effective treatment which repairs lung damage, however appropriate management and therapeutic intervention in line with evidence based guidelines can slow down progression and ensure that the quality of life of people with COPD is maintained as long as possible.
- 88. Breathlessness combined with the inability to undertake every day living activities are the issues that are cited as the most troublesome by people with COPD and interfere with their ability to work and to interact with their families, friends, and community.
- 89. People with long-term conditions such as COPD often live with more than one condition. A majority of people over 65 have two or more long-term conditions. A majority of people over 75 have at least three conditions, and over 80% of people with COPD have at least one other long-term 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 individual at the centre of decision making about their care.
- 90. Evidence suggests that delivery of services for people with COPD is most effective where an integrated care model is developed using multidisciplinary teams. These teams should promote key principles that provide the common spine for treatment and care of all people with long-term conditions, based on international evidence and best practice.<sup>28</sup> <sup>29</sup> <sup>30</sup> <sup>31</sup> <sup>32</sup>
- 91. Managing COPD as a long-term condition will help to keep people well, and prevent unnecessary hospital admissions. COPD is the second most common cause of emergency admission to hospital but there is robust evidence that many admissions are avoidable.<sup>33</sup>
- 92. There are three approaches that the NHS can to take to improve the quality of life of people with COPD:
  - i. *Risk stratify and understand the local population of people with COPD* assessing for disease severity and taking a chronic disease management approach
  - ii. Support self-management and shared decision-making ensuring people with COPD have the tools they need to self manage and share in decision-making about their care
  - iii. Provide and optimise pharmacological and non pharmacological treatment including pulmonary rehabilitation
- 93. The table below sets out the key actions and interventions the NHS can do to ensure these steps are taken, so that the quality of life for people with COPD is enhanced.

DOMAIN TWO: Enhancing the quality of life for people with long- term conditions				
NHS Outcomes Framework		roportion of people feeling supported to manage their ondition mployment of people with long-term conditions Inplanned hospitalisation for chronic ambulatory care ensitive conditions (adults) lealth-related quality of life for carers		
Outcomes Strategy for COPD and Asthma		ve 4: To enhance the quality of life for people with COPD		
NIC for	E Quality Standard	Stateme	ents 2, 3, 4, 6, 7, 10	
	Risk stratify and understand the lo population	ocal	Support self- management and shared decision- making	Provide and optimise pharmacological and non-pharmacological treatment
Why does the NHS need to act?	NICE guidance recomn that treatment should b tailored to disease seve impact on the individua	nends e erity and I	For someone with COPD there is a fivefold difference in risk of being admitted to hospital as an emergency depending on where they live Of those currently diagnosed with COPD, around 33% have hypertension, 19% have coronary heart disease, 18% have depression, 11% have diabetes and 6% have heart failure	There is substantial variation in evidence-based prescribing and medicines management for people with COPD Pulmonary rehabilitation has been shown to relieve shortness of breath and improve control over COPD
What can the NHS do to improve outcomes?	Assess for disease sev other complicating factor Provide proactive chror disease management appropriate for the seve level assessed – mild, moderate or severe	rerity and ors hic erity	Ensure people with COPD are offered support to self-manage their condition, and provide access to integrated community care teams with access to specialist respiratory advice	Ensure people with COPD receive evidence-based treatment in a structured medicines management approach Provide pulmonary rehabilitation for all people with COPD with an MRC score of three or above

94. More background and detail on the actions and interventions in Domain Two is given below.

#### Risk stratify and understand the local population of people with COPD

#### What can the NHS do to improve outcomes:

- Assess for disease severity and other complicating factors
- Provide proactive chronic disease management appropriate for the severity level assessed – mild, moderate or severe

#### Why?

- 95. The generic long-term conditions care pyramid describes three levels of care:
  - Level 1: self-care support and management (assumes applies to 60-70% of the population)
  - Level 2: high-risk disease and case management
  - Level 3: high complexity and case management
- 96. For COPD, this pyramid is translated to the figures shown in the box below.

Generic care pyramid levels	Current diagnosed population	Future – all diagnosed people
Level 3 – severe	600,000	1.1 million
disease		
Level 2 –	200,000	1.4 million
moderate disease		
Level 1 – mild	35,000	1.1 million
disease		

97. Over time, when more people with the disease are diagnosed, the shape of the care pyramid will change. The care needs of the population with COPD will also therefore change, which will require a stratified management approach involving both generalists in long-term condition management and specialists in respiratory care.

#### Assess for disease severity and other complicating factors

98. Determination of disease severity should be based on a comprehensive assessment that includes degree of airflow obstruction (percent predicted FEV1), degree of breathlessness, the frequency of exacerbations, presence of co-morbidities, body mass index, pulse oximetry and an evaluation of COPD related health status using a validated measure.

### Provide proactive chronic disease management appropriate for the severity level assessed – mild, moderate or severe

99. The current evidence for intervention and improvements in outcomes for people with COPD relates to the more severe disease population and specialist intervention, rather than more generalised care approaches which need to be applied in a mild to moderate

population. There is evidence to support improvements in chronic care management through specialist proactive management and interventions aimed at improving quality of life.<sup>34</sup> However, there is little existing evidence to support the model of care for more mild disease for people with COPD.

- 100. It is envisaged future delivery would be in an integrated care model of provision by a multidisciplinary team which incorporates:
  - Generalists focusing on the mild to moderate disease population and those with stable conditions
  - Specialists in respiratory care focusing on the more complex and unstable population and on diagnostics and more specialist interventions such as Non-Invasive Ventilation (NIV)
  - Specialists in the different co-morbid conditions
- 101. The central aim of chronic disease management is that interactions between those with COPD and health and social care professionals are productive, and that people are seen as partners in the management of their condition. This means that while health and social care professionals have access to up-to-date information, decision support and the resources needed to deliver care that is of a high-quality, people with COPD should also have the information, skills and confidence needed to make decisions about their health in order to better manage their condition, and be motivated to do so (see Box 9 in Domain Four on shared decision making).
- 102. The Wagner chronic care model has identified four essential elements in structured care that are likely to have a major impact on the quality, effectiveness and efficiency of care.<sup>35</sup> These components are the promotion of self-management, a comprehensive system to support clinical management, evidence-based support for decision-making and the use of clinical guidelines. The presence of at least two of these components is associated with improvement in outcomes, particularly with respect to unscheduled care.
- 103. There is considerable scope for improving the quality of care and support in COPD against this overarching chronic disease management framework. Its introduction will rely on the efforts of commissioners and providers alike. To support this it is important to ensure the development of integrated care pathways for COPD, which reflect the NICE clinical guidelines and other reliable sources of evidence for assessment and intervention. If commissioners decide to introduce and evaluate new models of care they should involve all sectors and agencies, including social care, so that high-quality care that is effective, efficient and offers value for money can be put in place to meet the needs of their local populations. Good clinical leadership will also be needed to ensure uptake across care sectors and agencies, and to reduce duplication in care provision.
- 104. Two studies have shown significant reduction in healthcare costs after review or disease management programmes (with an increase in drug costs, but reduction in emergency admissions).<sup>36 37</sup> The first of these also showed reduction in time lost from work,<sup>38</sup> which is an important factor as 44% of people with COPD in the UK are of working age. Currently, over half are prevented from working at all and a quarter limited in their ability to work,<sup>39</sup> however, appropriate treatment can improve physical exercise capacity.

#### Support self-management and shared decision-making

What can the NHS do to improve outcomes:

 Ensure people with COPD are offered support to self-manage their condition, and provide access to integrated community care teams with access to specialist respiratory advice

# Ensure people with COPD are offered support to self-manage their condition, and provide access to integrated community care teams with access to specialist respiratory advice

- 105. Self-management plans provide people with information, education and structured actions to take in response to changes in their condition. Self-management plans allow people to feel in control of their conditions. They can improve symptom control and improve outcomes such as exacerbation severity and preventable admission to hospital.
- 106. In COPD for example, the NICE clinical guideline for COPD recommends that people with COPD have home supplies of standby antibiotics and steroids with advice on when to self-medicate.<sup>40</sup> This reflects evidence that prompt medical management of acute exacerbations improves outcomes.
- 107. Despite this, the National Audit for COPD 2008 found that only one third of people with COPD admitted as an emergency during an exacerbation had been given standby drugs.<sup>41</sup>
- 108. Integrated community care teams, with access to specialist respiratory advice, are key to helping people with COPD manage their condition in the community and prevent hospital admissions.
- 109. Primary and community care teams may need support to provide high quality evidencebased care to: detect disease earlier in people with symptoms or functional disability; maintain accurate and comprehensive disease registers; conduct regular comprehensive clinical reviews that identify an individual's needs and optimise therapy; support self-management; respond promptly to exacerbations; and refer for specialist input when required. The support needed by primary and community care teams may include education, training and mentoring for nurses and GPs, audit of practice registers, computer templates for coding and prompting clinical behaviour, shared nursing and other resources, and improved partnership or integration with specialist services.

#### Box 5: Telehealth and telecare – supporting people in the community

Telecare and telehealth will play a crucial part in achieving in supporting independence through remote monitoring of vital signs and providing support through electronic devices.

The Department of Health has developed and run the largest randomised control trial of telehealth and telecare anywhere in the world. The Whole System Demonstrator (WSD) Programme was set up in 2008 to look at the clinical and cost-effectivess of telehealth and telecare across three sites (Kent, Cornwall and

Newham) involving 6191 participants, and 238 GP practices, with an evaluation team consisting of the country's top healthcare academics. The telehealth part of the study focussed on three diseases – COPD, diabetes and heart disease.

The early findings show that if used correctly telehealth can deliver a 15% reduction in A&E visits, a 20% reduction in emergency admissions, a 14% reduction in elective admissions, a 14% reduction in bed days and an 8% reduction in tariff costs. More strikingly the findings also demonstrate a 45% reduction in mortality rates.

#### **Box 6: Personal health budgets**

A personal health budget is an amount of money that is allocated to an individual to allow them to meet their health and wellbeing needs in a way that best suits them. At the heart of a personal health budget is a care plan. This sets out the individual's health and social care needs and includes the desired outcomes, the amount of money in the budget and how this will be spent. The care plan is agreed between the individual and the health professional or the individual taking the lead, before being checked and signed off by the NHS. Personal health budgets empower people to have greater control of when and where services are delivered, and how their health needs are met.

There is a clear Government commitment to roll out personal health budgets, subject to evidence from the pilots. This was set out most recently in the Government's response to the NHS Future Forum.

#### The Pilot programme

Personal health budgets are at an early stage of development and are currently being piloted in the NHS in England. There are currently over 60 pilot sites involved in the pilot programme, involving around half the PCTs in the country. An independent evaluation of the pilots will be published in 2012.

The pilots involve people with a range of long-term conditions, including COPD. Early anecdotal evidence from the pilots suggests that personal health budgets can have a positive effect for people with COPD.

#### **Optimise management and treatment**

What the NHS can do to improve outcomes:

- Ensure people with COPD receive evidence-based treatment in a structured medicines management approach
- Provide pulmonary rehabilitation for all people with COPD with an MRC score of three or above

- 110. NICE provides structured evidence-based guidance on the use of pharmacotherapy in COPD.<sup>42</sup> The guidance supports clinicians to select appropriate medications to offer people with COPD depending on their level of airflow limitation and symptoms. Use of evidence-based medication by people with COPD improves symptoms, functional capacity, quality of life and outcomes such as exacerbation frequency and severity and potentially mortality.
- 111. There is substantial unwarranted variation in the provision of evidence-based therapy for people with COPD some receive inadequate treatment and some receive inappropriate treatment. The many people with COPD who remain undiagnosed may receive no treatment at all. Clearly this lack of appropriate therapy is likely to have an adverse effect on quality of life and outcomes.
- 112. Commissioners and providers will also want consider the cost-effectiveness of treatments. The London Respiratory Team have produced a pyramid of interventions for COPD (in the box below) which shows the cost per QALY of the interventions people with COPD can receive. Prescribing of triple therapy will only be cost-effective if it is done according to the evidence-based guidelines from NICE, which detail when and in which people it will be most effective. The treatments below triple therapy in the pyramid will provide more cost-effective interventions for many people.

#### Box 7: London Respiratory Team – COPD 'value' pyramid

This work was developed by the London Respiratory Team as part of clinically-led workstreams on 'responsible respiratory prescribing' and 'stop smoking as a treatment'. From the outset, these were steered by the principles of relative value and right care.



### February 2011 - This work on value is now being continued by IMPRESS (www.impressresp.com)

References: J Epidemiol Community Health. 1998 Feb;52(2):120-5 £50 saving for over 65 Thorax. 65(8):711-8, 2010 Aug. Thorax 2001;56:779-784 £0-1000 per QALY Tiotropium in the treatment of COPD: Health technology Assessment KCE reports 108C Neyt M et al £7,456 per QALY OBA Y Cost effectiveness of long-acting bronchodilators for COPD. Mayo Clinic Proc 2007;82:575-582 £5,396 per QALY CADTH. LABA plus Corticosteroids vs LABA alone for COPD. Issue 83 March 2007. Mayers I et al £130,000 per QALY and NICE COPD management of COPD in adults in primary and secondary care 2010 £131,000 per QALY

- 113. Studies suggest that the majority of people who use inhalers do not do so correctly thus severely limiting drug delivery and effectiveness. Regular checking and teaching of inhaler technique by health professionals should be the first step in optimising drug therapy. Improving inhaler technique can have a substantial effect in improving symptoms and outcomes and reducing costs.
- 114. For people with COPD, non-concordance with medication can result in increased morbidity and mortality. It has been suggested that improving concordance with medication may have a greater effect on health than advances in treatment.<sup>43</sup>
- 115. People with COPD may be partially non-concordant, for example missing doses or taking the wrong amount of medication, or completely non-concordant, where they have stopped taking their medication altogether. To reduce non-concordance, healthcare professionals need to understand why individuals fail to adhere to drug regimens. It may be unintentional, for example where they forget to take their medication or misunderstand the instructions they have been given, or intentional.
- 116. A person-centred approach can eliminate or ameliorate some medication-based problems that lead to non-concordance, and identify where people have information needs.
- 117. The NICE clinical guideline for COPD states that most people with COPD, whatever their age, are able to acquire and maintain adequate inhaler technique given adequate instruction.<sup>44</sup> Those with significant cognitive impairment are an exception to this, as they are unable to use any form of inhaler device. In most people, however, a pragmatic approach guided by individual assessment is needed in choosing a device:
  - In most cases bronchodilator therapy is best administered using a hand-held inhaler device (including a spacer if appropriate)
  - If the person is unable to use a particular device satisfactorily, it is not suitable for him or her and an alternative should be found
  - Inhalers should be prescribed only after people with COPD have received training in the use of the device and have demonstrated satisfactory technique
  - People with COPD should have their ability to use an inhaler device regularly assessed by a competent healthcare professional and, if necessary, should be re-taught the correct technique.

- 118. NHS Employers and the Pharmaceutical Services Negotiating Committee PSNC) have worked together to introduce a number of service developments within the Community Pharmacy Contractual Framework. The changes comprise three key elements:
  - The introduction of a New Medicine Service (NMS) for people with long-term conditions newly prescribed a medicine to help people get the best from their medicines. The NMS is an advanced service provided by accredited pharmacists. This service is available to people with COPD and Asthma prescribed a new medicine
  - The introduction of national targeted Medicines Use Reviews (MURs) to ensure MURs are provided to those patient groups who will benefit the most. This includes people with asthma and COPD
  - Outcome measures and monitoring for the effectiveness of MURs are being introduced for each target group. These changes will ensure that high quality MURs are delivered to patients providing better health outcomes and greater value for money
- 119. Expert advice suggests that the key elements of a best practice MUR for people with respiratory disease should include:
  - Smoking cessation advice where relevant,
  - Inhaler technique,
  - Support for self management including the development of self management plans; and,
  - Assessment of disease control (asthma)

## Box 8: Supporting people with respiratory disease through community pharmacy

Pharmacists and their teams are increasingly supporting people with COPD (and asthma), helping to improve their health outcomes. In addition to the new services introduced within the Community Pharmacy Contractual Framework in October 2011, the growing number of Healthy Living Pharmacies (HLPs) are making a real difference to the health and well-being of their local populations across the country.

HLPs are underpinned by quality criteria, with three enablers in place including a workforce skilled to proactively engage with the public to improve their lifestyle, premises that are fit for purpose, with a dedicated health promotion zone and local engagement. Staff in HLPs, with the support of a health champion, use every interaction as an opportunity for a health promoting intervention, making every contact count.

Early indications are that HLPs are able to successfully deliver public health services alongside optimising the use of medicines.

HLPs in Portsmouth have demonstrated that out of over 1,000 patients who received a targeted MUR for their asthma or COPD, 48% of those reviewed after 6 months showed an improvement in their respiratory symptoms. Of these patients, 27% were smokers and over 40% of these had gone ahead and stopped smoking at four weeks. This has contributed to community pharmacies in Portsmouth
exceeding the PCT stop smoking quit target by 138%, achieving 664 quits at four weeks for 2010-11. Evaluation of the results has shown that a person walking into an HLP is twice as likely to set a quit date and give up smoking compared to a person walking into a conventional pharmacy.

Community pharmacy teams can further support people with asthma and COPD in other ways as they are easily accessible at the heart of local communities.

For instance, on World COPD Awareness Day, pharmacies in the Isle of Wight engaged in an initiative to raise awareness of COPD, its causes and the benefits of early detection. Staff were trained in the Pulmolife<sup>™</sup> screening device and, of the 400 people seen in the week, over 100 patients had reduced FEV1 of less than 80%. 81 of these were smokers and 36 accepted a referral to a stop smoking service. 37 people with reduced lung function accepted a referral to the GP for further investigation.

### Provide pulmonary rehabilitation for all people with COPD with an MRC score of three or above

- 120. As set out in the NICE clinical guideline for COPD, for those with moderate or more advanced COPD pulmonary rehabilitation (PR) is an essential part of the non-pharmacological treatment pathway.<sup>45</sup>
- 121. PR is a structured, evidence-based programme recommended for all people with COPD who have a MRC dyspnoea score greater than three. Evidence shows that PR is a highly cost-effective way of reducing admissions, improving exercise capacity and improving health-related quality of life. It is substantially below the NICE threshold for cost effectiveness, at only £2000-£8,000/QALY. PR is the only intervention to date that has been shown to reduce the high readmission rate seen in COPD (from 33% to 7%).<sup>46</sup> <sup>47</sup> Despite this impact on quality and productivity, its provision is very variable. The National COPD Audit 2008 found that 30% of PCTs did not offer community-based PR, and that there appears to be variable quality amongst services that are available.<sup>48</sup> In areas where the service is available, it is generally only provided to a minority of those who would benefit. Programme content varies (potentially affecting effectiveness and benefits to the individual and the system), and access may often be limited by low capacity. The COPD Commissioning Toolkit (which includes a section on PR) will set out what elements of the programme are critical to success.



## DOMAIN THREE: Helping people to recover from episodes of ill health or following injury

- 122. People with COPD will experience exacerbations associated with a sustained worsening of an individual's symptoms from their usual stable state, which is rapid in onset. Commonly reported symptoms are worsening breathlessness, cough and increased sputum production and change in colour. Worsening of these symptoms often necessitates a change in treatment. COPD exacerbations are associated with worse quality of life and faster disease progression as well as increased mortality.
- 123. This Domain focuses on helping people to recover as quickly and as fully as possible from ill health or injury. For many people with COPD, this means making as full a recovery as possible after an acute exacerbation, often, but not always, involving hospital admission. Prompt or early presentation for treatment from the onset of exacerbation symptoms has been shown to improve outcomes.
- 124. Exacerbations or episodes of worsening symptoms which may be infective or non infective in nature are a feature of COPD and in those with more severe disease.
- 125. There are three key approaches that the NHS can take to help people recover from episodes of ill health through COPD. They are:
  - i. Provide the right care in the right place at the right time agreeing locally a pathway of care for acute exacerbations including timing and location of initial assessment and delivery of care (hospital, GP surgery / community care, or in their own home)
  - ii. Ensure structured hospital admission ensuring people with COPD are seen by a respiratory specialist on admission to hospital and receive key interventions – like NIV – promptly
  - Support post-discharge ensuring people who have been admitted to hospital with a COPD exacerbation are supported back into the community to prevent readmissions
- 126. Managing COPD as a long-term condition, as set out in Domain Two, will help to prevent exacerbations and unnecessary admissions to hospitals.
- 127. The table below sets out the key actions and interventions the NHS can do to ensure these steps are taken, so that people are helped to recover.

DOMAIN THREE: Helping people to recover from episodes of ill			
health or following injury			
NHS Outcomes Framework	<ul> <li>Emergency admissions for acute conditions that should not usually require hospital admission</li> <li>Emergency readmissions within 30 days of discharge from hospital</li> </ul>		
Outcomes Strategy for COPD and Asthma	Objective 3: To reduce the number of people with COPD who die prematurely through proactive care and management at all stages		
NICE Quality Standard for COPD	Statements 7, 10, 11, 12		

	Provide the right care in the right place at the right time	Ensure structured hospital admission	Support post- discharge
Why does the NHS need to act?	Many people experience delay in treatment when exacerbations begin and many resort to Accident and Emergency to access care For someone with COPD there is a fivefold difference in risk of being admitted to hospital as an emergency depending on where they live The average length of stay for people admitted to hospital with COPD varies from five to nearly nine days depending on where they live	One in 12 people admitted to hospital with COPD die during their stay One in six people with COPD admitted to hospital die within three months Less than half are managed in hospital by a respiratory specialist	One in three people admitted to hospital with COPD are readmitted within three months Only 59% of respiratory units have an Early Supported Discharge Scheme
What can the NHS do to improve outcomes?	Agree locally a pathway of care for acute exacerbations – including timing and location of initial assessment and delivery of care (hospital, GP surgery / community care, or in their own home)	Ensure structured hospital admission with early access to specialist respiratory care, prompt management of COPD and co-morbidities in line with NICE guidance Ensure prompt assessment on admission to hospital, including blood gas analysis and provision of NIV within one hour of decision to treat being made, where clinically indicated	Ensure all people with COPD are assessed for suitability for an Early Supported Discharge Scheme Ensure that people admitted to hospital with an exacerbation of COPD are reviewed within two weeks of discharge

128. More background and detail on the actions and interventions in Domain Three is given below.

#### Provide right care in the right place at the right time

#### What the NHS can do to improve outcomes:

 Agree locally a pathway of care for acute exacerbations – including timing and location of initial assessment and delivery of care (hospital, GP surgery / community care, or in their own home)

Agree locally a pathway of care for acute exacerbations – including timing and location of initial assessment and delivery of care (hospital, GP surgery / community care, or in their own home)

- 129. Admission to hospital is a major adverse outcome for people with COPD and is not always necessary. There is great variation in the thresholds for hospital admission between comparable areas in England showing that in many areas there is substantial scope for reducing admissions. Because spend on COPD admissions is so high, action to prevent admissions could save substantial amounts of money as well as improving outcomes for people with COPD.
- PCTs that have achieved lower emergency admission rates have done so by ensuring more proactive care and by commissioning alternatives to admission (see also Domain 2) including:
  - Reviewing admissions to identify frequent exacerbators who need more proactive management
  - Early discharge schemes and hospital at home services commissioned to support evidence-based admission avoidance
  - Proactive chronic disease management in primary and community care. This should include clear action plans, optimisation of therapy and support for self-management and home provision of standby medication, and referral for pulmonary rehabilitation when indicated
  - Prompt support for people when they develop new or worsening symptoms, with access to specialist-led care in the community when appropriate.

#### Ensure structured hospital admission

#### What the NHS can do to improve outcomes:

- Ensure structured hospital admission with early access to specialist respiratory care, prompt management of COPD and co-morbidities in line with NICE guidance
- Ensure prompt assessment on admission to hospital, including blood gas analysis and provision of NIV within one hour of decision to treat being made, where clinically indicated

### Ensure structured hospital admission with early access to specialist respiratory care, prompt management of COPD and co-morbidities in line with NICE guidance

131. The National Audit for COPD 2008 audited 7,529 people with COPD in 234 units across the UK and showed a hospital death rate of 7.5%, appreciably higher than most OECD

countries.<sup>49</sup> Furthermore, 15% of people died within 90 days of admission. An acute episode of COPD thus carries a greater risk of death than acute myocardial infarction (MI) (13% in acute MI).<sup>50</sup> Importantly, the National COPD Audit 2008 exposed a variation in in-hospital mortality between 9 and 21%.<sup>51</sup> Only 25% of this difference could be explained on the basis of differences in case-mix and acuity. One important factor in this difference was the absence or presence of a structured admission with access to specialist respiratory care.

- 132. Hospital admission and readmission remains one of the most costly parts of COPD management. The economic and operational impact of COPD is compounded by the highly seasonal pattern of acute exacerbations of COPD, a major factor in the increased demand on acute NHS hospitals during winter months.
- 133. If admission to hospital is needed structured hospital admission with early access to specialist respiratory care will reduce avoidable mortality and morbidity, improve recovery and reduce the likelihood of readmission. A pathway for a structured COPD hospital admission should be developed and evaluated in terms of quality and economic utility. Such an evaluation could be undertaken through the Academic Health Science Centres.
- 134. NHS Improvement Lung have undertaken work to improve acute care for people with COPD. Several of the project sites across England chose to address specialist care as part of their work with NHS Improvement Lung and are trialling different approaches such as:
  - Early referral for specialist nursing review
  - Daily ward round with a consultant chest physician
  - Different approaches to bed management
- 135. Early data from the project sites suggest that these interventions may reduce length of stay as well as increasing the quality of care.
- 136. Similarly, work undertaken by NHS Improvement on emergency admissions in people with cancer and in a number of acute hospitals in redesigning emergency care has shown four winning principles associated with improvements in quality and reducing unnecessary hospital length of stay:
  - Unscheduled emergency patients should be assessed by a senior clinician prior to the decision to admit
  - People should have a clear, authoritative management plan within four hours of admission with inpatient pathways based on the individual underlying clinical needs relating to cancer and co-morbid conditions
  - Clinical decision making and senior review should be made on a daily basis to promote proactive case management
  - Individuals and their carers need to know about their condition and symptoms and encourage self-management and to know who to contact when needed
  - The application of these principles resulted in a 25% reduction in beds days/length of stay.
- 137. There is other evidence that increasing the frequency of consultant ward rounds, in this case changing from twice weekly to twice daily consultant ward rounds, reduces average length of stay by half with no increase in mortality or readmissions.<sup>52</sup> The case

for seven day care is supported by important research, that has backed up previous studies in showing that people in the NHS admitted to hospital at the weekend have a lower chance of survival than those admitted during the normal working week.<sup>53</sup>

- 138. Specialist respiratory assessment on referral would ensure that people with COPD are dealt with in a pathway that is most appropriate to meet their clinical needs. Evidence from a UK audit of management of COPD exacerbations in secondary care has shown that outcome is improved in hospitals where specialist respiratory physicians are present.<sup>54</sup> Thus people require assessment by medical teams with experience in the management of respiratory failure in COPD. The National COPD Audit 2008 showed that only 50% of people admitted with an acute episode of COPD were under a respiratory team at the time of discharge from hospital.<sup>55</sup> In order to achieve the improved outcomes described above the majority of people with COPD as a prime should be under the care of a respiratory team. These principles will be tested with the piloting as part of the NHS Improvement Lung programme
- 139. During the admission, the opportunity should be provided for education and review of the management of people's COPD by the specialist respiratory team. This is to ensure that:
  - Treatment remains optimal and the impact on progression of the disease is minimised;
  - Opportunities to promote and engage people still smoking in stop smoking programmes are maximised;
  - There are clear discharge plans in place including the early engagement and involvement of social care agencies if appropriate;
  - Continued improvements in the length of stay are made and subsequent readmission rates are made.

### Ensure prompt assessment on admission to hospital, including blood gas analysis and provision of NIV within 1 hour of decision to treat being made, where clinically indicated

- 140. NIV through a nasal- or face-mask has been shown to reduce mortality, tracheal intubation and complications associated with invasive ventilation.<sup>56</sup> The use of NIV has also been shown to be highly cost-effective.<sup>57</sup>
- 141. According to the NICE clinical guideline for COPD, people with acute respiratory failure should be identified and investigated promptly and treated with NIV and controlled oxygen therapy usually as the first choice therapy.<sup>58</sup> In view of the dangers of hypercapnia in these people, any supplemental oxygen therapy must be controlled during admission.<sup>59</sup>
- 142. NIV can be provided on specialist respiratory wards with appropriately trained staff and thus does not require intensive care admission. Facilities for NIV should be available in all acute hospitals where people with exacerbations complicated by respiratory failure are managed.
- 143. Those requiring invasive ventilatory support should be managed jointly by the critical care team and the respiratory specialist team. Equitable access to intensive care for all people with COPD should also be provided.

- 144. If not previously established, wishes should be sought about:
  - Accepting therapy with ventilatory support
  - Preferred place of care in conjunction with hospital based pathways such as the Liverpool care pathway
  - Advanced directives regarding escalation of care
- 145. Any earlier decisions should be reviewed in the light of the current condition of the person and with open and honest communication.
- 146. Those people with respiratory failure not suitable for ventilatory support should be offered and supported with appropriate end of life care plans (see paragraphs 175 182), with recognition of the individual's and their relatives' wishes, which take into consideration cultural and religious end of life care requirements.

#### Support post-discharge

#### What the NHS can do to improve outcomes:

- Ensure all people with COPD are assessed for suitability for an Early Supported Discharge Scheme
- Ensure that people admitted to hospital with an exacerbation of COPD are reviewed within 2 weeks of discharge

### Ensure all people with COPD are assessed for suitability for an Early Supported Discharge Scheme

- 147. Early discharge schemes or hospital at home can prevent hospital admission, and provide the person and carer with all the support they require.<sup>60</sup> A more structured and systematic approach to any admission, similar to approaches in other respiratory diseases such as cystic fibrosis or following acute myocardial infarction, would help to ensure that any hospital stay results in optimal assessment and treatment from specialist respiratory professionals, a potential reduction in length of stay and subsequent readmission rates.
- 148. The National COPD Audit 2008 showed considerable variation in length of stay for an acute exacerbation of COPD with a median stay of six days.<sup>61</sup> The audit showed that approximately 25% of hospitals had no Early Supported Discharge Scheme. Those health systems with the lowest bed use had both a shorter length of stay as well as fewer people with COPD admitted to hospital, with no increase in mortality. It is clear from this data that there are community and hospital length of stay initiatives that could alter it. Such models of early supported discharge and integrated care have been pioneered by the IMPRESS.<sup>vii</sup>

## Ensure that people admitted to hospital with an exacerbation of COPD are reviewed within two weeks of discharge

149. Readmissions are a significant problem in COPD. Of all emergency readmissions to hospital, COPD is the fifth most common cause, and at any one time, around a third of

<sup>&</sup>lt;sup>vii</sup> IMPRESS is a joint initiative between the two leading respiratory clinical societies in the UK: the British Thoracic Society and the Primary Care Respiratory Society (PCRS)-UK.

all people admitted as an emergency with COPD have been treated in hospital for the same condition within the previous 30 days.

- 150. The Respiratory Atlas of Variation has shown a three-fold variation in readmissions between PCTs across the country from 10% to over 30%.<sup>62</sup> So for someone discharged from hospital after a COPD exacerbation, the risk of being readmitted within one month can be up to three times greater depending on where they live.
- 151. Some readmissions are necessary and unavoidable: a small number will be due to new clinical problems and some will result from complications that could not be avoided. But the wide variation in performance suggests that many readmissions could be prevented through better management during the first stay in hospital and better care following discharge.
- 152. It is likely that PCTs achieving lower readmission rates are doing so by ensuring that the care provided to those admitted during a COPD exacerbation is proactive, integrated and comprehensive. The NICE Quality Standard for COPD recommends that people admitted to hospital with an exacerbation of COPD are reviewed within two weeks of discharge. It is likely that the review will want to consider therapy optimisation (including stopping smoking and exercise) out of hospital to help people recover and stay well. PR should be offered to all people with COPD requiring admission since it prevents functional decline, improves physical capacity, improves self-management and prevents readmission.
- 153. Given the impact of exacerbations on the progressive nature of COPD, they should all be followed with a review when clinically stable to ensure treatment remains optimal and any residual or changed symptoms are dealt with promptly. After severe exacerbations, individuals may require a further course of PR, especially the exercise component.
- 154. There should be effective communication between all involved in the care of the person with COPD following a review after an exacerbation. Particular problems arise with medications (including oxygen therapy) following hospital admission. Strategies to improve communication include appropriate and prompt communication of discharge summaries and the use of paper-based or IT-based patient-held records.
- 155. Some people will manage their own exacerbations either with increased inhaled medication if the exacerbation is mild in severity or with oral corticosteroids and/or antibiotics if the exacerbation is more severe, according to their individual care plan. People who are able to self-manage their exacerbations should receive clear instructions on how to make contact with a healthcare professional in the event of failure of therapy.
- 156. Transfer of information is required between all health and social care professionals and informal carers involved in the acute care of people with COPD with the development of shared records. How this can be improved and streamlined will be explored together with potential solutions as part of the work of the NHS Improvement Lung programme.
- 157. Where people have managed their COPD exacerbation themselves, they should inform a healthcare professional, ideally within two days of the start of exacerbation therapy. In

these circumstances, their care plan and self-management plan need to be reviewed within six weeks of the onset of symptoms of exacerbation.

## DOMAIN FOUR: Ensuring that people have a positive experience of care

- 158. This Domain reflects the importance of providing a positive experience of care for people with COPD and their carers. It is important that it is not just the clinical interventions that are of a high quality for people with COPD, but also the compassion, dignity and respect with which they are treated, and the extent to which they are given the level of comfort, information and support they require. It is also important in a positive experience of care for people with COPD to feel they are partners in their care, and that there is 'no decision about me without me'.
- 159. COPD is the cause of death for approximately 23,000 people a year but they receive far less palliative care input as an essential part of their ongoing disease management than in other disease areas. In the UK, people with severe COPD have a five year survival rate of 24% to 30%, and this prolonged trajectory towards death can affect the bereavement experience of those left behind.
- 160. Ensuring people with COPD have a positive experience of care needs to extend across the whole pathway of care until the end of life.
- 161. There are three key approaches that the NHS can take to ensure people with COPD have a positive experience of care. They are:
  - i. *Empower people with COPD by providing information and education* offering information and support throughout their care
  - ii. Assess psychosocial support and social care needs and refer for additional support to facilitate reablement and independent living
  - iii. Assess palliative care needs and referring for additional support
- 162. The table below sets out the key actions and interventions the NHS can do to ensure these steps are taken, so people with COPD have a positive experience of care.

DOMAIN FOUR: Ensuring that people have a positive experience of care					
NHS Outcomes Framework In		<ul> <li>Pati</li> <li>Pati</li> <li>Imp thei</li> </ul>	ient experience of primary care ient experience of hospital care proving the experience of care for people at the end of ir lives (indicator still in development)		
Outcomes Strategy for COPD and Asthma		Objective right throu	4: To enhance the quality of life for people with COPD igh to the end of life		
NIC Sta	E Quality ndard for COPD	Statement	s 2, 7, 13		
	Empower throu information	ugh	Assess psychosocial support and social care needs	Assess palliative care needs	
Why does the NHS need to act?	Knowledge empowers people to manage their own health if their information needs are addressed and delivered in a format the person can understand		A significant proportion of people with COPD also have depression and/or anxiety disorder Many people with severe COPD have significant social care needs which are variably addressed but are critical to their effective reablement	20% of people with COPD in the last year of life did not know they might die Carers are often involved for many years in the care and management of the person with COPD they care for which can impact on their bereavement experience	
What can the NHS do to improve outcomes?	Ensure all people with COPD are offered personalised information, with support to understand it, at key points throughout their care, which enables them to make choices and to fully participate in shared decision making		Assess the psychosocial needs of people diagnosed with COPD and ensure people identified with psychosocial needs are referred for appropriate treatment and support	Ensure that people with COPD who have an FEV1 < 30 predicted, frequent exacerbations or a history of NIV, are assessed for end of life care needs Ensure people identified with end of life care needs are referred for appropriate treatment and support	

163. More background and detail on the actions and interventions in Domain Four is given below.

#### Empower people with COPD by providing information and education

#### What the NHS can do to improve outcomes:

• Ensure all people with COPD are offered personalised information, with support to understand it, at key points throughout their care, which enables them to make choices and to fully participate in shared decision making

## Esure all people with COPD are offered personalised information, with support to understand it, at key points throughout their care, which enables them to make choices and to fully participate in shared decision making

- 164. 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.
- 165. *Liberating the NHS: An Information Revolution'* set a vision for care where:
  - People 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.
- 166. 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.
- 167. As a routine part of their practice, healthcare professionals should support and encourage self-care, signposting people to reputable information sources such as information prescriptions, voluntary organisations (such as the BLF and Asthma UK), and other resources such as 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 and/or carers. Information prescriptions are an important means of providing this information.<sup>63</sup>
- 168. Education and information on these topics need to be provided to people on diagnosis, and then on an ongoing basis at cyclical reviews. The following ways support service providers and people through information:
  - Information available via the internet (including NHS Choices)<sup>64</sup>
  - The Expert Patient programme

- Information prescriptions
- Information provided by third sector organisations, such as the BLF and Asthma UK
- 169. *'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 treatment;
  - Which organisation delivers treatment and care;
  - Which team delivers the treatment; and
  - What form of clinically appropriate treatment to have.
- 170. 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.
- 171. Supporting people with COPD to participate in shared decision making is an essential part of their care see Box 9 below.

#### Box 9: Shared decision-making

Shared decision-making is essential for everyone who provides or receives health services. It offers a more empowering, adult-adult relationship which helps give people "the care they need and no less, the care they want and no more" by:

- Improving the satisfaction, experience, knowledge of people using the healthcare service;
- Helping people make healthcare choices aligned with their personal needs, values and circumstances ;
- Improving clinical outcomes and safety;
- Improving clinical safety;
- Achieving the right intervention rate and reducing unwarranted practice variation;
- Reducing litigation costs.

The aim of the National Shared Decision Making (SDM) Programme is to embed SDM in routine NHS care. This is part of the wider ambition to promote personcentred care, to increase choice, autonomy, involvement and empowerment in clinical decision making and make 'no decision about me without me' a reality. The SDM Programme is part of the Quality Improvement Productivity and Prevention (QIPP) *Right Care* Programme, led by NHS East of England, and comprises three workstreams:

- Workstream 1: Developing a suite of Patient Decision Aids (PDAs) and related tools, together with (Patient Decision Support PDSs) (e.g. telephone coaching);
- Workstream 2 : Embedding PDAs and SDM in routine NHS Systems

(commissioning and provision);

• Workstream 3: Creating a receptive culture among physicians, patients and the general public for SDM.

For commissioners struggling to manage the inexorable demand for healthcare, shared decision making provides a new paradigm where demand is managed by informed and empowered people making informed decisions about their care - making the right decision for them and for society. However, in order to achieve this significant cultural shift in the NHS, not only clinicians but also patients, carers and the public will have to take up healthcare leadership positions and work in partnership with their clinical and managerial leadership colleagues. This puts SDM, not only at the patient care level but also at the strategic and commissioning level with patients, carers and the public involved in the co-design, co-commissioning and, indeed, co-production of healthcare.

#### Assess psychosocial support and social care needs

What the NHS can do to improve outcomes:

 Assess the psychosocial needs of people diagnosed with COPD and ensure people identified with psychosocial needs are referred for appropriate treatment and support

## Assess the psychosocial needs of people diagnosed with COPD and ensure people identified with psychosocial needs are referred for appropriate treatment and support

- 172. Various studies have shown that a significant proportion of people with COPD have depression and/or anxiety disorder.<sup>65 66</sup> Recognising 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.
- 173. 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 PR/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.<sup>67</sup>
- 174. In order to better inform the NHS in this area, methods for identifying those people with COPD who have more severe needs and who require intervention and for embedding CBT principles more broadly into ongoing assessment and review as well as in PR programmes will be reviewed and where possible incorporated into pilot projects being undertaken by the NHS Improvement Lung programme.

#### Assess palliative care needs

What the NHS can do to improve outcomes:

- Ensure that people with COPD who have an FEV1 < 30 predicted, frequent exacerbations or a history of NIV, are assessed for end of life care needs
- Ensure people identified with end of life care needs are referred for appropriate treatment and support

Ensure that people with COPD who have an FEV1 < 30 predicted, frequent exacerbations or a history of NIV, are assessed for end of life care needs

### Ensure people identified with end of life care needs are referred for appropriate treatment and support

- 175. COPD is a chronic progressive condition characterised by repeated exacerbations and a gradual deterioration in lung function. People may die acutely during an exacerbation or after a period of terminal decline. Because of the chronic nature of the condition, the terminal phase is often not detected by clinicians until death is imminent. As a result, people who are dying, and their carers, frequently do not receive appropriate care.
- 176. A study in 2005 found that in the last year of life, 40% of people with COPD had breathlessness unrelieved, 68% had low mood unrelieved and 51% had pain unrelieved. At the same time, a third saw their GP less than once every three months and 20% did not know they might die.
- 177. A survey by the National Council for Palliative Care and the BTS showed that there was patchy access to specialist end of life care services. The National COPD Resources and Outcomes Project survey found that only 42% of respondents (those providing clinical services in the NHS) had formal arrangements for people to receive end of life care services for COPD.
- 178. The needs of people within the terminal phase of their disease must be recognised and services put in place. At this phase of the disease, palliative rather than disease-modifying approaches are required that reflect the person's practical, social, psychological and spiritual needs. The needs of family and carer(s) should also be assessed, and support given by suitably trained and competent health and social care professionals throughout the last phase of the person's life, and afterwards into bereavement.
- 179. GP practices have developed effective systems for providing palliative care to people with cancer. QOF currently rewards practices for maintaining a palliative care register and for conducting three-monthly multi-disciplinary reviews of people on those registers.
- 180. 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 where they 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.

- 181. The prolonged trajectory towards death in people with COPD means that carers are often involved for many years in the care and management of their relative, often an allencompassing role. Therefore, when the death eventually occurs it can affect the bereavement experience of those left behind.
- 182. The box below details what end of life care looks like for someone with COPD and their carers.

#### Box 10: End of life care support

End of life care support for people with COPD covers the following:

- a comprehensive holistic needs assessment leading to a care plan;
- active management of dyspnoea;
- active management of pain;
- identification and management of anxiety and depression;
- management of cachexia and fatigue;
- management of nausea and vomiting;
- assessment and provision of home oxygen for palliation of symptoms;
- assessment of information needs;
- choice about place of care in management of acute exacerbations;
- preference for non-invasive or invasive ventilation and DNAR ('Do not attempt resuscitation');
- religious and spiritual support;
- recognition of the dying phase, with planned and co-ordinated care;
- preferred place of end of life care and death discussed with the person and their relatives;
- social and financial support;
- advance care planning, for example using Preferred Priorities for Care;
- access to equipment; and
- support for carers, including into bereavement

## DOMAIN FIVE: Treating and caring for people in a safe environment

- 183. This Domain recognises that safety is of paramount importance in terms of quality of care and to delivering better health outcomes. As well as the more generic issues of safety that are relevant to all people being treated within the NHS, because many people with COPD are treated with oxygen and/or with steroids there are particular safety issues that need to be addressed.
- 184. There are three key approaches the NHS can take to help people have a safe experience of care. They are:
  - i. Deliver high flow and emergency oxygen safely including issuing oxygen alert cards where appropriate
  - ii. Prescribe steroids according to evidence-based guidance to avoid unnecessary harm from inhaled steroids
  - iii. Robustly risk manage home oxygen environments including risk assessment of the premises of people using home oxygen services
- 185. The table below sets out the key actions and interventions the NHS can do to ensure these steps are taken, so people with COPD are treated and cared for in a safe environment.

DOMAIN FIVI environment	E: Treating and caring for people in a safe
NHS Outcomes Framework	<ul> <li>Patient safety incidents reported</li> <li>Safety incidents involving harm or death</li> </ul>
Outcomes Strategy for COPD and Asthma	Objective 5: To ensure that people with COPD receive safe and effective care
NICE Quality Standard for COPD	Statement 9

	Deliver high flow and emergency oxygen safely	Prescribe steroids according to evidence- based guidance	Robustly risk manage home oxygen environments
Why does the NHS need to act?	30% of people with COPD receive high-flow oxygen in emergency situations without assessment – some of those will be at high risk of developing life threatening respiratory failure as a result	A significant majority of people treated with steroids are given high doses when low doses are just as effective and less risky	In the year from April 2010 to March 2011, there were 141 fires in people's homes due to home oxygen being used unsafely Four deaths were caused as a direct result of those fires
What can the NHS do to improve outcomes?	Identify individuals who would be at risk if they received high- flow oxygen Give those identified as high- risk an oxygen alert card	Prescribe steroids in accordance with evidence- based guidance Give appropriate people steroid treatment cards	Risk assess the home environment of someone receiving long-term oxygen therapy to ensure that all safety requirements are in place

186. More background and detail on the actions and interventions in Domain Five is given below.

#### Deliver high flow and emergency oxygen safely

#### What the NHS can do to improve outcomes:

- Identify individuals who would be at risk if they received high-flow oxygen
- Give those identified as high-risk an oxygen alert card

#### Identify individuals who would be at risk if they received high-flow oxygen

- 187. A proportion of people with severe COPD will develop type 2 respiratory failure. This is characterised by the presence of raised CO2 levels in the blood and the development of acidosis. Type 2 respiratory failure is often fatal and is a major cause of death in people with COPD.
- 188. Oxygen is an important therapeutic agent used in the management of COPD exacerbations and type 2 respiratory failure more generally. However, if the concentration (dose) of oxygen is too high, it can worsen the respiratory failure and cause death. It is therefore essential that the dose is carefully calibrated to the needs of the person with COPD and delivered safely.
- 189. Guidance is very clear on the use of low flow oxygen in people with COPD at risk of respiratory failure.<sup>68 69</sup> However, oxygen is often poorly controlled. People with COPD who are transported by ambulance or seen in emergency departments are frequently given high dose oxygen by staff who are unaware of the need for accurate dosing. This puts people with COPD at considerable risk.
- 190. Overall for all people receiving emergency and high flow oxygen a significant number of deaths could be prevented by delivering practical implementation of 2008 BTS guidelines and best practice learning.<sup>70</sup>
- 191. Commissioners, providers and ambulance services will need to work together on the safe delivery of high flow and emergency oxygen.

#### Give those identified as high-risk if they received high-flow oxygen an oxygen alert card

192. Risk could be minimised locally for people with COPD through the introduction of oxygen alert cards. This was proposed by patients reflecting on their experience of care during the *Consultation on a Strategy for Services for COPD* in 2010, and is also recommended in the *BTS Emergency Oxygen Guidelines* (recommendations 23 and 24).<sup>71</sup> The card would be carried by patients with severe COPD who are at risk of type 2 respiratory failure, and they would be told to show the card to the ambulance crew and emergency department staff in the event of an exacerbation. This would help ensure that the correct dose of oxygen was administered during emergency response.

#### Prescribe steroids according to evidence-based guidance

#### What the NHS can do to improve outcomes:

- Prescribe steroids in accordance with evidence-based guidance
- Give appropriate people steroid treatment cards

#### Prescribe steroids in accordance with evidence-based guidance

- 193. Prolonged use of high-dose inhaled steroids in people with COPD can lead to physical, psychological and/or behavioural side effects. Recent studies have shown that low-dose inhaled steroids can be just as effective as high-dose inhaled steroids, and are much less risky for the individual.<sup>72</sup> However, although some people do require high doses evidence shows that high-dose preparations are prescribed to people with COPD much more frequently than low-dose preparations.<sup>73</sup>
- 194. To minimise harm from inhaled steroids, the NHS should ensure that prescribing in COPD is in line with evidence-based guidance.

#### Give appropriate people steroid treatment cards

195. The NICE clinical guideline for COPD states that healthcare professionals should be aware of the potential risk of developing side effects in people with COPD treated with inhaled steroids and be prepared to discuss these with the person. In order to make clinicians and people with COPD aware of the potential side effects of high-dose steroids, and for clinicians to understand the significance of prescribing a high dose, steroid treatment cards could be issued for each individual prescribed with high-dose steroids.

#### Robustly risk manage home oxygen environments

#### What the NHS can do to improve outcomes:

- Risk assess the home environment of someone receiving long-term oxygen therapy to ensure that all safety requirements are in place
- 196. A number of people with COPD who are receiving long-term oxygen therapy continue to smoke or live in a home where smokers are present which poses risks to both the individual with COPD and others.
- 197. In the year to March 2011, there were 141 fires in people's homes due to home oxygen being used unsafely, including four deaths.
- 198. Fire services must be notified where oxygen is used or stored in a person's home, especially where any occupant of the property is a smoker. Commissioners and suppliers of home oxygen should ensure that risk assessments by the local fire service of the home environments of all people receiving long-term oxygen is an essential element of contractual arrangements to ensure that all safety requirements are in place. If necessary, the fire service will install smoke alarms and take such other precautions to minimise the risk of fire.

# Chapter 3: Improving quality and outcomes for people with asthma

199. This chapter sets out the suggested actions for the NHS to meet the asthma objective in the *Outcomes Strategy for COPD and Asthma* across all five domains of the NHS Outcomes Framework.

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 to reduce the need for unscheduled health care and risk of death

- 200. Undertaking the actions and interventions outlined in this chapter will impact on mortality rates, the quality of life of people with asthma, recovery from acute episodes, on the experience people with asthma have of the health services they use, and on safety.
- 201. Integrated services and good communication across the NHS are essential to ensure that person-centred care is provided. Evidence-based national asthma guidelines, such as the British Asthma Guideline, should be followed by all clinicians working with people with asthma. The Good Practice Guides for asthma in adults and children will be published later this year and will expand on the key points in this chapter for the NHS to address.
- 202. NICE is currently developing a Quality Standard for Asthma. This will set out aspirational, but achievable, markers of high-quality, cost-effective care to guide commissioners and clinicians on services for people with asthma. The final NICE Quality Standard is expected to be published in February 2013, and the actions in this chapter set the context on which NICE will need to develop the NICE Quality Standard.
- 203. Most deaths from asthma are preventable, and lessons should be learned from every one. The National Review of Asthma Deaths was therefore commissioned by the Department of Health in 2011, and will provide information about how and why people die from asthma, by investigating the circumstances surrounding every death. Data collection started in February 2012, and will run for 12 months. The project involves a consortium of 17 organisations and is led by the Royal College of Physicians. Results are expected in 2014.

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 to reduce the need for unscheduled health care and risk of death

		NICE Quality Standard for Asthma (to be published February 2013)				
	NHS Outcomes Framework					
	Domain 1: Preventing people from dying prematurely Domain 2: Enhancing the 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 that people have a positive experience of care	Domain 5: Treating and caring for people in a safe environment	
	Under 75 mortality rate from respiratory disease	<ul> <li>Proportion of people feeling supported to manage their condition</li> <li>Unplanned hospitalisation for chronic ambulatory care sensitive conditions (adults)</li> <li>Unplanned hospitalisation for asthma in under 19s</li> </ul>	<ul> <li>Emergency admissions for acute conditions that should not usually require hospital admission</li> <li>Emergency readmissions within 30 days of discharge from hospital</li> </ul>	<ul> <li>Patient experience of primary care</li> <li>Patient experience of hospital care</li> </ul>	<ul> <li>Patient safety incidents reported</li> <li>Safety incidents involving severe harm or death</li> </ul>	
need to act?	There are around 1,000 deaths a year from asthma, with preventable factors in up to 90% of them 80% of spending on asthma is spent on the 20% with the severest symptoms	Loss of control of asthma symptoms can lead to hospitalisation. Hospital admission rates for asthma in adults vary sixfold across the country	40% of people with asthma admitted as an emergency may have also been admitted in the last 12 months	People with asthma express a strong desire to be listened to by their doctors and want opportunities to express fears and concerns	Many people are having medication increased or changed without a thorough review of existing treatment	
the NHS do?	Prompt, accurate, quality- assured diagnosis Aim for freedom from asthma symptoms once diagnosed	Structured, ongoing management of asthma, using a shared decision making approach to achieve control of asthma	Prompt action to avoid or manage asthma exacerbations	Shared decision-making between professional and person with asthma	Optimal treatment based on a stepwise approach to prescribing	

Why does the NHS

What can

## DOMAIN ONE: Preventing people from dying prematurely

#### Prompt, accurate, quality-assured diagnosis

What the NHS can do to improve outcomes:

- Ensure clinicians diagnosing asthma have a good understanding of best practice outlined in the British Asthma Guideline, and have received adequate training in asthma management to be competent in diagnosing asthma
- Include a record of the basis for diagnosis in patient notes
- Investigate people developing asthma in adulthood for the possibility that asthma is being caused by the workplace

## Ensure clinicians diagnosing asthma have a good understanding of best practice outlined in the British Asthma Guidelines, and have received adequate training in asthma management to be competent in diagnosing asthma

- 204. Diagnosis of asthma is not always straightforward. Asthma can be confused with other lung conditions, and it is possible for people to have more than one lung condition. If there is one of the following symptoms wheeze, cough, breathlessness, chest tightness and variable airflow obstruction, then asthma should be considered as a possible diagnosis after taking a full clinical history.
- 205. It is important to diagnose asthma as promptly as possible, in order that the person receives appropriate treatment quickly. However, there is an increasingly large range of tests that can be performed, and doing more rather than fewer tests may help to reduce diagnostic uncertainty. Testing may include allergic status, lung function via spirometry or peak flow, bronchodilator reversibility, bronchial hyperresponsiveness and lung inflammation.
- 206. Diagnostic services should ensure that professionals are competent to undertake the tests and to interpret the results. The British Asthma Guideline recommends auditing the percentage of clinicians who have taken part in an asthma educational update in the last two years, to ensure that clinicians diagnosing asthma have a good understanding of best practice and have received adequate training.<sup>74</sup>
- 207. Differentiating asthma from COPD in adults can be particularly challenging, but is important in order that the person receives appropriate treatment. The main differences between COPD and asthma are set out clearly in Annex B.

#### Include a record of the basis for diagnosis in patient notes

208. It is important that the rationale for diagnosis is recorded in the patient's notes.

### Investigate people developing asthma in adulthood for the possibility that asthma is being caused by the workplace

209. If asthma develops as a result of exposure to an occupational sensitiser, then removal of that irritant may remove the symptoms of asthma completely. Access to a specialist service for occupational asthma is important to address asthma in these people.

#### Aim for freedom from asthma symptoms once diagnosed

#### What the NHS can do to improve outcomes:

- Structured management of asthma (see Domain 2 below)
- Prompt action to avoid or manage asthma exacerbations (see Domain 3 below)
- 210. The goal of asthma management is for the person with asthma to be completely free of symptoms. Many people are not achieving this, in spite of the fact that the British Asthma Guideline sets out clearly the interventions and approaches that will help to achieve good outcomes.

#### Box 11: The British Asthma Guideline defines controlled asthma as:

- No daytime symptoms
- No night-time awakening due to asthma
- No need for 'rescue' medication
- No exacerbations (i.e. acute episodes)
- No limitations on activity, including exercise
- Normal lung function
- 211. Many people with asthma are not well controlled. It was reported in 2008 that 57% of people with asthma were poorly controlled. Over 50% were having daytime symptoms more than once a week, and almost 40% were having their sleep interrupted. Results of the latest Health Survey for England indicate that 30% men and 39% of women with asthma had experienced an asthma attack in the last 12 months.<sup>75</sup>

## Box 12: There are many reasons why people may not be achieving freedom from symptoms:

- They may not have the right diagnosis
- They may not have sufficient understanding of their asthma to know how to avoid symptoms developing
- They may not have a self management plan (or asthma action plan) that enables them to monitor their symptoms and peak flow rates
- People with asthma may continue to smoke, which makes their asthma worse and makes some medication less effective
- They may not be prescribed the most appropriate medication
- They may not be prescribed the most appropriate dose of medication
- They may not take their medication as recommended
- They may take their medication, but may not have been taught to use their inhaler correctly, so do not get the maximum benefit from it
- They may not attend their GP practice for regular review
- They may have a type of asthma that is very difficult to control

- If they develop asthma late in life, it may be caused by a substance in the workplace, and removal of that cause may stop their asthma occurring
- The healthcare professionals looking after them may not have sufficient knowledge about asthma to help them achieve optimal control
- Healthcare professionals may not spend enough time supporting the person in understanding their asthma
- Healthcare professionals may not be adopting a management style that uses shared decision making and actively engages the person with asthma in decisions about their own care
- The person with asthma may leave hospital without being on inhaled steroids and without an appointment for follow up by GP or specialist
- The person with asthma may not be followed up by the practice after they have been to the hospital with a bad asthma attack

## DOMAIN TWO: Enhancing the quality of life for people with long-term conditions

## Structured, ongoing management of asthma, using a shared decision making approach

What the NHS can do to improve outcomes:

- Carry out regular structured reviews to ensure that control of symptoms is achieved
- Support self-management and include an up-to-date personalised care plan in patients' notes, with evidence of a written asthma action plan
- Offer support to stop smoking
- Stratify GP practices' asthma registers according to people's risk of an attack or of losing control
- Ensure specialist services are available for those who need them

#### Carry out regular structured reviews to ensure that control of symptoms is achieved

- 212. Proactive structured review has been shown to improve clinical outcomes such as reduced exacerbations and fewer days lost from normal activity. An annual review should be regarded as a minimum level for good quality care in primary care, although people with asthma may seek consultations more frequently than this, or clinicians may decide that more regular review is required for some individuals. There is no evidence for better or worse outcomes according to whether the person with asthma is reviewed by a doctor or nurse, but the evidence does show that clinicians with specific training in asthma care deliver improved outcomes in asthma.
- 213. Structured regular review, a personalised care plan, an asthma action plan and supportive education in the context of shared decision making are all key elements in a structured approach to asthma care. Many of these are key components in any long-

term condition, where people are having to manage their condition on a daily basis – taking their medication and avoiding exacerbations.

- 214. The British Asthma Guideline recommends that a structured regular review should comprise:
  - An assessment of symptom control using a recognised assessment tool, such as Royal College of Physicians (RCP) three questions, Asthma Control Questionnaire or Asthma Control test – included in the Quality and Outcomes Framework from April 2012
  - Lung function test using spirometry or peak flow measurement
  - Record of exacerbations, oral steroid use or time off school or work
  - Checking inhaler technique
  - Adherence to treatment, from repeat prescription information
  - Checking frequency of use of short acting bronchodilators which may indicate suboptimal control
  - Adjustment of medication as necessary
  - Education about asthma, how to recognise loss of control, and what action to take
  - Creation or review of written asthma action plan

### Support self-management and include an up-to-date personalised care plan in patients' notes, with evidence of a written asthma action plan

- 215. People need to be helped to live with their long-term condition and supported to make decisions that are right for them, and there is considerable evidence that a shared decision making approach is the best way to achieve this. A consultation needs to encompass information sharing, discussion of the individual's goals and a mutual agreement about treatment and how to avoid exacerbations. A comprehensive personalised care plan should be drawn up from the discussion and reviewed on a regular basis.
- 216. There is good evidence that written action plans lead to improved outcomes. So an output of the care planning discussion in a review session should be a written asthma action plan which the person can take away with them, to guide their self management. This should help people identify when their asthma is starting to get out of control and two or three action points such as what to do if their asthma deteriorates and when to seek emergency help. The written plan should arise from a structured educational discussion checking that the person understands their condition and how to use their medication.

#### Offer support to stop smoking

217. People who have asthma and continue to smoke are likely to have worse outcomes. Smoking adversely affects quality of life, lung function, and the need for rescue medications for acute episodes of asthma. Smoking has been shown to reduce the efficacy of inhaled steroids. All people with asthma should be encouraged to stop smoking, and given appropriate support to do so.

### Stratify GP practices' asthma registers according to people's risk of an attack or of losing control

- 218. In contrast to COPD, many people with asthma are at Level 1 of the long-term conditions pyramid (see paragraph 95), and can be managed effectively with a personalised care plan, support for self management, a written asthma action plan held by the person themselves, appropriate medication and an annual review within the GP practice. Some people with asthma may be at Level 2 and require more intensive and proactive management in order to keep their asthma under control. A relatively small proportion will be at Level 3, and have asthma that is so difficult to manage that they need to have their care supervised by specialists, in conjunction with a multidisciplinary team.
- 219. Most people with asthma should regard their GP practice as the primary source of support and treatment, and continuity of care in primary care is a key component of good asthma care for the majority of people with asthma.
- 220. All GP practices should have an asthma register which enables them to track their contact with people with asthma, and it makes sense to stratify people with asthma according to risk since some people's need for proactive, intensive input may be greater than others, and may help to keep their asthma under control. It will also help in identifying people with asthma who are the greatest users of NHS resources.

#### Ensure specialist services are available for those who need them

- 221. Commissioners should be aware that while most care for asthma is led by primary care, there is also a need for some specialist support.
- 222. There is an allergic component to some asthma. Understanding and management of the allergic component is key to ensure that asthma is well controlled. People may need to be referred to a specialist allergy centre to be investigated fully in order that they can manage their sensitivity to certain substances or situations. Specialist allergy centres are not evenly distributed across the country resulting in inequitable access, and this needs to be addressed through local commissioning.
- 223. People with severe asthma or asthma that is difficult to manage need support from specialist services which provide care from a multidisciplinary team, comprising specialist doctors and nurses, psychological support, social care and allergy services. Again, such services are not evenly distributed across the country.
- 224. As young people who have regular contact with hospitals move into their late teens, they move from the care of paediatricians to the care of adult specialists. Since most people develop asthma in childhood, the process of transition is an important one which both paediatricians and adult specialists need to engage with in order to make the transition as smooth as possible for the young people concerned. Young people also need to have the opportunity to be seen on their own, without parents or carers, as they move into adolescence and take responsibility for their asthma.

## DOMAIN THREE: Helping people to recover from episodes of ill health or following injury

#### Prompt action to avoid or manage asthma exacerbations

What the NHS can do to improve outcomes:

- Provide the right care in the right place at the right time
- Provide rapid access to specialist care when needed
- Follow up and review with person with asthma following hospital attendance or admission

#### Provide the right care in the right place at the right time

- 225. Loss of control of asthma results in an acute attack or exacerbation, which needs urgent treatment. The best defence against loss of control of asthma is an individual who understands their condition, is able to identify when they are starting to lose control of their asthma, and is able to take appropriate action by adjusting their medication or seeking medical help. This is the aim of regular review, developing a personalised care plan, supported self management guidance and a written asthma action plan. People should be encouraged to identify loss of control of their asthma early and to seek help to regain control in order to avoid hospital attendance or admission
- 226. Not all acute attacks need to be managed in a hospital setting. GP practices or other community settings could provide appropriate care but would need to have systems in place to ensure that people were able to access urgent care immediately from clinical staff with asthma training. Attention should be given to the quality of out of hours care services commissioned and their ability to cope effectively with asthma attacks.
- 227. Acute care of asthma is extremely expensive and it is therefore widely cited that poor asthma care is more expensive than good quality asthma care.<sup>76 77</sup> Many emergency department attendances and acute admissions for asthma are the result of deterioration of control for six hours or more, and sometimes several days or nights previously, so could be avoided by people taking earlier action.<sup>78</sup> The Atlas of Variation highlights enormous variation between PCTs in the rates of admission for acute asthma attacks around the country as much as sixfold for adults and 25-fold for children.<sup>79</sup>. Studies have shown that as many as 40% of emergency department attenders may have been admitted in the previous 12 months.<sup>80 81</sup>
- 228. Acute attacks which are life threatening do need to be treated urgently in a hospital setting, and the British Asthma Guideline describes clearly what the features of acute severe asthma or life threatening asthma are.
- 229. Early warning of environmental factors which may precipitate a worsening of asthma control may be of value to people with asthma. People with asthma are not necessarily more sensitive to such factors, but, if affected, may wish to adjust their treatment in line with their asthma action plan.

- 230. An acute exacerbation presents an opportunity for intensive input to someone with asthma to restore control of their symptoms and lung function, and educational input in order that they can avoid a recurrence of poor control. They may be particularly receptive to learning about their asthma, and what has triggered an attack. Hospital staff should therefore ensure that the person leaves with an asthma action plan, as a core part of the strategy to avoid further acute events. This has been identified as an area of weakness in the BTS acute asthma audit <sup>82</sup>and respiratory and emergency departments should work together to address this issue.
- 231. It is important that when an asthma exacerbation results in a hospital admission, there is good communication between respiratory departments and emergency departments, and that treatment given in emergency departments follows guidance set out in the British Asthma Guideline.

#### Provide rapid access to specialist respiratory care when needed

- 232. The components of good care for acute exacerbations are clearly set out in the British Asthma Guideline. The focus is on restoring lung function and controlling symptoms.
- 233. Nebulised treatment used to be widely used in the care of acute attacks, but it is now recommended that a short-acting bronchodilator delivered via a metered dose inhaler and spacer device is usually preferable, unless the attack is actually life-threatening. Use of nebulisers may also encourage people to be over-reliant on hospital care, whereas use of a spacer achieves equivalent results and can be delivered anywhere. When an asthma attack is life threatening and nebulised bronchodilator treatment is appropriate, it should be administered with an oxygen-driven nebuliser, not an air-driven one, for safety.

### Follow up and review with person with asthma following hospital attendance or admission

- 234. Follow-up with people with asthma after an acute exacerbation requiring hospital care is a weakness of many asthma services. The BTS audit of adult asthma in 2010 showed that while 68.8% of people had a further hospital review within the recommended four weeks following discharge, only 37.4% were advised to attend their GP surgery within the following week, and only 39.8% of people had their action plan reviewed or were provided with an asthma action plan.<sup>83</sup>
- 235. Acute attacks should be seen as a failure of previous care, and should prompt a full review of the person's care and written asthma action plan once control has been regained, ideally both before discharge, and afterwards, either by a specialist or their practice. In some parts of the country it is believed that high admission rates may result from poor engagement of people with asthma with primary care services, and an overreliance on acute care. Every effort should be made to ensure that people are engaging with and receiving appropriate care from their GP practice. Frequent attenders in acute settings should be identified in primary care as part of the risk stratification process and appropriate personalised care plans put in place to reduce the frequency of attendance at hospital.

236. Some people with very severe asthma may need to be in the care of hospital specialists and receive the majority of care from them, but this is usually a very small group of people, with asthma that is particularly difficult to control. It is important for services to differentiate between these people and those who are relying on hospital care inappropriately.

## DOMAIN FOUR: Ensuring that people have a positive experience of care

#### Shared decision-making to manage asthma

#### What the NHS can do to improve outcomes:

- Ensure a shared decision-making approach to managing asthma
- Assess for psychosocial and mental health needs

#### Ensure a shared decision-making approach to managing asthma

- 237. People express a strong desire to be listened to by their doctors, have an opportunity to express their fears and concerns, and to hear clear explanations about their condition and its management. They wish to take control of their own condition in a supported manner and to receive adequate support as they themselves manage their own condition.
- 238. The doctor and person with asthma should work together to decide the optimal therapy, and that should be supported with appropriate follow up (which may not necessarily be face-to-face).
- 239. The shared decision-making approach should run through all of the actions and interventions described in domains 1, 2 and 3 above.
- 240. See also Box 9 in Domain 4 of the COPD chapter on shared decision-making.

#### Assess for psychosocial and mental health needs

241. Psychological conditions, such as anxiety and depression, are more common in people with asthma than in the general population, yet these needs are often under-recognised in spite of the fact that they may impact the extent of control of asthma and may lead to worse outcomes – such as increased hospital attendance. This area needs much more attention if people with asthma are to achieve freedom from symptoms.

## **DOMAIN FIVE:** Treating and caring for people in a safe environment

#### Optimal treatment based on a stepwise approach to prescribing

#### What the NHS can do to improve outcomes:

 Ensure that the stepwise approach to prescribing, as set out in the British Asthma Guideline, is being followed

### Ensure that the stepwise approach to prescribing, as set out in the British Asthma Guideline, is being followed

- 242. Routine therapies for asthma are remarkably safe and effective. Unfortunately medicines are often over-prescribed. Reasons for this needs to be explored on a case-by-case basis, and action taken to ensure that all are on the lowest dose of medication that controls their condition.
- 243. Medication should be prescribed in accordance with the British Asthma Guideline which sets out clearly a stepwise approach to the use of medicines for asthma. Since the goal of asthma care is freedom from symptoms and no night time waking due to asthma, the appropriate medication for people is the lowest dose of medication on which they can be maintained free of symptoms. Yet it is clear that many people with asthma continue to experience symptoms during the day or night. Most asthma medication is inhaled. People need to be taught how to use their inhaler devices, and inhaler technique should be checked at every opportunity. Before changing any medication, the clinician should check adherence, inhaler technique and eliminate trigger factors.
- 244. The service developments within the Community Pharmacy Contractual Framework on the New Medicine Service and Medicines Use Reviews are also relevant to asthma (see paragraphs 118-119, in the COPD chapter).
- 245. Respiratory medication is a significant cost to the NHS. Therefore ensuring that people with asthma are on the lowest effective dose of their prescribed treatment to achieve symptom control is essential in order that both people with asthma and the NHS derive maximum benefit possible, while using the prescribing budget wisely.
- 246. Prescribing records should indicate that the stepwise approach to prescribing, as set out in the British Asthma Guideline, is being followed. The Guideline recommends that people with asthma use no more than two canisters a month of short-acting bronchodilator inhalers and that no-one is prescribed a long-acting bronchodilator without an inhaled steroid.
- 247. As stated in paragraph 233, the overuse of nebulisers as a route of administration of bronchodilators may encourage people to be over-reliant on hospital care, whereas use of a spacer achieves equivalent results and can be delivered anywhere. When an asthma attack is life threatening and nebulised bronchodilator treatment is appropriate, it should be administered with an oxygen-driven nebuliser, not an air-driven one, for safety.

## Chapter 4: Links with Public Health and Social Care

#### Introduction

- 248. Where local communities want to take action to improve COPD and/or asthma outcomes in their areas, the *Outcomes Strategy for COPD and Asthma* and this *NHS Companion Document* will help commissioners and providers to design and target the most appropriate services for them. The best possible results will be achieved through the NHS, public health and social care services all working closely together. There are direct links between working towards the objectives set in the *Outcomes Strategy for COPD and Asthma* and improving outcomes across the three Outcomes Frameworks (Public Health, NHS and Social Care). Indeed the high-level indicator on mortality from respiratory disease in people under 75 is shared by both the NHS and the Public Health Outcomes Frameworks.
- 249. The new approach to local strategic planning will mean that local authorities and the NHS will agree their joint priorities and ways of improving health and wellbeing for their communities, with health and wellbeing boards making a full and independent assessment of health and social care needs of the local population in Joint Strategic Needs Assessments (JSNAs), and developing a strategy to meet the key local priorities through the Joint Health and Wellbeing Strategy (JHWS).

#### **Public Health**

- 250. As the Outcomes Strategy for COPD and Asthma set out, the areas for action in public health and prevention 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
- 251. A range of services relevant to the delivery of the objectives set out in the *Outcomes Strategy for COPD and Asthma* will in future be the responsibility of Public Health England (PHE), including public health intelligence and targetted campaigns to raise public awareness of disease and early symptoms and to encourage early presentation. Local authorities will have a new duty from April 2013 to commission services to improve the health of their populations.

- 252. Around 17% of deaths from flu each year are in people with chronic respiratory disease. People with COPD and some people with asthma<sup>viii</sup> are eligible for the seasonal flu vaccine, and should be made aware by their healthcare professionals.
- 253. Both the NHS and Public Health will be working to improve against a shared outcome measure in their respective Outcomes Frameworks on chronic respiratory disease ('Mortality rate from respiratory disease in persons less than 75 years of age'). As well as supporting the NHS to improve the treatment and care of people with COPD and asthma (thus contributing to improvements against that measure), the *Outcomes Strategy* and this *Companion Document* should also help empower local areas to develop and support strategies to tackle environmental factors that affect COPD (and therefore the Public Health Outcomes Framework outcome measure too), such as air pollution.
- 254. In the vast majority of cases lifestyle choices, such as smoking, affect 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.
- 255. 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 'COPD toolkit' published on the NHS Improvement website.<sup>ix</sup>

#### Environmental factors

- 256. Public Health England and the NHS can work with local authorities to raise awareness of the health impacts of air pollution and the need for people with COPD and asthma to protect themselves. Raising awareness can also help to support individual and community action to improve air quality. Local authorities have responsibility to assess local air quality and to reduce pollution where this does not meet national objectives for health pollutants. With the new approach to public health delivery there are opportunities for public health to work with local authorities to influence strategies to improve air quality and to support local action to reduce pollution where this is a local priority.
- 257. For example, joint communications and local awareness raising on air quality can help to raise understanding of local air quality risks and what action can be taken by individuals to reduce exposure and to improve air quality. Examples of initiatives include:
  - Promoting healthy travel options (walking, cycling, greater and better use of public transport) e.g. Derbyshire has a 'Wheels to Work' scooter or bicycle loan scheme

<sup>&</sup>lt;sup>viii</sup> that requires continuous or repeated use of inhaled or systemic steroids or with previous exacerbations requiring hospital admission.

ix http://www.improvement.nhs.uk/lung/LinkClick.aspx?fileticket=po5wWd-LFuk%3d&tabid=162

for those living in areas (often deprived) from which it is difficult to access training, employment, educational or other vital services.

- Promoting a 'joined up' travel planning e.g. walking and catching the bus rather than making the entire journey by car, or advertising the best way to get to medical centres/hospitals by foot/public transport. Providing local travel information in medical waiting rooms.
- Promoting local greenway and low pollution routes (walkit.com provides advice on low pollution routes in cities)
- 258. The weather can also affect those with lung disease:
  - In winter, cold air may cause a narrowing of the airways (bronchoconstriction), increasing symptoms of breathlessness.
  - In winter, there is a general increase in the number of chest infections, often caused by an increased circulation of viruses that are the major cause of exacerbations and which account for increased hospital admissions during the winter months.
  - In summer, air pollution, heat and humidity can cause breathing difficulties.
- 259. This means that changes of temperature and other aspects of the weather, such as humidity and air pollution, may worsen symptoms of lung disease and lead to exacerbations, especially in cold winter weather. At such times the need to ensure that treatment is optimal and symptoms remain well controlled is paramount.
- 260. The Department of Health has published a *Cold Weather Plan for England* which sets out a series of clear actions triggered by a Met Office alert system. These actions are to be taken by the NHS, social care and other public agencies professionals working with vulnerable people as well as by individuals and local communities themselves designed to minimise the effects of severe cold weather on health. People with underlying health conditions (such as COPD) are one of those groups considered to be particularly vulnerable in the Plan.

#### Social care

- 261. Working with public health and the NHS, adult 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.
- 262. Through improved and strengthened partnership working the NHS, public health and social care services can ensure individuals with respiratory disease maintain good health and wellbeing. This will include timely intervention to prevent avoidable ill health through re-ablement or intermediate care services, early intervention and supported discharge from hospital to help reduce repeat emergency admissions and also support carers in care planning arrangements.
- 263. The NHS can work with social care on the actions described in Domain 2 and 3 in both the COPD and Asthma chapters above, to develop future models of care, shifting balance away from over reliance on acute sector provision and strengthening community, prevention and early intervention models of care and support. This would help to reduce admissions and length of stay in hospital.

264. In the future, commissioning arrangements, health and wellbeing boards will identify local health and social care needs through JSNAs and strategic priorities aimed at addressing those needs will be agreed in the JHWS. JSNAs identify local health and social care needs and JHWSs will identify areas for priority action – both will underpin local commissioning plans. Health and wellbeing boards will have a duty to involve users and the public in the JSNA and JHWS process; 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.
# Chapter 5: Levers for change

265. There are various levers and tools that commissioners, providers and health and social care professionals can make use of to foster the sort of improvements in COPD detailed in Chapter 2, and for asthma in Chapter 3.

#### **Quality and Outcomes Framework**

266. The Quality and Outcomes Framework (QOF) is the annual reward and voluntary incentive programme detailing GP practice achievement against specific indicators. Since its introduction in 2004, the QOF has included indicators related to the identification and management of COPD, and asthma, to incentivise high quality management and care by GP practices.

#### COPD

- 267. NICE is currently 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)

#### Asthma

- 268. NHS Employers and the British Medical Association (BMA) have recently agreed an indicator which became effective from April 2012, 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 includes an assessment of asthma control using the RCP 3 questions
- 269. NICE is also currently considering indicators for inclusion in the menu for the 2013/14 QOF. For asthma, these are:
  - 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

or

- 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.
- 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

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

#### NICE Quality Standards, clinical guidelines and commissioning guidance

#### COPD

#### NICE Quality Standard

- 271. The NICE Quality Standard for COPD 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 NICE Quality Standard focusses on management and treatment of diagnosed COPD, and is framed explicitly as addressing this territory. Its content is based on NICE's existing clinical guideline, reflects acknowledged good clinical practice and on the issues it covers is consistent with the *Outcomes Strategy for COPD and Asthma*. However, not all those with COPD are receiving services that meet these standards, and the NICE Quality Standard for COPD will be valuable in supporting improved quality of care for this group of people.
- 272. The NICE Quality Standard for COPD, the *Outcomes Strategy for COPD and Asthma* and this *NHS Companion Document* 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.

#### NICE clinical guideline for COPD

- 273. NICE published updated guidelines on the *Management of chronic obstructive pulmonary disease in adults in primary and secondary care* in 2010.
- 274. Wherever possible we have ensured that there is consistency between NICE's recommendations and the contents of this document. The NICE clinical guideline can be found at: <u>http://www.nice.org.uk/Guidance/cg101</u>

#### NICE Commissioning guidance

275. NICE commissioning guides provide support for the local implementation of NICE guidance through commissioning, and are a resource for people involved in commissioning health and social care services and public health programmes within the NHS and partner organisations in England.

- 276. NICE published a commissioning guide on services for people with COPD in October 2011, to assist commissioners, clinicians and managers to commission high quality and evidence-based services across England.
- 277. This NICE guide will be complementary to the Department of Health's Commissioning Toolkit on COPD that will be published shortly, and is also consistent with the NICE clinical guideline for COPD.
- 278. The commissioning guide can be found at: <u>http://www.nice.org.uk/usingguidance/commissioningguides/copd/copd.jsp</u>

#### Asthma

#### NICE Quality Standard

279. NICE have begun work to develop a Quality Standard for Asthma, and it is anticipated that it will be published in February 2013.

#### Clinical guideline

- 280. The *British Guideline for the Management of Asthma* was first developed in 2003 as a joint initiative between the Scottish Intercollegiate Guidelines Network (SIGN) and the BTS, building on the separate guidelines produced by each organisation prior to this. NHS Evidence accredited this guideline in 2012, which means that it has the same status as guidelines developed by NICE. Sections of the guideline are updated annually, based on whether new evidence has become available. The section on pharmacological management is updated most frequently. It is regarded as a comprehensive and authoritative guide to high quality management of both acute and chronic asthma, and covers evidence-based best practice for both childhood and adult asthma.
- 281. The latest version is the 2008 edition which was further revised in 2012.
- 282. The latest guideline is available here: <u>http://www.brit-</u> <u>thoracic.org.uk/Portals/0/Guidelines/AsthmaGuidelines/sign101%20Jan%202012.pdf</u>

#### Atlas of variation

- 283. The NHS Atlas of Variation is a practical tool to help commissioners increase the value and improve the quality of the service they commission through identifying and tackling unwarranted variation in care. It uses maps and graphs to communicate graphically variations in activity and expenditure in a number of clinical areas across the country and contains suggested best practice options for action and further resources to help tackle local variation.
- 284. The Atlas currently includes an indicator on COPD bed days ('emergency bed-days per 1000 population'). The latest data show a fourfold variation among PCTs in emergency bed-days per 1000 population weighted by COPD prevalence.
- 285. A respiratory-themed Atlas of Variation is planned for July 2012. The substantial variation across a range of indicators illustrates the potential to improve outcomes. For

example, after adjusting for deprivation and need, there is a twofold variation between PCTs in prevalence recording, in-patient spend and mortality.

#### Commissioning for Quality and Innovation (CQUIN) payment framework

286. The CQUIN payment framework enables commissioners to reward excellence, by linking a proportion of English healthcare providers' income to the achievement of local quality improvement goals. Since the first year of the CQUIN framework (2009/10), many COPD and asthma CQUIN schemes have been developed and agreed locally.

#### Box 13: Case study - North East COPD Discharge Bundle CQUIN

The COPD discharge bundle is a group of evidence-based items that should be delivered to all patients being discharged from the hospital following an acute exacerbation of COPD. The bundle includes:

- Smoking cessation assistance offered to all smokers
- Assessed for suitability of pulmonary rehabilitation
- Self-management support offered including self-management plan, rescue packs, Breathe Easy, and oxygen alert cards as appropriate
- Assessment of satisfactory use of inhalers demonstrated and understood
- Follow up arrangements made with a respiratory specialist within one month of discharge and given to patient.

The discharge bundle aims to improve quality of care, patient experience and minimise the risk of re-hospitalisation. To ensure the bundle can apply to all, a combination of actions and documents to facilitate the discharge process were developed.

The North East Joint Respiratory Leads have been successful in implementing the COPD discharge bundle CQUIN across 75% of their Foundation Trusts.

#### Payment by results

- 287. Payment by Results (PbR) is a system of national prices for activity commissioned by the NHS. It covers around a third of total NHS spend and currently mainly covers acute admissions, outpatients and A&E attendances.
- 288. As part of PbR rules hospitals are not paid for avoidable emergency readmissions. Commissioners are required to invest any savings from the non-payment of readmissions into services to help avoid readmissions. As many readmissions occur in people with long-term conditions such as COPD, this policy has the potential to improve the care of people with COPD and help avoid unnecessary admissions to hospital.
- 289. The QIPP programme are also looking to develop a 'year of care' capitated funding model for long-term conditions which facilitates the delivery of integrated health and social care based on their underlying need, not just predominant disease. These people will be identified through risk profiling the GP population and by using a national

assessment and classification system grouped according to their need. Work to develop this will be taken forward with six whole system Early Implementers. An advert to seek Expressions of Interest was placed in the Department of Health's The Week 19<sup>th</sup> April 2012.<sup>84</sup>

#### Patient-reported outcome measures (PROMs)

- 290. Patient-reported outcome measures (PROMs) have been used in the NHS since 2009 to assess health outcomes of four elective surgical procedures. For these four procedures, patients are asked to fill in one short questionnaire about their health and quality of life before the operation, and another about their health and the effectiveness of the operation after it. The results help the NHS measure and improve the quality of its care.
- 291. A pilot is currently being carried out for the Department of Health to assess whether PROMs could be used for long-term conditions treatment and care. COPD and asthma are two of six long-term conditions being looked at in the pilot.
- 292. The results of the pilot, together with some estimation of costs, will inform Department of Health decisions about whether PROMs are an acceptable way of involving the public and measuring health outcomes of the NHS on a large, national scale in individuals with one of these conditions.

# **Chapter 6: Implementation support**

#### Introduction

- 293. 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. However, it is up to the NHS, working with local authorities, voluntary organisations, business, and the public to ensure that the objectives of the *Outcomes Strategy for COPD and Asthma* are achieved.
- 294. Implementation of the *Outcomes Strategy* will be supported in 2012/13 by the joint National Clinical Directors, NHS Improvement Lung and respiratory leads appointed to each Strategic Health Authority (SHA). The respiratory leads will need to consider how they can best align themselves with the new structures and arrangements during transition. Assessing progress on delivery of this *Outcomes Strategy* during transition and beyond will be important. As agreed with the respiratory leads locally, they will each publish an annual report at the end of 2012/13 to measure progress on implementation and on improving outcomes so far.
- 295. After 2012/13, the NHS Commissioning Board will review the architecture of support for implementation.

#### **National support**

#### **National Clinical Directors**

296. In December 2009 joint National Clinical Directors (NCDs) for respiratory disease in England were appointed. As joint NCDs, Professor Sue Hill and Dr Robert Winter have overseen the development of the *Outcomes Strategy for COPD and Asthma* and have steered the improvement of respiratory services in the NHS more widely. Their national clinical leadership provides an important overview of respiratory services in England. They will be overseeing how the implementation of the *Outcomes Strategy* progresses, and offering national level support where appropriate.

#### **NHS Improvement Lung**

- 297. The NHS Improvement Lung programme provides national support for the local improvement of respiratory services. It aims to support clinical teams, commissioners, service managers and other key stakeholders deliver effective clinical practice through process improvement and redesign.
- 298. The NHS Improvement Lung website contains a wealth of information including good practice examples, service improvement tools and relevant policies and publications.
- 299. The NHS Improvement Lung programme also oversees national improvement projects on diagnosis, transforming acute care, chronic self-management, oxygen, and end of life. The projects are aimed at testing different innovations on a small scale with a view

to determining improved ways of working which can eventually be rolled out across the NHS.

300. More information is available at: http://www.improvement.nhs.uk/lung/

#### **Regional support**

#### SHA Respiratory Clinical Leads and Programme Managers

- 301. The NHS Improvement Lung programme is also supported by clinical leads from each SHA region across the country. The clinical leads work with NHS teams in their local areas to improve respiratory services. They also provide a local oversight and support role to the different national improvement projects being trialled across the country.
- 302. Their work priorities for 2012/13 include five national priorities:
  - 1. The development and rolling out of our networks at a local level including the importance of linking into any changes locally with other network programmes including cancer and stroke
  - 2. A core data set to monitor quality and local outcomes
  - 3. Medicine usage, optimisation and prescribing
  - 4. Integrated care & QIPP including new models for management of long-term conditions and acute care
  - 5. Late Diagnosis leading to poorer outcomes
- 303. This leaves space for an additional and locally-determined priority.
- 304. The National Clinical Directors are also keen that each regional team has a designated Asthma Lead to make progress in this area. This is in anticipation of the NICE Quality Standard for Asthma which is expected to be published in February 2013.
- 305. They will publish an annual report setting out what action has been taken locally to deliver on the above objectives.

#### Partnership with industry

- 306. The Department of Health has established a programme of joint working with a number of pharmaceutical companies to support implementation of the Outcomes Strategy for COPD and Asthma. This draws on the 2010 DH/ABPI Guidance on Joint Working between Pharmaceutical Companies and the NHS for the Benefit of Patients. Several project areas are being explored:
  - Brand development for the Outcomes Strategy for COPD and Asthma
  - Supporting use of the work place as setting for lung health promotion
  - Supporting research into impact of COPD on work and productivity
  - Analysis and presentation of local outcome and activity data to help local leaders drive quality improvement
  - Developing education and training support for health professionals and patients
  - Using industry workforce to disseminate key *Outcomes Strategy for COPD and Asthma* messages

#### Stakeholder support

307. The implementation of the *Outcomes Strategy* will also depend on the support of many other stakeholders with an interest in seeing improvements in outcomes for people with COPD and asthma.

#### The British Lung Foundation

- 308. The British Lung Foundation (BLF) is the only charity supporting everyone affected by all the different lung diseases. The BLF works towards positive change by campaigning, raising awareness, supporting people with lung disease and their families and funding world-class research.
- 309. The BLF is working with the Department of Health to support the *Outcomes Strategy for COPD and Asthma* in the following ways:
  - By using different methods of raising public awareness of lung disease throughout the UK, aimed at helping people to identify symptoms and act on them. The charity has particular expertise in identifying people with COPD using social marketing techniques.
  - By providing patient and carer support groups, known as Breathe Easy, which are led by patients, carers, friends and supporters including healthcare professionals and supported through a regional network of the BLF.
  - By providing information through a variety of media and in a variety of languages on COPD and asthma including a helpline which is staffed by respiratory nurse specialists and welfare benefit advisers. This information has the Department of Health Information Accreditation mark and our telephone helpline is accredited with the Telephone Helplines Association.
  - By providing the BLF Nurse scheme which trains and supports specialist respiratory nurses and gives them access to the whole of the BLF support system for their patients.
  - By providing exercise maintenance opportunities through BLF Active. These sessions are taken by fitness instructors who have been specially trained in the provision of exercise suitable to people with COPD following on from pulmonary rehabilitation. The BLF also supplies an Exercise Handbook to accompany pulmonary rehabilitation and BLF Active classes.
  - By providing patient education sessions in self-management based on the BLF's extensively used COPD self management plan.
  - By training and supporting patient representatives to sit on different bodies.
- 310. As can be seen, the BLF is providing an extensive range of support services to people with COPD and asthma and would like to work with NHS bodies to improve the way in which people with COPD are supported and managed.

#### www.lunguk.org

#### Asthma UK

- 311. Asthma UK is the charity dedicated to improving the health and well-being of the 5.4million people in the UK whose lives are affected by asthma. We aim to substantially reduce the number of asthma attacks that result every day in preventable hospital admissions and deaths. We also aim to encourage the development of new treatments that will give more people control over their asthma.
- 312. We pursue our aims by funding world-class medical research, providing practical and life-saving services and giving people with asthma a strong voice in public policy and local care delivery.
- 313. Our resources for patients and health professionals have won prestigious medical awards and are independently accredited. These include a free Adviceline service 0800 121 6244), a comprehensive website, self management plans, an active Facebook site and a range of targeted materials for both adults and children with asthma and their healthcare professionals.
- 314. Asthma UK is in receipt of grants from the Department of Health to the following key projects:
  - Asthma Activists Liverpool's emergency admissions are amongst the highest in the country which is why Asthma UK has launched the Liverpool Asthma Activist Project which recruits people with good asthma management to support those with poorly managed asthma in order to improve their quality of life and reduce the number of costly, stressful and potentially life-threatening emergency admissions.
  - Local Asthma Impact Project (LAIP) in the North West of England with three Primary Care Trusts with the aim of reducing the high numbers of emergency admissions for asthma in the region.
  - Asthma UK and the North of England Strategic Health Authority (SHA) are working on a second LAIP to improve children's asthma services in one of the country's asthma hot spots. This SHA is the only one to have a specific target to reduce emergency childhood asthma admissions by 50% over ten years. Building on the experience of the first LAIP in the North West, Asthma UK is working with local clinicians in both primary and secondary care, NHS commissioners, schools and local authorities to improve asthma management.

#### www.asthma.org.uk

#### **British Thoracic Society**

- 315. The BTS is a professional body and registered charity whose members include doctors, nurses, respiratory physiotherapists, scientists and other professionals with an interest in respiratory disease. The Society had 2,780 members in August 2011.
- 316. BTS' main charitable objective is to improve the care of people with respiratory and associated disorders, which is achieved in a number of ways:
- 317. By promoting optimum standards of care and developing tools for quality improvement: treatment best practice guidelines; clinical audit tools; the development of the BTS Lung Disease Registry and the forthcoming work on care bundles;

- 318. By promoting and advancing knowledge about the causes, prevention and treatment of respiratory diseases: the Society runs a large Continuing Medical Education (CME) conference each year for a multi-professional audience, plus a range of short courses, and has developed a number of e-learning modules since 2009 (more details via the BTS Education Hub on the website);
- 319. By promoting and disseminating research (through the Winter Meeting as well as the journal *Thorax*, which is published jointly with the British Medical Journal and is the second highest ranking respiratory journal in the world.
- 320. BTS is committed to working in partnership with a range of organisations to achieve its objectives. It greatly values the IMPRESS project, which was established in 2007 with the Primary Care Respiratory Society UK (PCRS-UK) in anticipation of the need to develop good practice pointers for the provision of integrated respiratory care, commissioning advice and related issues. Two IMPRESS conferences have been well attended and the new IMPRESS Blog and presence on Twitter is attracting increasing numbers of followers each month. See <u>www.impressresp.com</u>
- 321. Also of relevance is the work that the BTS is doing in relation to smoking cessation. The British Association of Stop Smoking Professionals (BASSP) was established within the BTS in 2006. The Society was awarded a small grant by the Department of Health in 2010 to establish a network of Stop Smoking Champions in Secondary Care. The first BTS Stop Smoking Champions conference took place in October 2011, and the work plan for 2011/12 includes the development of a CQUIN for Smoking Cessation as a treatment for COPD, the revision of the *Guide to Smoking Cessation Services in the Hospital Setting* and the development of an audit tool to monitor effectiveness of the hospital-based intervention.

#### www.brit-thoracic.org.uk

#### The Primary Care Respiratory Society UK

- 322. The Primary Care Respiratory Society UK (PCRS-UK) is a membership-led charity supporting primary care health professionals. Their mission is to give every member of the primary care practice team the confidence to deliver quality respiratory care, improve the quality of life for patients with respiratory disease, and help practices hit their Quality and Outcomes Framework (QOF) and PMS contract targets as well as relevant enhance service targets.
- 323. Through practice and individual membership schemes, PCRS-UK offers a wealth of practical resources for primary care health professionals whether they are relatively new to respiratory medicine or a respiratory expert:
  - Extensive COPD and asthma resources
  - Concise, easy-to-follow summary publications
  - Tools and resources designed specifically for practice nurses
  - Help with professional development

- 324. Through their Respiratory Leaders Programme, PCRS-UK provides primary care health professionals with training workshops, policy updates as well as IMPRESS resources, to enable them to take the lead, motivate and inspire best practice within their locality.
- 325. The Primary Care Respiratory Society UK Quality Award, developed in conjunction with the British Thoracic Society, Royal College of General Practitioners, Association of Respiratory Nurse Specialists, Asthma UK, British Lung Foundation, Education for Heath and Respiratory Education UK, sets out the principles that best define high quality respiratory care in primary care, providing:
  - Recognition of practices providing a high standard of respiratory care serving as a quality assurance mark not only for patients, but also commissioning groups and the wider NHS.
  - A developmental framework that can be used at practice, locality and national level to promote, support and reward quality respiratory care in the primary care setting.

#### www.pcrs-uk.org

#### **Royal College of Physicians**

- 326. Working in partnership with the BLF and the BTS, the Royal College of Physicians has managed three rounds of National COPD Audit since 1997. The most recent audit, carried out in 2008, collected clinical and organisational data from acute healthcare settings, surveyed primary care organisations, general practices and people upon discharge from hospital following a COPD exacerbation (http://www.rcplondon.ac.uk/resources/chronic-obstructive-pulmonary-disease-audit).
- 327. The audit achieved outstanding participation from healthcare professionals and patients alike, and demonstrated significant improvements in the provision of some COPD specific services since the previous round in 2003. However, it also highlighted variable quality and failure to fully meet service quality indicators. Whilst the majority of patients who responded to the survey reported they understood what COPD meant and knew they already had it, they exacerbated frequently and less than one quarter had a written plan for what to do when their chest was getting bad. The general practice survey indicated that COPD patients are frequent users of primary care services, with three quarters of those who are admitted to hospital with an exacerbation making contact with their general practice in the month beforehand and a third had three or more contacts during this period. A significant number of GPs appeared concerned about the quality of discharge information they receive from their local hospitals.
- 328. Since publication, national COPD audit data have contributed to local service improvement initiatives, policy development at national level and significantly influenced the development of a European COPD Audit that is managed by the European Respiratory Society.

#### www.rcplondon.ac.uk

#### **NHS Primary Care Commissioning**

- 329. NHS Primary Care Commissioning (NHS PCC) provides commissioning, contracting and communications support for SHAs, PCTs and the Department of Health. NHS PCC operates on a subscription model and all PCTs currently subscribe to its services.
- 330. NHS PCC provides PCTs, GP commissioning organisations and providers with local insight into national policy and supports implementation and best practice in commissioning and contracting across all areas of primary and community care. PCC's network of regional advisers and associates have technical expertise, and provide tailored, local support to PCTs to help them to reduce health inequalities, meet NHS operational standards on waiting times and achieve financial health through effective commissioning.
- 331. NHS PCC works in parallel with Primary Care Commissioning Community Interest Company (PCC CIC). PCC CIC shares the values of the NHS and supports primary care organisations to raise quality, increase productivity and realise efficiencies.
- 332. PCC has worked with the Department of Health's home oxygen team since February 2006, providing a link to the NHS, communications support and event co-ordination. A primary focus has been the promotion of commissioning, development of assessment and review services for all home oxygen patients, and sharing examples of this within the NHS. PCC has also worked on supporting the NHS through reprocurement transitions (2006 and 2011). The home oxygen order form (HOOF) and consent form (HOCF) continue to be housed on the PCC website and are widely accessed by the NHS this way.

#### www.pcc.nhs.uk

#### The Association of Respiratory Nurse Specialists

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

#### www.arns.co.uk

#### **Royal College of GPs**

- 337. The Royal College of General Practitioners (RCGP) welcomed the publication of the *Outcomes Strategy for COPD and Asthma*. The RCGP recognises that respiratory disease confers a high morbidity and mortality within primary care and is keen to work with the Department to implement the *Outcomes Strategy*.
- 338. The RCGP has shown leadership in the prevention and treatment of swine flu and continues to have respiratory disease as a clinical priority. The current RCGP respiratory clinical champion, Dr Kevin Gruffydd-Jones, is a member of the Department of Health's Respiratory Programme Board and represents the College on the Steering Committee of the National Review of Asthma Deaths.
- 339. The College's Clinical Innovation and Research Centre (CIRC) is also working in partnership with the Royal College of Physicians and other stakeholders on a Department of Health-funded national clinical audit for COPD.

#### www.rcgp.org.uk

#### **Respiratory Education UK**

- 340. Respiratory Education UK (REUK) is a charity working to improve the lives of people with respiratory conditions. This is achieved through:
  - Raising the profile of respiratory disease nationally and regionally
  - Designing, developing and delivering education and training to healthcare professionals across primary and secondary care settings
  - Supporting the redesign and redevelopment of respiratory services
- 341. REUK offers a range of academic courses for healthcare professionals at all levels. The programmes are underpinned by the *Outcomes Strategy* and mapped to the competency framework. These resources are the basis for education through which they support practitioners to deliver high quality respiratory care and drive forward services to meet the needs of individuals within their local communities.
- 342. Alongside academic provision, REUK has a broad portfolio of short courses and training events which promote advances in respiratory disease management to staff within the NHS and related areas
- 343. REUK also undertakes, promotes and disseminates relevant research as part of its evidence-based programmes.
- 344. REUK hosted a range of workshops around the country, specifically focused upon the *Outcomes Strategy for COPD and Asthma*. The events brought together commissioners and practitioners and were designed to include workshops in which a range of people across localities were encouraged to consider their preparedness for the *Outcomes Strategy*, and set into action activities that would be needed to support its

implementation. A Master Class aimed at commissioners of respiratory services has been developed to further help support the implementation of the *Outcomes Strategy*.

345. REUK has also developed a new commercial arm of its operations to assist commissioners of respiratory services to implement elements of the *Outcomes Strategy*, linked specifically to screening, spirometry and review.

#### www.respiratoryeduk.com

#### Skills for Health

- 346. Skills for Health, in collaboration with the Respiratory Programme in the Department of Health, has led on the development of a respiratory disease competence framework that describes the knowledge, skills and attitudes that are required to deliver patient-centred respiratory care. Competence frameworks are focused on outcomes and are an indispensible tool for those managing and developing a highly-skilled workforce. They inform the development of education and training programmes as well as assessment strategies, all of which are going to be vital in implementing the *Outcomes Strategy*.
- 347. The purpose of this work is to provide an underpinning framework, including units of learning, for the respiratory care workforce, so that people can plan and develop their services more effectively. These were identified following much consultation with the members of the development group, and with input from healthcare professionals as well as professional bodies and other national groups.
  - The suite of resources includes:
  - Main report this outlines the rationale and uses for the Units of Learning for COPD
  - Mapping document shows how the Units of Learning relate to the COPD Spectrum
  - Case Studies demonstrates how services will use the Units of Learning
  - Units of Learning

#### www.skillsforhealth.org.uk

#### **Education for Health**

- 348. Education for Health is a charity focussing on the education of health professionals as a key factor in improving patient health and quality of life. They specialise in assisting healthcare professionals to:
  - Improve their ability to make earlier diagnoses
  - Assess patients with long-term conditions
  - Work in partnership with patients to treat and manage their conditions more effectively
  - Teach patients to better understand and manage their conditions
  - The clinical respiratory education they offer spans Open University-accredited diploma and degree modules as well as interactive workshops and bespoke study days. Modules are delivered via e-learning and face-to-face study and assessment days. They deliver study days throughout the country on COPD, asthma and spirometry (accredited additionally by the ARTP) or and at their regional venue in Warwick.

All courses are up-to-date, reflecting current primary healthcare practice, and are designed to satisfy relevant national guidelines and legislation.

#### www.educationforhealth.org.uk

#### National Council for Palliative Care

- 349. The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. NCPC works to ensure that everyone approaching the end of life has access to the highest quality care and support, wherever they live, and whatever their condition.
- 350. NCPC has produced a number of resources to help support people approaching the end of life with chronic respiratory disease and their carers, decision-makers and staff, including:
  - A Fresh Approach: Palliative and end of life care for people with Chronic Respiratory Disease (2008) - This guidance, produced by NCPC's Chronic Respiratory Disease (CRD) Group, highlights the need for partnership working across sectors and settings of care to identify the palliative care needs of people with CRD and deliver services.
  - *Difficult Conversations for COPD (2010)* A short, practical booklet which helps professionals supporting people with chronic obstructive pulmonary disease (COPD) open up conversations about end of life care, dying and bereavement.
  - The annual Minimum Data Set (MDS) for Specialist Palliative Care Services is a useful resource for commissioners and service providers, providing data on current access to specialist palliative care for people with CRD.
  - Dying Matters Coalition information, leaflets and videos a range of materials to help the public and professionals talk more openly about dying, death and bereavement, and to help plan for the end of life.

(These resources are available at <u>www.ncpc.org.uk/site/lung</u> and <u>www.dyingmatters.org</u>)

351. NCPC also produces regularly updates on developments in end of life care, including for people with CRD, in its quarterly magazine *Inside Palliative Care* and monthly *Policy Roundup* e-bulletin, as well as national conferences and events.

#### www.ncpc.org.uk

#### Association for Respiratory Technology and Physiology

352. The Association for Respiratory Technology and Physiology (ARTP) is the sole professional organisation in the UK for practitioners working in clinical respiratory physiology and technology. The ARTP provides the only national, professionally recognised, professional qualifications in Pulmonary Function Testing and Spirometry. An important function of the ARTP is the provision for Continuing Professional Development. The ARTP organises an Annual Conference and training courses on many respiratory topics including practical blood gas sampling, interpretation of lung function results, respiratory muscle assessment, sleep disorders and cardiopulmonary exercise testing. Additionally, ARTP coordinates spirometry training centres throughout the UK. The ARTP also write and publish textbooks in lung function testing and physiology. The ARTP have launched ARTP Sleep to represent practitioners working in Sleep Medicine.

- 353. The ARTP works in conjunction with the BTS, PCRS-UK and other relevant organisations to produce national best practice guidelines for good practice in the performance of respiratory measurement or treatment. It works closely with the Department of Health in helping to develop policy and in the strategic direction of the profession and clinical services. ARTP will continue to support the *Outcomes Strategy* in the future.
- 354. The ARTP has developed web-based learning for spirometry, has published a book about respiratory physiology in conjunction with Professor Mike Hughes, and continues to support the implementation of the *Outcomes Strategy* in other ways. It also has close involvement with Assembly 9 (the Allied Respiratory Professionals Assembly) of the European Respiratory Society in establishing worldwide standards for lung function.

#### www.artp.org.uk

#### Association of Chartered Physiotherapists in Respiratory Care (ACPRC)

- 355. The Association of Chartered Physiotherapists in Respiratory Care (ACPRC) exists to promote best practice in respiratory physiotherapy for the benefit of patients. As a professional network of the Chartered Society of Physiotherapy, ACPRC works to:
  - promote the exchange of ideas amongst those interested in respiratory physiotherapy and respiratory care,
  - facilitate education and training in respiratory physiotherapy and
  - promote clinical excellence in respiratory physiotherapy to colleagues and clients throughout the UK
- 356. ACPRC supports its members through national conferences, study days and regular electronic communication, building skills in evidence based practice and facilitating the dissemination of research. Through its website and professional web-forum, ACPRC promotes critical discussion of challenges within the field of respiratory care and facilitates the national exchange of best practice, professional networking and peer support.
- 357. ACPRC works collaboratively with other respiratory care, governmental and NHS organisations to influence the development of national policy and the development of respiratory services. ACPRC is working with the Department of Health to help promote the *Outcomes Strategy for COPD and Asthma*, and will continue to encourage its members to facilitate its implementation.

#### www.acprc.org.uk

#### Health and Safety Executive

- 358. The Health and Safety Executive's (HSE's) mission is the prevention of death, injury and ill health for those at work and those affected by work activities. The HSE, together with local authorities, is the regulator for workplace health and safety. It provides strategic direction and advice as well as enforcing the Health and Safety at Work etc Act and associated legislation, but the legal responsibility for ensuring that workplaces are safe both for those who work there and for members of the public who may be affected by work activities lies with the owner of the business. Suppliers of materials and equipment, and employees have responsibilities in law too. One of the key aims of the HSE's strategy *'The Health and Safety of Great Britain – Be part of the solution'* is to ensure the focus is on real health and safety risks and to create healthier, safer workplaces through partnerships with other stakeholders.
- 359. The causes of accidents in the workplace are generally well understood and the HSE will continue focusing on their prevention. However, this is not always the case for ill health. Some ill health is clearly work-related, albeit with long latency in certain cases, while in other instances the causes are not solely work-related, or the seriousness of an illness may be exacerbated by non-work factors. COPD and asthma can both be caused by occupational exposures and work is thought to play a part in the development of about 15% of cases of each of them. The HSE's intention is to work with stakeholders on preventing work-related ill health while offering its expertise to support other programmes addressing the wider issues, e.g. the Government's Health, Work and Well-being initiative.
- 360. It is estimated that each year around 12,000 people die prematurely because of past exposure to harmful substances during the course of their work. This equates to around 98% of annual occupationally-related deaths. The vast majority of these deaths are caused by cancer (estimated around 8,000 deaths) and COPD (estimated around 4,000 deaths) due to inhalation of harmful fumes, chemicals, vapours and dusts. The latency period between exposure and onset of these diseases can be anything up to between 50 and 60 years.
- 361. HSE is working in partnership with stakeholders to identify ways to reduce workplace exposures by ensuring the right messages get to those at risk and by encouraging changes in behaviour among employers and workers in targeted industries where the risks of exposures to chemicals or substances known to cause long-latency diseases are higher.

www.hse.gov.uk

# Annex A – NICE Quality Standard for COPD

#### NICE Quality Standard for COPD

1 – People with COPD have one or more indicative symptoms recorded, and have the diagnosis confirmed by post-bronchodilator spirometry carried out on calibrated equipment by healthcare professionals competent in its performance and interpretation

2 – People with COPD have a current individualised comprehensive management plan, which includes high-quality information and educational material about the condition and its management, relevant to the stage of disease

3 – People with COPD are offered inhaled and oral therapies, in accordance with NICE guidance, as part of an individualised comprehensive management plan

4 – People with COPD have a comprehensive clinical and psychosocial assessment, at least once a year or more frequently if indicated, which includes degree of breathlessness, frequency of exacerbations, validated measures of health status and prognosis, presence of hypoxaemia and comorbidities

5 – People with COPD who smoke are regularly encouraged to stop and are offered the full range of evidence-based smoking cessation support

6 – People with COPD meeting appropriate criteria are offered an effective, timely and accessible multidisciplinary pulmonary rehabilitation programme

7 – People who have had an exacerbation of COPD are provided with individualised written advice on early recognition of future exacerbations, management strategies (including appropriate provision of antibiotics and corticosteroids for self-treatment at home) and a named contact

8 – People with COPD potentially requiring long-term oxygen therapy are assessed in accordance with NICE guidance by a specialist oxygen service

9 – People with COPD receiving long-term oxygen therapy are reviewed in accordance with NICE guidance, at least annually, by a specialist oxygen service

10 – People with admitted to hospital with an exacerbation of COPD are cared for by a respiratory team, and have access to a specialist early supporteddischarge shceme with appropriate community support

11 – People admitted to hospital with an exacerbation of COPD and with persistant acidotic ventilator failure are promptly assessed for, and receive, non-invasive ventilation delivered by appropriately trained staff in a dedicated setting

12 – People admitted to hospital with an exacerbation of COPD are reviewed within 2 weeks of discharge

13 – People with advanced COPD, and their carers, are identified and offered palliative care that addresses physical, social and emotional needs

# Annex B – Key similarities and differences between COPD and asthma

	COPD	Asthma
Age of patients	Generally older.	Asthma may start at any age, and is common in childhood.
Cause	Usually smoking related, but also linked to environment, employment and genetic pre- disposition.	Disease onset reflects host factors (genetic and familial) and interaction with environmental factors, but a strategy to prevent onset of disease is not yet possible. Once the disease is established, environmental factors such as viruses, allergens, pollution, tobacco smoke, workplace sensitisers, or exercise may all make the condition worse.
Diagnosis	Spirometry and other tests.	Careful history-taking, and trials of therapy monitored by recording symptoms, lung function, and other tests where appropriate. Under-diagnosis and delayed diagnosis may occur, and over-diagnosis may occur with insufficient diagnostic rigour.
Case finding	Value in case finding of undiagnosed COPD but no case for population screening at present.	No useful pre-symptomatic intervention and no case for population screening. Early diagnosis of cases of occupationally induced asthma is essential so that avoidance strategies can be undertaken.

	People's symptoms deteriorate over time. They move through the tiers of the long-term conditions 'pyramid' over time, becoming increasingly reliant on intensive health services.	People's symptoms can be well controlled and they can maintain normal activities of daily life into old age with appropriate treatment – except those with the most severe asthma. Lack of control may result from both under-treatment or disease progression or both. Only a minority of people may be in tier 3 of the pyramid. Others have more variable disease necessitating increased support and care for only some of the time.
Predictability	The progression of COPD is relatively predictable, with function declining with time albeit at different rates in different individuals.	Asthma is not progressive but can be unpredictable, with people moving between different levels of severity with little warning.
Aims of care	To manage or slow the declining lung function and maximise the quality of life. Best treatment can improve quality of life and reduce the frequency of exacerbations.	To restore and maintain normal lung function and help people achieve as near normal activities of daily life as possible for the duration of their lives. To avoid acute attacks.
Management	COPD requires many different types of input to co-ordinate care, due to hospitalisation and treatment of exacerbations, need for pulmonary rehabilitation, management of co-morbidities and, for many, end of life care.	Largely managed in primary care by GPs, practice nurses and pharmacists. Specialist services will be needed for severe and potentially fatal asthma. There should be clear, agreed criteria to ensure there is appropriate referral from primary to specialist care. More severe asthma requires a multidisciplinary team- based approach to co-ordinate care and achieve best outcomes.

Treatment	Treated with some of the same medicines as asthma. Symptomatic COPD is treated with regular bronchodilation with high-dose inhaled steroids or ICS/LABA combinations reserved for more severe cases. Long-term oxygen therapy improves prognosis in advanced disease.	Inhaled steroids are the cornerstone of treatment, with add-on, long-acting bronchodilators or other agents if necessary. Other anti- inflammatory or anti-allergic medicines are sometimes needed, e.g. oral steroids. Oxygen is only used during severe exacerbations.
Triggers of symptoms	A person's COPD will become poorly controlled because their treatment is suboptimal or their condition is deteriorating.	A person's asthma will become poorly controlled for a variety of reasons, including under- treatment, infection or exposure to triggers, particularly allergens. People with asthma need to be taught how to recognise a deterioration in their condition and how to promptly adjust therapy and start reserve therapies to avoid progression.
Compliance problems	May be more about physical disability – inability to use an inhaler, or lack of access to care due to social isolation.	Due to range of factors – reduced perception of need for medication, associated with intermittent nature of the condition and tolerance of symptoms due to low expectations of control, lack of perceived efficacy, excessive concern about side effects, or lack of desire to take regular medication, or may simply be due to forgetting to take their medication if they are feeling well.
Co- morbidities	Many people with COPD may also have smoking-related co- morbidities such as coronary heart disease, and systemic problems such as osteoporosis, cardiac failure and muscle wasting.	Many people with asthma will have other allergic conditions, including hay fever and allergic rhinitis. In some cases expert assessment is necessary to separate the relative contribution of co-morbidities.

Exercise	People with mild COPD should be encouraged to take regular exercise. Pulmonary rehabilitation programmes for moderate to severe COPD.	People with asthma should be encouraged to take regular exercise in order to be able to achieve normal activities of daily living.
Avoidable death vs. condition causing death	People with COPD usually die of COPD or an associated condition. Only smoking cessation and long-term oxygen use can reduce mortality.	The majority of deaths have avoidable factors. Death from asthma should be regarded as an avoidable event and enquiry into each death is recommended. With appropriate treatment most people with asthma die of other unrelated causes late in life.
Palliative and end of life care	Relevant for COPD where it is widely recognised that there is a major need for improvements to meet the specific needs of people with COPD at the end of their lives.	Deaths from asthma tend to occur acutely, so there is rarely a need for palliative care for asthma. However, because death is likely to have been unexpected, specialist bereavement support should be available for relatives, especially when the deceased was a young person.

# Annex C - Summary of actions and interventions outlined in the NHS Companion Document

#### COPD – What can the NHS do to improve outcomes?

#### Domain One: Preventing people from dying prematurely

#### **Diagnose earlier and accurately**

- Identify people whose treatment history and symptoms suggest that COPD may have been missed, and those currently diagnosed with COPD without a clear diagnosis
- Perform quality-assured diagnostic spirometry on those identified and confirm diagnosis, together with other investigations to assess severity and coexistence of other conditions
- Assess for the presence of alpha-1-antitrypsin deficiency and for bronchiectasis in patients with a suggestive history
- Recognise the link between COPD and lung cancer and explore the use of proactive strategies to diagnose earlier

#### **Prevent progression**

- Ensure people with COPD receive evidence-based treatment
- Offer appropriate smoking cessation support to people with COPD who smoke
- Identify and treat exacerbations promptly

#### Prolong survival

- Promote regular physical activity in all people with COPD
- Identify those who may need Non-Invasive Ventilation (NIV) both in the acute setting and as a long-term domiciliary treatment, and ensure structured assessment of need for NIV is carried out by a respiratory specialist
- Ensure routine pulse oximetry is performed in people with COPD whose FEV1 is lower than 50% predicted to identify those who may need long-term home oxygen therapy and, for those identified, ensure structured assessment of need by a home oxygen assessment and review service

#### Domain Two: Enhancing the quality of life for people with long-term conditions

#### Risk stratify and understand the local population

- · Assess for disease severity and other complicating factors
- Provide proactive chronic disease management appropriate for the severity level assessed mild, moderate or severe

#### Support self-management and shared decision-making

• Ensure people with COPD are offered support to self-manage their condition, and provide access to integrated community care teams with access to specialist respiratory advice

#### Provide and optimise pharmacological and non-pharmacological treatment

- Ensure people with COPD receive evidence-based treatment in a structured medicines management approach
- Provide pulmonary rehabilitation for all people with COPD with a MRC score of three or above

### Domain Three: Helping people to recover from episodes of ill health or following injury

#### Provide the right care in the right place at the right time

 Agree locally a pathway of care for acute exacerbations – including timing and location of initial assessment and delivery of care (hospital, GP surgery / community care, or in their own home)

#### Ensure structured hospital admission

- Ensure structured hospital admission with early access to specialist respiratory care, prompt management of COPD and co-morbidities in line with NICE guidance
- Ensure prompt assessment on admission to hospital, including blood gas analysis and provision of NIV within 1 hour of decision to treat being made, where clinically indicated

#### Support post-discharge

- Ensure all people with COPD are assessed for suitability for an Early Supported Discharge Scheme
- Ensure that people admitted to hospital with an exacerbation of COPD are reviewed within 2 weeks of discharge

#### Domain Four: Ensuring that people have a positive experience of care

#### Empower people with COPD by providing information and education

• Ensure all people with COPD are offered personalised information, with support to understand it, at key points throughout their care, which enables them to make choices and to fully participate in shared decision making

#### Assess psychosocial support and social care needs

• Assess the psychosocial needs of people diagnosed with COPD and ensure people identified with psychosocial needs are referred for appropriate treatment and support

#### Assess palliative care needs

- Ensure that people with COPD who have an FEV1 < 30 predicted, frequent exacerbations or a history of NIV, are assessed for end of life care needs
- Ensure people identified with end of life care needs are referred for appropriate treatment and support

#### Domain Five: Treating and caring for people in a safe environment

#### Deliver high flow and emergency oxygen safely

- Identify individuals who would be at risk if they received high-flow oxygen
- Give those identified as high-risk an oxygen alert card

#### Prescribe steroids according to evidence-based guidance

- Prescribe steroids in accordance with evidence-based guidance
- Give appropriate people steroid treatment cards

#### Robustly risk manage home oxygen environments

• Risk assess the home environment of someone receiving long-term oxygen therapy to ensure that all safety requirements are in place

#### Asthma – What can the NHS do to improve outcomes?

#### Domain One: Preventing people from dying prematurely

#### Prompt, accurate, quality-assured diagnosis

- Ensure clinicians diagnosing asthma have a good understanding of best practice outlined in the British Asthma Guideline, and have received adequate training in asthma management to be competent in diagnosing asthma
- Include a record of the basis for diagnosis in patient notes
- Investigate people developing asthma in adulthood for the possibility that asthma is being caused by the workplace

#### Aim for freedom from asthma symptoms once diagnosed

- Structured management of asthma (see Domain 2 below)
- Prompt action to avoid or manage asthma exacerbations (see Domain 3 below)

#### Domain Two: Enhancing the quality of life for people with long-term conditions

## Structured, ongoing management of asthma, using a shared decision making approach

- Carry out regular structured reviews to ensure that control of symptoms is achieved
- Support self-management and include an up-to-date personalised care plan in patients' notes, with evidence of a written asthma action plan
- Offer support to stop smoking
- Stratify GP practices' asthma registers according to people's risk of an attack or of losing control
- Ensure specialist services are available for those who need them

### Domain Three: Helping people to recover from episodes of ill health or following injury

#### Prompt action to avoid or manage asthma exacerbations

- Provide the right care in the right place at the right time
- Provide rapid access to specialist care when needed
- Follow up and review with person with asthma following hospital attendance or admission

#### Domain Four: Ensuring that people have a positive experience of care

#### Shared decision-making to manage asthma

- Ensure a shared decision-making approach to managing asthma
- Assess for psychosocial and mental health needs

#### Domain Five: Treating and caring for people in a safe environment

#### Optimal pharmaceutical treatment based on a stepwise approach to prescribing

• Ensure that the stepwise approach to prescribing, as set out in the British Asthma Guideline, is being followed

# References

<sup>1</sup> Department of Health. *Consultation on a Strategy for Services for Chronic Obstructive Pulmonary Disease (COPD) in England.* DH, 2010.

<sup>2</sup> Department of Health. An Outcomes Strategy for COPD and Asthma. DH, 2011.

<sup>3</sup> <u>http://www.rightcare.nhs.uk/index.php/atlas/atlas-of-variation-2011/</u>

<sup>4</sup> Celli BR, Thomas NE, Anderson JA, et al. Effect of pharmacotherapy on rate of decline of lung function in chronic obstructive pulmonary disease: results from the TORCH study. Am J Respir Crit Care Med 2008;178:332e8.

<sup>5</sup> Calverley PM, Anderson JA, Celli B, et al. Salmeterol and fluticasone propionate and survival in chronic obstructive pulmonary disease. N Engl J Med 2007;356:775e89.

<sup>6</sup> Jenkins CR, Jones PW, Calverley PM, et al. Efficacy of salmeterol/fluticasone propionate by GOLD stage of chronic obstructive pulmonary disease: analysis from the randomised, placebocontrolled TORCH study. Respir Res 2009;10:59.

<sup>7</sup> Tashkin DP, Celli B, Senn S, et al. A 4-year trial of tiotropium in chronic obstructive pulmonary disease. N Engl J Med 2008;359:1543e54.

<sup>8</sup> Decramer M, Celli B, Kesten S, et al. Effects of tiotropium on outcomes in patients with moderate chronic obstructive pulmonary disease (UPLIFT): a prespecified subgroup analysis of a randomised controlled trial. Lancet 2009;374:1171e8.

<sup>9</sup> Decramer M, Celli B, Tashkin DP, et al. Clinical trial design considerations in assessing longterm functional impacts of tiotropium in COPD: the UPLIFT trial. COPD 2004;1:303e12.

<sup>10</sup> Mapel et al. Value in Health 2008;11:628-36

<sup>11</sup> Jones R, et al. Missed Opportunities to diagnose COPD: a real-world, UK database study. Oral Presentation. 2011 European Respiratory Society International Conference, Amsterdam.

<sup>12</sup> NICE. Chronic obstructive pulmonary disease: Management of chronic obstructive pulmonary disease in adults in primary and secondary care. NICE, 2010.

<sup>13</sup> Jones RCM, Dickson-Spillmann M, Mather MJC et al. Accuracy of diagnostic registers and management of chronic obstructive pulmonary disease: the Devon primary care audit. *Respiratory Research* 2008; 9 (62).

<sup>14</sup> Holme J, Stockley RA. Radiologic and clinical features of COPD patients with discordant pulmonary physiology: Lessons from a-1-alphatrypsin deficiency. *Chest* 2007; 132: 909-915

<sup>15</sup> Sveger T, Thelin T, McNeil TF. Young adults with alpha-1 antitrypsis deficiency identified neonatally: their health, knowledge about an adaptation to the high-risk condition. *Acta Paediatrica* 1997 Jan; 86(1): 37-40

<sup>16</sup> Bull World Health Organ 1997; 75(5): 397-415

<sup>17</sup> BTS Guideline for non-CF Bronchiectasis, Thorax 2010;65, Supplement 1, page 50, Appendix 1

<sup>18</sup> NICE. Chronic obstructive pulmonary disease: Management of chronic obstructive pulmonary disease in adults in primary and secondary care. NICE, 2010.

<sup>19</sup> NICE. Chronic obstructive pulmonary disease: Management of chronic obstructive pulmonary disease in adults in primary and secondary care. NICE, 2010.

<sup>20</sup> Wilkinson TMA, Donaldson GC, Hurst JR, Seemungal TAR, Wedzicha JA. Impact of Reporting and Early Therapy on Outcome of Exacerbations of COPD. Am J Respir Crit Care Med 2004: 169: 1298-1303

<sup>21</sup> Holguin F, Folch E, Redd SC, Mannino DM. Comorbidity and mortality in COPD-related hospitalizations in the United States, 1979 to 2001. Chest. 2005 128:2005-11.

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http://www.improvement.nhs.uk/lung/NationalImprovementProjects/TransformingAcuteCare/Le arningfromNationalprojects/tabid/202/Default.aspx

<sup>23</sup> <u>http://www.impressresp.com/</u>

<sup>24</sup> Garcia-Aymerich J, Lange P, Benet M et al. Regular physical activity reduces hospital admission and mortality in chronic obstructive pulmonary disease: a population based cohort study. *Thorax* 2006; 61: 772-778

<sup>25</sup> Royal College of Physicians. The National COPD Audit 2008. Royal College of Physicians, London

<sup>26</sup> McEvoy R et al. Nocturnal non-invasive nasal ventilation in stable hypercapnic COPD: a randomised controlled trial. Thorax 209; 64:561-566.

<sup>27</sup> www.pcc.nhs.uk/home-oxygen-service-good-practice-guide-for-assessment-and-review

<sup>28</sup> Kennedy et al. 'The effectiveness and cost effectiveness of a national lay-led self care support programme for patients with LTCs: a pragmatic RCT' *J Epidemiol. Community Health* 2007;61;254-261

<sup>29</sup> Department of Health. *Supporting People with Long Term Conditions, An NHS and Social Care Model to support local innovation and integration.* DH, 2005.

<sup>30</sup> Department of Health. Raising the Profile of Long Term Conditions Care: A Compendium of Information. DH, 2008

<sup>31</sup> Ellen Nolte, Cecile Knai, Martin Mckee. 'Managing Chronic Conditions, Experience in eight countries' Health Affairs – Web Exclusive, 2008

<sup>32</sup> Wagner, EH. 'Chronic disease management: What will it take to improve care for chronic illness?' *Effective Clinical Practice*. 1998;1:2-4

<sup>33</sup> King's Fund (2012). Emergency hospital admissions for ambulatory care-sensitive conditions: identifying the potential for reductions.

<sup>34</sup> NHS Institute for Innovation and Improvement. 2006. *Improving care for people with long-term conditions*. NHS Institute, 2006.

<sup>35</sup> Wagner, EH. Chronic disease management: What will it take to improve care for chronic illness? *Effective Clinical Practice* 1998; 1(1): 2–4.

<sup>36</sup> Negro et al Resp Med 2008;102:92-101

<sup>37</sup> Tunsäter. Health Policy 81 (2007) 309–319

<sup>38</sup> Tunsäter. Health Policy 81 (2007) 309–319

<sup>39</sup> Confronting COPD survey (Respir Med 2003;97 (suppl C):S71-9

<sup>40</sup> NICE. Chronic obstructive pulmonary disease: Management of chronic obstructive pulmonary disease in adults in primary and secondary care. NICE, 2010.

<sup>41</sup> Royal College of Physicians. The National COPD Audit 2008. Royal College of Physicians, London

<sup>42</sup> NICE. Chronic obstructive pulmonary disease: Management of chronic obstructive pulmonary disease in adults in primary and secondary care. NICE, 2010.

<sup>43</sup> Haynes RB, Montague P, Oliver T, et al. Interventions for helping patients to follow prescriptions for medications. *The Cochrane Library Database, CD*. 2001;000011(1):1–29

<sup>44</sup> NICE. Chronic obstructive pulmonary disease: Management of chronic obstructive pulmonary disease in adults in primary and secondary care. NICE, 2010.

<sup>45</sup> NICE. Chronic obstructive pulmonary disease: Management of chronic obstructive pulmonary disease in adults in primary and secondary care. NICE, 2010.

<sup>46</sup> Puhan et al. Cochrane Database of Systematic Reviews 2009, Issue 1. Art. No.: CD005305. DOI:10.1002/14651858.CD005305.pub2

<sup>47</sup> Seymour et al Thorax 2010;65:423-428 doi:10.1136/thx.2009.124164

<sup>48</sup> Royal College of Physicians. The National COPD Audit 2008. Royal College of Physicians, London

<sup>49</sup> Royal College of Physicians. The National COPD Audit 2008. Royal College of Physicians, London

<sup>50</sup> <u>http://www.hesonline.nhs.uk/Ease/servlet/ContentServer?siteID=1937&categoryID=1299</u>

<sup>51</sup> Royal College of Physicians. The National COPD Audit 2008. Royal College of Physicians, London

<sup>52</sup> Ahmad A, Purewal TS, Sharma D, Weston PJ. The impact of twice-daily consultant ward rounds on the length of stay in two medical wards Clinical Medicine 2011; 6:524-8

<sup>53</sup> Freemantle N, Richardson M, Wood J, et al. <u>Weekend hospitalization and additional risk of</u> <u>death: An analysis of inpatient data</u>. Journal of the Royal Society of Medicine. Published online on February 2 2012

<sup>54</sup> Price LC, Lowe D, Hosker HSR, Anstey K, Pearson MG, Roberts CM on behalf of the British Thoracic Society and the Royal College of Physicians Clinical Effectiveness Evaluation Unit (CEEU) UK National COPD Audit 2003: impact of hospital resources and organisation of care on patient outcome following admission for acute COPD exacerbation Thorax 2006; 61: 837 - 842.

<sup>55</sup> Royal College of Physicians. The National COPD Audit 2008. Royal College of Physicians, London

<sup>56</sup> Lightowler JVJ, Wedzicha JA, Elliott MW, Ram FSF. Non-invasive positive pressure ventilation for the treatment of respiratory failure due to exacerbations of chronic obstructive pulmonary disease: a Cochrane systematic review and meta-analysis. BMJ 2003; 326:185-7

<sup>57</sup> Plant PK, Owen JL, Elliott MW. Cost effectiveness of ward based non-invasive ventilation for acute exacerbations of chronic obstructive pulmonary disease: economic analysis of randomised controlled trial. BMJ 2003;326:956

<sup>58</sup> BTS Guidelines: Non-invasive ventilation in acute respiratory failure Thorax, Mar 2002; 57: 192 - 211.

<sup>59</sup> BTS Acute Oxygen guidelines Thorax to be submitted later this year

<sup>60</sup> National Collaborating Centre for Chronic Conditions. Chronic obstructive pulmonary disease. National clinical guideline on management of chronic obstructive pulmonary disease in adults in primary and secondary care. Thorax 2004;59 (Suppl 1) :1–232

<sup>61</sup> Royal College of Physicians. The National COPD Audit 2008. Royal College of Physicians, London

<sup>62</sup> Department of Health. The NHS Atlas of Variation in Healthcare. DH, 2011

#### <sup>63</sup> See

http://www.nhs.uk/aboutnhschoices/professionals/healthandcareprofessionals/other%20resour ces/pages/information-prescription-service.aspx

<sup>64</sup> To help avoid the overloading or under-provision of information, *Liberating the NHS: An Information Revolution* stressed the need for a coherent view of the nationally-managed channels needed to support access to information, combining the advantages of a single 'place to go' for health issues of the kind offered by NHS Choices, with the benefits from opening up the analysis and presentation of information to a wider range of information 'intermediaries'.

<sup>65</sup> van Manen JG, Bindels PJ, Dekker FW et al. Risk of depression in patients with chronic obstructive pulmonary disease and its determinants. *Thorax.* 2002; 57(5):412-416.

<sup>66</sup> NICE. Chronic obstructive pulmonary disease: Management of chronic obstructive pulmonary disease in adults in primary and secondary care. NICE, 2010.

<sup>67</sup> American Thoracic Society/European Respiratory Society. Statement on Pulmonary Rehabilitation, 2005

<sup>68</sup> NICE. Chronic obstructive pulmonary disease: Management of chronic obstructive pulmonary disease in adults in primary and secondary care. NICE, 2010.

<sup>69</sup> British Thoracic Society, 2008. *Guideline for emergency oxygen use in adult patients.* 

<sup>70</sup> British Thoracic Society, 2008. *Guideline for emergency oxygen use in adult patients.* 

<sup>71</sup> British Thoracic Society, 2008. *Guideline for emergency oxygen use in adult patients.* 

<sup>72</sup> Loke, Y. Cavallazzi, R, Singh, S. Thorax 2011; 66: 699 - 708

<sup>73</sup> Lindenauer, P. JAMA 2010; 303: 2359 – 2367, 2409 – 2410

<sup>74</sup> BTS / SIGN. British Guideline on the Management of Asthma. 2008, revised 2012.

<sup>75</sup> Health Survey for England - 2010: Respiratory health. The NHS Information Centre, 2011.

<sup>76</sup> Barnes, P.J., Jonsson, B., Klim, J.B. The costs of asthma. Eur Respir J, 1996, 9, 636–642

<sup>77</sup> Franco, R. et al. Cost-effectiveness analysis of a state funded programme for control of severe asthma. BMC Public Health 2007, 7:82 doi:10.1186/1471-2458-7-82

<sup>78</sup> Turner, MO. Risk factors for near-fatal asthma. A case-control study in hospitalized patients with asthma. <u>Am J Respir Crit Care Med.</u> 1998 Jun;157(6 Pt 1):1804-9.

<sup>79</sup> Department of Health. The NHS Atlas of Variation in Healthcare. DH, 2011

<sup>80</sup> Partridge, M. A national census of those attending UK accident and emergency departments with asthma JAccid Emerg Med 1997;14:16-20

<sup>81</sup> Salmeron, S. Asthma severity and adequacy of management in accident and emergency departments in France: a prospective study. <u>Lancet.</u> 2001 Aug 25;358(9282):629-35.

<sup>82</sup> British Thoracic Society. Adult Asthma Audit 2010.

<sup>83</sup> British Thoracic Society. Adult Asthma Audit 2010.

<sup>84</sup> <u>http://www.dh.gov.uk/health/category/publications/bulletins/theweek/</u>