

# Primary Care Respiratory Society UK

Formerly General Practice Airways Group



## Bridging the Gap

The Bridging the Gap document was produced in January 2003 before the General Practice Airways Group changed its name to Primary Care Respiratory Society UK.

If you wish to utilise the Bridging the Gap document please bear in mind the date that it was produced taking into account that there have been significant changes in healthcare delivery since that time.

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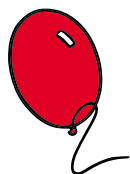
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# BRIDGING THE GAP

Commissioning and delivering high quality integrated respiratory healthcare

A report from the Respiratory Alliance

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# FOREWORD

- Despite the considerable burden imposed on patients, the health service and society, respiratory diseases are not currently a priority in the national strategy for health, and there is no national service framework (NSF) to guide those responsible for commissioning and providing respiratory services.
- This booklet aims to bridge this gap, and assist primary care trusts (PCTs) and Strategic Health Authorities in their role of commissioning and delivering high quality respiratory care to their local populations.
- In doing so, there is plenty of scope to bring real improvements to patient care, reduce emergency admissions and reduce healthcare resource utilisation.
- The booklet:
  - provides a brief summary of the burden imposed by the major long-term respiratory diseases (asthma, rhinitis and chronic obstructive pulmonary disease\*)
  - describes current health service provision
  - outlines the improvements required to meet reasonable patient expectations.
- The report has been developed by the Respiratory Alliance, an informal group of medical charities, organisations and professional bodies with an interest in the provision of respiratory healthcare services.
- Although it is the prerogative of government to define policy, it is right that healthcare professionals should indicate how policy may distort clinical practice. There is a danger that those suffering from conditions that are not prioritised (like respiratory disease) will become disadvantaged, leading to potential discrimination by disease.

*Respiratory charities  
and professional  
bodies forming the  
Respiratory Alliance*

- Respiratory Education & Training Centres (RETC)
- National Respiratory Training Centre (NRTC)
- National Asthma Campaign (NAC)
- General Practice Airways Group (GPIAG)
- British Thoracic Society (BTS)
- British Society for Allergy and Clinical Immunology (BSACI)
- British Paediatric Respiratory Society (BPRS)
- British Lung Foundation (BLF)

\* Lung cancer, which is the most common cause of cancer deaths in both males and females in the UK and contributes a major part of the workload of those caring for long term respiratory conditions, is not included here because it forms part of the cancer NSF.

## 1 Summary

- To ensure that respiratory services are delivered in an integrated fashion, every primary care trust (PCT) should nominate a clinical and non-clinical leader of respiratory services for the local population.
- Primary care-based specialists (GPs with a special clinical interest, GPSCI) may be able to take the lead in spreading good practice throughout the PCT.
- There is a pressing need to increase the skills base in asthma self-management education, allergy, COPD, spirometry and smoking cessation – PCTs should ensure that these training needs are met as rapidly as practicable.
- All PCTs need to appreciate that funding of education and medical interventions for respiratory and allergy services is an investment that can offset future NHS and societal costs arising from long-term ill health.
- The accompanying tables summarise the minimum standards of care for long-term respiratory diseases, in terms of reasonable patient expectations, together with a checklist for the key health service provisions required to meet these expectations.

### Bridging the gap in care of patients with asthma

<i>Reasonable patient expectations</i>	<i>Checklist of key health service provisions</i> ✓
<ul style="list-style-type: none"> <li>● Timely and accurate diagnosis</li> <li>● The best possible control of their symptoms, and management in line with approved guidelines</li> <li>● Structured care to defined standards</li> <li>● Education about controlling their own symptoms</li> </ul>	<ul style="list-style-type: none"> <li>○ Healthcare professionals trained in asthma management</li> <li>○ Defined service delivery standards for patients in primary care</li> <li>○ Practice-based asthma registry</li> <li>○ Patients given written personal asthma action plans, highlighting steps to take if control deteriorates</li> <li>○ Systems in place for regular patient review and follow-up, using telephone or e-mail as alternatives to face-to-face consultations where appropriate</li> <li>○ Availability of specialist services in primary care</li> <li>○ Specialist referral when required</li> </ul>

### Bridging the gap in care of patients with rhinitis and other allergies

<i>Reasonable patient expectations</i>	<i>Checklist of key health service provisions</i> ✓
<ul style="list-style-type: none"> <li>● To be taken seriously by primary healthcare professionals</li> <li>● Investigation of potential triggers and education about allergen avoidance and treatment options</li> <li>● Appropriate management</li> <li>● Integrated healthcare services</li> </ul>	<ul style="list-style-type: none"> <li>○ Convenient access to a service appropriate to needs (i.e. through pharmacy or primary care team) with adequate staffing and resource to meet the need</li> <li>○ Education of primary healthcare professionals in allergy, simple diagnostic tools (e.g. skin prick testing) and appropriate management</li> <li>○ Patient education in allergen avoidance and the use of nasal and inhaler devices</li> <li>○ Secondary care centres with facilities for specialised testing</li> <li>○ Tertiary support in regional centres with adequate staffing by allergy specialists</li> </ul>

### Bridging the gap in care of patients with COPD

<i>Reasonable patient expectations</i>	<i>Checklist of key health service provisions</i> ✓
<ul style="list-style-type: none"> <li>● Coordinated smoking cessation services</li> <li>● Timely and accurate diagnosis</li> <li>● Management in line with approved guidelines</li> <li>● Access to pulmonary rehabilitation services at an early stage in their disease</li> <li>● Access to appropriate secondary care services</li> <li>● Appropriate assessment and practical support for the use of supplementary oxygen</li> <li>● Integrated health, social and palliative care services</li> </ul>	<ul style="list-style-type: none"> <li>○ Healthcare professionals with specialist training in COPD, spirometry and smoking cessation</li> <li>○ Smoking cessation services</li> <li>○ Spirometry available for screening and diagnosis</li> <li>○ Registry of COPD patients</li> <li>○ Vaccination programme specifically targeting COPD patients</li> <li>○ Formalised assessment, review and recording of oxygen prescribing</li> <li>○ Pulmonary rehabilitation services in primary and secondary care</li> <li>○ Access to specialist respiratory services for diagnostic confirmation, assessment for surgical intervention and exacerbation management</li> <li>○ Facilities for non-invasive ventilation (NIV)</li> <li>○ Hospital at home for management of non-life threatening moderate to severe exacerbations</li> <li>○ Palliative care services</li> </ul>

### Bridging the gap in care of patients with other long-term respiratory diseases

<i>Reasonable patient expectations</i>	<i>Checklist of key health service provisions</i> ✓
<ul style="list-style-type: none"> <li>● For obstructive sleep apnoea, timely and accurate diagnosis, and appropriate management</li> <li>● For tuberculosis, timely and accurate diagnosis, and appropriate support during management</li> <li>● Adequate resources and appropriately trained healthcare professionals to meet the needs of patients with conditions requiring specialised respiratory services</li> </ul>	<ul style="list-style-type: none"> <li>○ Education of primary healthcare professionals on the diversity of respiratory conditions, to aid differential diagnosis</li> <li>○ For obstructive sleep apnoea, sufficient hospital facilities to meet the demand for diagnosis and management, based on prevalence of the condition</li> <li>○ For tuberculosis, adequate facilities for diagnosis, isolation of patients, and out-reach nurses for on-going support during maintenance therapy, with adequate public health support and back-up</li> <li>○ Maintenance of the skills base to address the diversity of respiratory conditions</li> </ul>

## 2 Respiratory diseases: the need for effective services

### 2.1 Mortality from respiratory diseases

- Respiratory disease kills one in four people in the UK, and accounts for more deaths each year (153,000) than coronary artery disease (132,000) or non-respiratory cancer (119,000)<sup>1</sup>.
- Deaths from respiratory disease do not appear to be falling. Indeed, the number of females dying from lung disease has increased by 28% in the last 14 years, while lung cancer has now overtaken breast cancer as the most common cause of cancer deaths in British women today<sup>1</sup>.
- It is also disturbing to note that the UK death rate from respiratory disease is twice the European Union average. Apart from Ireland, there is no other European country with a higher respiratory death rate until one gets as far east as Kyrgyzstan, Kazakhstan, Turkmenistan, and Uzbekistan<sup>1</sup>.

### 2.2 Morbidity from respiratory diseases

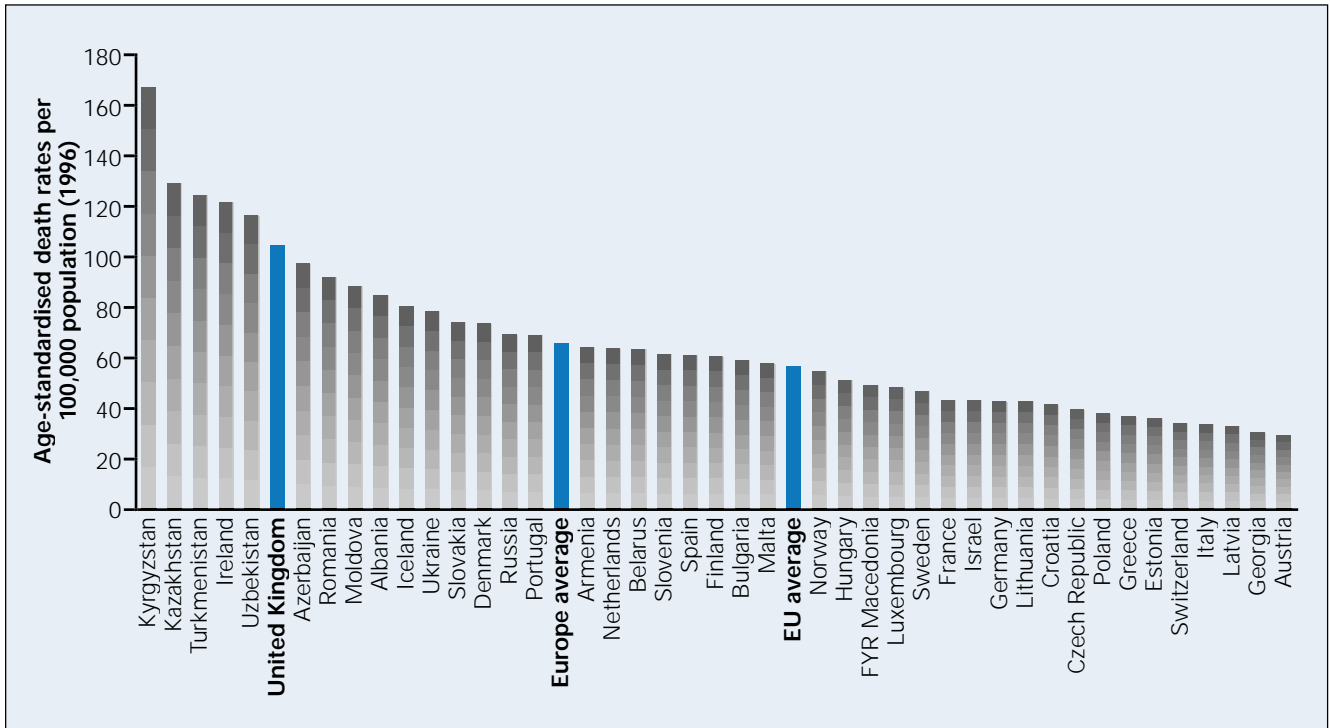
- Death from respiratory disease represents one tragic marker of the burden of these conditions, but for many of the 8 million sufferers in the UK, it is the long-term burden of respiratory illness that imposes considerable personal discomfort.
- Respiratory illness represents the most common long-term illness among children in the UK today<sup>1</sup>.
- Respiratory disease also places a high burden on the health service, being the most common reason for general practice consultation or emergency medical admission to hospital<sup>1</sup>. A third of the population visit their GP at least once a year because of a respiratory condition<sup>1</sup>.
- Chronic obstructive pulmonary disease (COPD), pneumonia and chest infections account for more than 2.8 million hospital bed-days per year<sup>1</sup>.
- The cost of respiratory disease to the National Health Service is higher than in any other disease area, at an estimated £2.5 billion in the year 2000, with around two-fifths of these costs (£1 billion) being for in-patient care<sup>1</sup>.

### 2.3 Social inequality

- Both mortality and morbidity from respiratory disease in the UK are linked to socio-economic background. Social inequality accounts for a higher proportion of deaths in respiratory disease (44%) than in any other disease<sup>1</sup>.
- Men from unskilled, manual occupations are fourteen times more likely to suffer COPD and nine times more likely to develop tuberculosis than their more affluent peers<sup>1</sup>.

### 2.4 Prevalence

- The prevalence of respiratory and allergic diseases is on the increase<sup>2-4</sup>.
- The prevalence of asthma in males increased by 114% and in females by 165% between the 1980s and the 1990s. Primary care consultations for seasonal allergic rhinitis increased fourfold between the 1950s and the 1980s<sup>5</sup>. Prevalence of COPD between 1990 and 1997 increased by 68.7% in women and by 25.3% in men<sup>6</sup>. The prevalence of pulmonary tuberculosis increased by 22% during the 1990s and the prevalence of mesothelioma (an asbestos-related malignancy affecting the lining of the lungs) increased by 75% over a ten year period<sup>1</sup>.



The death rate from respiratory diseases in the UK is twice that of the European Union average

## 2.5 A national priority?

- These facts, and many more, demonstrate the size of the problem. It is astounding that the management of respiratory diseases is not attracting greater national attention.
- Respiratory disease is not currently one of the priority areas defined in the national strategy for health.
- Although it is the prerogative of government to define policy, it is right that healthcare professionals should indicate how policy may distort clinical practice. There is a danger that those suffering from conditions that are not prioritised (like respiratory disease) will become disadvantaged, leading to potential discrimination by disease.
- The fact that government spending on research is targeted towards those diseases covered by national service frameworks means that those with respiratory disease are doubly disadvantaged – less care now, less hope for a better future.
- The challenge now is to ensure that respiratory disease is given the priority it warrants from the extent of the burden it imposes on individuals, the health service and society.
- In priority areas, such as cardiac disease, diabetes and cancer, national service frameworks are enhancing the delivery of optimal care. In the absence of an equivalent national service framework for chronic respiratory diseases, this short booklet aims to:
  - summarise the burden of the major respiratory conditions
  - define reasonable expectations for patients with these conditions
  - clarify the service requirements to bridge the gap between current services and expectations.
- The hope is that this document, compiled by a wide range of medical charities and professional bodies with an interest in respiratory care, will aid those responsible for commissioning and providing respiratory services.

## 3 Asthma

Asthma is a major long-term respiratory disorder in the UK, affecting 5 million people of all ages and social backgrounds<sup>7</sup>. While improvements have been made in recent years in the management of asthma (as shown by declining hospitalisation and death rates at a time of increased prevalence), there are still areas of weakness that should be addressed by those who commission healthcare services.

### 3.1 The burden of asthma

- Asthma is a long-term disease that restricts the passage of air into the lungs. Characteristic symptoms are recurrent wheezing and breathlessness, tightness or pain in the chest, and cough (particularly at night). Symptoms are often worsened or prolonged by triggers such as the common cold virus, house dust mite, pollen and exercise.
- There is currently no cure for asthma, though effective treatments are available to prevent and relieve symptoms. Well-respected management guidelines<sup>8</sup> have increased the use of prophylactic medication. However, it is estimated that one in four people with severe asthma experiences symptoms that could be relieved if appropriately managed<sup>9,10</sup>.
- Of the 5 million people in the UK with asthma, 1.4 million are children below 16 years<sup>11</sup>.
- Although deaths from asthma have declined over the past decade, over 1,500 people still die from the illness each year, including 25 children and 500 adults under 65 years<sup>7</sup>.
- There are almost 4 million consultations and 74,000 hospital admissions for asthma each year in the UK, and the annual cost of asthma to the NHS has been estimated at over £850 million<sup>7</sup>.
- An average primary care trust (PCT), with a population of a third of a million people, can expect to include:
  - 66,000 people who wheezed in the last year, including 45,000 people with diagnosed asthma
  - 25,000 people treated for asthma, including 17,000 receiving prophylactic therapy
  - over 400 emergency admissions to hospital for asthma each year
  - eight deaths from asthma attacks each year, three of which will be in people under 65 years<sup>7</sup>.
- Asthma care is likely to cost a PCT over £4.25 million a year<sup>7</sup>. Half of the costs may be expected to arise from the one fifth of people who experience an asthma attack.
- Improved control of asthma symptoms and better recognition of an imminent asthma attack can provide the foundation for the general improvement of asthma healthcare services.

### 3.2 Health service provision for people with asthma

- Most asthma healthcare is provided within primary care, often in dedicated clinics, though there may be limited uptake of these services. However, as few as 3% of patients have a personal written asthma action plan agreed with their health professional, despite the demonstrated value of this intervention<sup>12</sup>. Contact with the health service tends to be reactive (e.g. to obtain a repeat prescription, seek treatment for deterioration, obtain emergency care).
- Treatment guidelines, designed to support service provision that meets standards of care, recommend that people with severe asthma should be seen by a healthcare professional at least once every 6 months<sup>8</sup>, though one survey shows that at least one third of such people have not been seen by a healthcare professional for over a year<sup>12</sup>.
- Despite widespread awareness of management guidelines, there is still a general failure to provide care to guideline standards of accurate diagnosis, optimal control of symptoms and minimal exacerbations<sup>9,10</sup>.
- Although there is evidence that effective management of the rhinitis that is often associated with asthma can decrease asthma symptoms and bronchial hyperresponsiveness, rhinitis is frequently ignored<sup>13</sup>.
- The extent to which the primary care provider has specialist services within the practice depends primarily on the level of investment in training.

*Reasonable expectations for patients with asthma*

***Patients with asthma have a right to timely and accurate diagnosis***

- Accurate diagnosis of their disease, with referral to an asthma (or respiratory) specialist within the practice or as an out-patient referral, if necessary
- Automatic referral to a chest physician where occupational asthma is suspected, including direct referral from an occupational physician where appropriate
- Examination of the upper respiratory tract, as well as the lower, with referral to an ENT specialist if required

***Patients with asthma have a right to the best possible control of their symptoms, and management in line with approved guidelines***

- Attainment of the individual's normal or best lung function
- Freedom from symptoms and reduction in avoidable ill health
- A medication regimen that is easy to use and without significant side effects, offered by a healthcare professional who encourages full discussion of any fears or concerns about the medication
- Few self-imposed restrictions on daily activities
- Effectiveness of asthma care assessed from the patient's point of view
- Specific difficulties of some patient groups (e.g. adolescents, ethnic minorities, people with psychosocial problems) should be addressed
- Referral to specialist services if asthma is difficult to manage (e.g. if there are sudden severe attacks, symptoms persist despite high doses of inhaled steroids, pregnant women with worsening asthma)


***Patients with asthma have a right to expect that the availability and standards of local primary care services will be defined***

- Practices that follow the recommendations of the latest national evidence-based guidelines for treatment and care, and provide support for the management of asthma care
- Practices that maintain a practice-based asthma register, with review and follow up arrangements for all patients who require an emergency visit or admission to hospital
- Healthcare professionals who are specifically trained in asthma management
- Systems in place to support patients with deteriorating asthma (e.g. people with imminent asthma attacks or those with high levels of requests for repeat prescriptions who do not attend for review)
- Standards and systems in place for the clinical governance of asthma management

***Patients with asthma have a right to education about controlling their symptoms***

- Written guidance on actions to take if symptoms deteriorate (personal asthma action plans)

*Checklist of key components of healthcare provision for patients with asthma*

- Healthcare professionals trained in asthma management
  - Defined service delivery standards for patients in primary care
  - Practice-based asthma registry
  - Patients given written personal asthma action plans, highlighting steps to take if control deteriorates
  - Systems in place for regular patient review and follow-up, using telephone or e-mail as alternatives to face-to-face consultations where appropriate
  - Availability of specialist services in primary care
  - Specialist referral when required
- 

## 4 Rhinitis and other allergies

Allergy is important in respiratory disorders as 30% of patients with allergic rhinitis also have asthma, while up to 80% of the 5 million people in the UK with asthma have significant rhinitis<sup>13</sup>. Furthermore, patients often consider that rhinitis impairs quality of life more than asthma<sup>14</sup>.

### 4.1 The burden of rhinitis and other allergies

- There is a wide range of allergic disorders, including asthma, occupational asthma, rhinitis, hayfever, some skin disorders (eczema and urticaria), food allergy, and potentially fatal anaphylactic reactions to food, drugs, insect venom and anaesthetic agents.
- Allergy is a systemic disorder arising from an exaggerated immune response to triggers such as grass, house dust mite and domestic pets, though only around half of the people with this atopic tendency develop clinical expression of allergic disease.
- Patients with an atopic tendency may manifest symptoms of more than one allergic condition, either concurrently or sequentially over time. Eczema is often the first manifestation of allergy in young children, who may go on to develop other allergic conditions such as asthma<sup>15-17</sup>. Rhinitis is a recognised risk factor for subsequent development of asthma, and treatment of rhinitis has the potential to improve asthma symptoms<sup>13</sup>.
- Although food allergy is unusual in adult patients with asthma, those with food allergy may also suffer from severe eczema, rhinitis and asthma. Indeed, asthma is a major risk factor for sudden death in patients with food allergy.
- Most of the deaths from anaphylaxis could be avoided with appropriate education and support<sup>18</sup>.
- Over 30% of the UK population have experienced symptoms of allergic rhinitis, asthma or eczema, and 20% are likely to be experiencing active allergies (St George's Hospital Medical School, unpublished research), yet these conditions may be trivialised, dismissed or treated inappropriately by GPs or alternative practitioners<sup>16</sup>.

### 4.2 Health service provision for patients with rhinitis and other allergies

- With the huge proportion of the UK population having a tendency towards allergic disorders, it is essential that most allergy cases are managed in primary care. However, allergy is not currently part of the undergraduate medical curriculum at most medical schools. GPs receive virtually no formal training in allergy, and current resources for post-graduate allergy training are limited.
- There are accredited training courses available for GPs and practice nurses, though take-up is currently low and few practices have access to personnel with such specialist training.
- With appropriate training and resources, allergy skin prick testing can be carried out in primary care to determine common trigger allergens in the majority of people with suspected rhinitis.
- Where skin prick testing in primary care is not appropriate (e.g. if there is the potential for a severe reaction, or in suspected occupational asthma with potential socio-legal consequences), patients should be referred to specialist services, with appropriate facilities (including resuscitation) for conducting advanced immunological tests.
- Currently, allergy in secondary care is usually treated by organ-based specialists (e.g. chest physicians, ENT specialists, dermatologists), despite the considerable overlap between allergic manifestations of this systemic disorder. In the UK, there are currently fewer than a hundred allergy clinics offering one or two sessions per week and staffed by organ-based specialists with a limited spectrum of diagnostic and treatment facilities. Such clinics should offer diagnostic skin prick testing, spirometry, and patient education on allergen avoidance, use of nasal and inhaler devices, and dietetic support.
- At present, there are few specialist allergy clinics within the UK (defined as consultant NHS allergists offering five allergy clinic sessions per week), with most located in the south east. Out-patient waiting lists for referral to these centres varies from 3 months to 2 years. Specialist provision is equivalent to one whole-time allergist per 2.1 million UK population, compared with one consultant per 90-100,000 for chest physicians<sup>16</sup>.

- To address the geographical inequality in allergy provision, each of the NHS regions should have a minimum of one specialist allergy clinic, consisting of at least two full-time allergists (or equivalent), a full-time specialist nurse in allergy, a half-time dietician with an interest in allergy and a minimum of one Calman specialist registrar in allergy (or two specialist registrars seeking dual accreditation in allergy and general medicine).
- Specialist centres should include facilities for allergen immunotherapy (e.g. for patients with allergies to insect venom), inhalation challenges (particularly for diagnosis of occupational allergens), and in-patient or day ward facilities for provocation testing (e.g. for drugs and foods). Immediate access to resuscitation equipment is required.

*Reasonable expectations for patients with rhinitis and other allergies*

***Patients with symptoms consistent with an allergic condition have a right to be taken seriously by primary healthcare professionals***

- Education of primary healthcare professionals on allergic conditions
- Collection of a careful history encompassing all potential manifestations of allergic conditions and evidence of atopy in other family members
- Consideration of the impact of symptoms on patient quality of life

***Patients with a potential allergic condition have a right to investigation of potential triggers and education on allergen avoidance***

- Allergen testing by appropriately trained healthcare professionals in primary or secondary care (as appropriate and according to local service configuration)
- Education of patients about avoidance of allergens as a way to control symptoms

***Patients with allergic conditions have a right to appropriate management***

- Awareness of all possible manifestations of allergic disease, with appropriate treatment in line with management guidelines
- Specifically asking all patients with rhinitis about asthma symptoms, and all patients with asthma about rhinitis symptoms, and ensuring that management of each manifestation takes the other into account
- Education of patients about warning signs for severe allergic reactions, with appropriate actions to take

***Patients with allergic conditions have a right to integrated healthcare services***

- Care in the primary sector for the majority of patients (i.e. diagnosis, identification of triggers and management)
- Referral to specialist allergy services when appropriate (e.g. for allergen testing where this cannot be carried out in primary care, or for suspected occupational asthma)
- Multidisciplinary care (e.g. dietetic advice, respiratory specialists, specialist nurse support)
- On-going support and advice for patients with potentially fatal allergies

*Checklist of key components of healthcare provision for patients with rhinitis and other allergies*

- Convenient access to a service appropriate to needs (i.e. through pharmacy or primary care team) with adequate staffing and resource to meet the need
- Education of primary healthcare professionals in allergy, simple diagnostic tools (e.g. skin prick testing) and appropriate management
- Patient education in allergen avoidance and the use of nasal and inhaler devices
- Secondary care centres with facilities for specialised testing
- Tertiary support in regional centres with adequate staffing by allergy specialists

# COPD

## 5 Chronic obstructive pulmonary disease

Chronic obstructive pulmonary disease (COPD) is usually a smoking-related disease, suffered by approximately one in six smokers, and resulting in over 30,000 deaths per year in the UK<sup>1</sup>. Currently, this condition is diagnosed at a late stage when the health interventions required to manage COPD are costly and damage to the lungs may already be severe. There is considerable scope to improve markedly the diagnosis of COPD, with earlier intervention having long-term benefits for patients, the health service and society as a whole.

### 5.1 The burden of COPD

- COPD primarily affects those aged over 45 years and is characterised by chronic slowly progressive decline in lung function, usually associated with exposure to cigarette smoke. The underlying pathology and presenting symptoms may vary. There may be excessive mucus production in the lung (chronic bronchitis) or inflammatory changes in the smaller airways leading to fixed airway narrowing and alveolar wall destruction (emphysema).
- In the early stages of COPD, patients are largely free of symptoms, but as the disease progresses, patients may report symptoms of cough, sputum production and breathlessness. Progressive lung function deterioration increases breathlessness and leads to premature disability, restricting daily living activities. Patients with severe COPD may become house-bound, socially isolated and depressed, with increasing dependence on carers, social and health services.
- Patients may also experience exacerbations, which occur with increasing frequency in patients with moderate or severe disease, and often require hospital management. In the final stages of COPD, often following a period of recurrent exacerbations, patients usually develop respiratory failure and become dependent on supplementary oxygen.
- As COPD is largely due to cigarette smoking, it is almost entirely preventable. Even after the decline in lung function associated with smoking has started, smoking cessation can prevent progression. Early diagnosis of COPD allows targeted efforts to support smoking cessation, improving prognosis.
- Therapy is available to ameliorate symptoms of COPD, while exercise-based rehabilitation programmes can reduce the disability associated with the disease.
- Over 600,000 patients have been diagnosed with COPD in the UK<sup>19</sup>, though it has been estimated that diagnosed patients represent only 25% of those with the disease<sup>20</sup>.
- There are considerable social inequalities associated with COPD, with the majority of sufferers among the least affluent of the population and in the urban conurbations.
- COPD is a major health problem, accounting for over 30,000 deaths, 1.4 million GP consultations and 1 million in-patient bed days every year<sup>19</sup>. The total annual cost of COPD to the NHS has been estimated at over £800 million<sup>21</sup>.
- As patients with COPD and their carers may lose time from work, COPD also has a considerable socio-economic impact. In the UK in 1994/5, 24 million working days were lost due to COPD, and the cost of lost productivity was estimated at £2.7 billion<sup>19</sup>.
- Because of the ageing of the population and the cumulative effect of smoking by women, the public health burden of COPD in the UK is likely to increase<sup>6</sup>. Worldwide, mortality from COPD is expected to increase from the sixth leading cause in 1990, to the third leading cause by 2020<sup>22</sup>.

### 5.2 Health service provision for people with COPD

- The prevalence and socio-economic burden of COPD, together with the individual suffering, highlight the need for local and national strategies for universal diagnostic screening services and effective management of this condition.

- Coherent and effective national and local policies towards smoking cessation are vital to the primary prevention of COPD, and the secondary prevention of COPD progression. Currently, the provision of smoking cessation services across the country varies widely.
- Although screening for COPD in primary care is possible with the simple and non-invasive measurement of lung function (spirometry) using relatively inexpensive equipment, this is rarely carried out, thereby losing the opportunity to target smoking cessation services at those at considerable risk of subsequent disease. The number of trained personnel able to carry out and interpret spirometric measurements is increasing, but still remains low. Ideally, spirometry should be available within each practice and offered by properly trained staff. Where it is not provided in this way, peripatetic technicians or open access to secondary care lung function laboratories should be arranged.
- As a progressive disease, patients with COPD must pass through mild and moderate stages before they have the most debilitating, costly and potentially fatal severe stage. Despite this, most patients with COPD are diagnosed only when the disease has progressed to the moderate or severe forms. Many patients with a smoking history who suffer repeated chest infections with sputum production are still treated with repeated courses of antibiotics and not investigated further for any underlying pathology.
- Despite the availability of accredited specialist training in the management of COPD, use and interpretation of spirometry, and smoking cessation, many practices lack the access to such appropriately trained personnel.
- Evidence-based guidelines for the management of COPD are available, but awareness and implementation is variable<sup>23,24</sup>.
- All patients with COPD should be identified and entered on a chronic disease register, to aid intervention strategies such as influenza vaccinations, anti-pneumococcal vaccination, structured review of prescribing and assessment for entry into rehabilitation programmes.
- Pulmonary rehabilitation services (providing exercise-based therapy to reduce disability) may be limited or not available in many places. As many patients with COPD suffer other co-morbidities (particularly cardiovascular problems also associated with smoking)<sup>25</sup>, there is considerable scope for integrated rehabilitation programmes to improve overall exercise tolerance with documented benefits on quality of life, ability to function and healthcare utilisation. Configuration of such services will depend on local facilities. Currently, most pulmonary rehabilitation services are led by secondary care teams of physiotherapists, though as understanding of COPD increases among primary healthcare professionals, it should be possible to have more community-based exercise programmes, which can be just as effective.
- Non-invasive ventilation (NIV) using a mask system for patients with acute exacerbations of COPD complicated by carbon dioxide retention has been shown to reduce mortality, and the need for intubation and invasive ventilation in intensive care<sup>26</sup>. Such an approach is recognised by the Department of Health to be valuable and should be considered the standard of care for acute respiratory failure in COPD, and yet provision of mask ventilation services for those with COPD is currently limited<sup>26</sup>. Healthcare professionals need education on NIV to understand its role in the management of exacerbations.
- All hospitals should have a dedicated acute lung service so that patients with COPD can receive full medical therapy, NIV and continuous respiratory monitoring until the exacerbation has stabilised. Facilities should also include access to pulse oximetry and analysis of blood gases.
- All intensive care units and respiratory wards should also have staff and specific equipment to deliver NIV as this is the initial treatment of choice for patients with COPD. NIV may also facilitate the weaning of intubated ventilated patients with COPD, and in this situation, NIV has been shown to improve outcomes and reduce length of stay<sup>26</sup>.

## ***All smokers have the right to coordinated smoking cessation services***

- Every practice and PCT should have a coherent and implemented policy on smoking cessation
- Accurate record-keeping at practice level to identify smokers
- All smokers should receive brief, non-confrontational and non-judgmental advice from all healthcare professionals at all consultations
- For those committed to quitting, there must be access to an appropriately trained healthcare professional, with the time and resources to undertake effective support during smoking cessation
- Smokers over the age of 45 years should be offered spirometric assessment every 3 years, with discussion of the findings with an appropriately trained healthcare professional

## ***Patients with COPD have a right to timely and accurate diagnosis***

- This requires education of the general public and healthcare professionals in primary care about the disease, its early signs and symptoms, and actions to be taken
- There should be a coherent policy on spirometry, with appropriate equipment and personnel trained in the use and interpretation of lung function tests, available either within the practice, within the PCT or by arrangement with hospital-based services
- Provision for spirometry in primary care should be increased, with appropriate training of personnel

## ***Patients with COPD have a right to management in line with approved guidelines***

- All patients with COPD should be entered on a practice chronic disease register to help ensure that they receive appropriate structured care
- Annual vaccination against influenza and pneumococci for all patients with COPD
- Each practice should have access to health professionals with appropriate specialist training in the management of COPD to provide patient education on the condition, the use of medication and appropriate response to exacerbations

## ***Patients with COPD have a right to access to pulmonary rehabilitation services from an early stage in their disease***

- Improving exercise tolerance can have a sustained positive effect on patient quality of life and ability to carry out daily activities, reducing health service utilisation
- Services can be provided in primary or secondary care, according to local facilities
- Ongoing support is required to maintain benefits

## ***Patients with COPD have a right to access to appropriate secondary care services***

- Early referral is required if diagnosis in doubt, in cases of suspected COPD in those below the age of 45 years, if there is rapid deterioration and for assessment for surgical intervention
- Hospital treatment (including NIV) may be required for the management of exacerbations that do not respond to treatment initiated in primary care

*Reasonable expectations for patients with COPD*

**Reasonable expectations for patients with COPD (continued)**


**Patients with COPD have a right to appropriate assessment and practical support for the use of supplementary oxygen**

- Assessment of blood gases is required prior to the onset of long term oxygen therapy
- Access to prompt assessment for supplementary oxygen
- Easy to use domiciliary oxygen

**Patients with COPD have a right to integrated health, social and palliative care services**

- Practices should ensure integrated care (primary and secondary specialists in COPD, physiotherapists, domestic home services) for optimal management of COPD
- With adequate support, patients with non-life threatening exacerbations can be managed at home (hospital at home)
- In the final stages, patients with COPD require the holistic approach of a palliative care team to aid symptom management and shape a care package

**Checklist of key components of healthcare provision for patients with COPD**

- Healthcare professionals with specialist training in COPD, spirometry and smoking cessation
  - Smoking cessation services
  - Spirometry available for screening and diagnosis
  - Registry of COPD patients
  - Vaccination programme specifically targeting COPD patients
  - Formalised assessment, review and recording of oxygen prescribing
  - Pulmonary rehabilitation services in primary and secondary care
  - Access to specialist respiratory services for diagnostic confirmation, assessment for surgical intervention and exacerbation management
  - Facilities for non-invasive ventilation (NIV)
  - Hospital at home for management of non-life threatening moderate to severe exacerbations
  - Palliative care services
- 

## 6 Other long-term respiratory diseases

Although asthma, COPD and allergic conditions are recognised as significant chronic respiratory diseases, there are other important conditions that should not be overlooked.

### 6.1 Obstructive sleep apnoea (OSA)

- The most common form of sleep-related breathing disorder is obstructive sleep apnoea (OSA). This is the temporary cessation of breathing during sleep, caused by the relaxation of muscles in the throat that obstruct the airway. Oxygen deprivation causes brief waking to stimulate breathing, and then the sufferer falls asleep again, often without being aware of the repeated pattern of sleep interruptions, though patients suffer daytime sleepiness.
- Most commonly, patients with OSA are middle-aged, overweight with a large neck and a previous history of snoring. Treatment is with continuous positive airway pressure (CPAP), using a mask over the nose during sleep. OSA can occur in children, most commonly due to enlarged tonsils – this is now the most common reason for tonsillectomy.
- OSA is common, affecting up to 5% of the population, and the condition is associated with significant cardiovascular comorbidity<sup>27</sup>. Patients with OSA may be up to seven times more likely than others to have road accidents<sup>28</sup>.
- From the perspective of society, treatment of OSA is highly cost-effective. It has been estimated that treating 500 patients with CPAP for 5 years would cost £0.4 million but would yield savings of £5.3 million due to prevention of fatal accidents, personal injury and property damage<sup>29</sup>. Currently, there are widespread geographical inequalities in the provision of services for the diagnosis and management of OSA.

### 6.2 Tuberculosis (TB)

- Tuberculosis (TB) is an infection caused by inhalation of *Mycobacterium tuberculosis* which may result in damage to the lungs and symptoms of cough (often accompanied by bloodstained sputum), chest pain, loss of appetite, weight loss and fever (particularly at night).
- With universal vaccination of children, there was a marked decline in the prevalence of TB, but since 1987 it has become more common again (particularly in those in contact with the elderly population in the Indian sub-continent, the immunocompromised and homeless people).
- Diagnosis requires hospital referral for a chest X-ray and examination of a sputum sample. There are other significant non-respiratory manifestations of TB (e.g. bone, kidney and lymph TB) which are looked after by respiratory services.
- Hospital isolation facilities may be required for patients during the initial week of treatment. Effective treatment is available but must be taken every day for 6-9 months.

### 6.3 Conditions requiring specialised respiratory services

- Tertiary services are required for patients with rare respiratory conditions (e.g. occupational lung disease, cystic fibrosis), as well as those with more common respiratory diseases that are difficult to diagnose or manage. It is important to ensure that the diversity of respiratory conditions is recognised, and the skill base to diagnose and manage this diversity is maintained.
- With improved management of the common chronic respiratory conditions in primary care, more costly secondary care can focus on rare conditions and those requiring hospital care.

*Checklist of key components of healthcare provision for patients with conditions requiring specialised respiratory services*

- Education of primary healthcare professionals on the diversity of respiratory conditions, to aid differential diagnosis
- For obstructive sleep apnoea, sufficient hospital facilities to meet the demand for diagnosis and management, based on prevalence of the condition
- For tuberculosis, adequate facilities for diagnosis, isolation of patients, and out-reach nurses for on-going support during maintenance therapy, with adequate public health support and back-up
- Maintenance of the skills base to address the diversity of respiratory conditions



*Reasonable expectations for patients with obstructive sleep apnoea (OSA)*

***Patients with suspected OSA have a right to timely and accurate diagnosis***

- The general public and primary healthcare professionals (GPs, practice nurses and pharmacists) require education on this respiratory disorder to increase awareness
- Adults presenting with the symptoms of heavy snoring and daytime sleepiness should be referred promptly to a specialist hospital clinic for a sleep study to confirm diagnosis
- There should be sufficient hospital facilities to meet the demand for diagnosis and management, based on prevalence of the condition
- Children with symptoms of snoring and daytime sleepiness, associated with daytime breathing difficulties, should be referred to an ENT specialist for possible tonsillectomy

***Patients with OSA have a right to appropriate management***

- When clinically appropriate, patients with OSA should be offered CPAP treatment for nightly use at home

*Reasonable expectations for patients with tuberculosis (TB)*

***Patients with suspected TB have a right to timely and accurate diagnosis***

- The general public and primary healthcare professionals (GPs, practice nurses and pharmacists) require education on this respiratory disorder to increase awareness
- Immediate referral for diagnosis is required for suspected TB
- Hospitals must have the facilities to cope with increasing demand for rapid diagnosis

***Patients with TB have a right to appropriate support during treatment***

- To be effective and to avoid the risk of resistant organisms developing, treatment must be taken regularly over a prolonged period
- Hospitals must have sufficient and appropriately trained personnel to ensure adequate support of patients with TB, including out-reach nurses to meet the needs of homeless people, and those able to communicate effectively with patients in ethnic minority groups
- The special needs of immunocompromised patients with TB must be met, with integrated care between respiratory and other specialists to tailor treatment packages (taking into account potential interactions between treatments for TB and HIV infection)

***The public has a right to well resourced public health teams to prevent TB infections and to contain outbreaks of the disease***

- It is vital that historic TB services are not dismantled
- All areas should continue to maintain monitoring of statutory reporting and have dedicated services for contact tracing, screening and TB management

*Reasonable expectations for patients with conditions requiring specialised respiratory services*

***Patients with conditions requiring specialised respiratory services have a right to expect appropriately trained healthcare professionals and adequately resourced services available to meet their needs for diagnosis and management***

- The diversity of respiratory conditions must be recognised, with maintenance of an adequate skills base

## 7 Delivering integrated respiratory healthcare

### 7.1 Organisation of service delivery

- Diagnosis and management of the majority of patients with common chronic respiratory diseases (e.g. asthma, rhinitis and COPD) must be provided at primary care level.
- It makes sense to ensure that respiratory services are delivered in an integrated fashion, taking into account the overlap in patient population and in the personnel providing care, as well as the need to ensure a seamless transition between primary and secondary care.
- Consequently, every PCT should have an identified clinical and non-clinical leader of respiratory services provided for the population, with a respiratory care commissioning team.
- There is a considerable skills base in the primary healthcare community, with over 6,000 GPs declaring a specialist interest in at least one respiratory condition (mainly in asthma) and over 15,000 healthcare professionals (primarily practice nurses) completing a diploma or degree level course in one or more respiratory condition (again, mainly in asthma).
- PCTs should ensure that these healthcare professionals are able to take a leading role in bringing about improvements in respiratory care at all practices within the trust.
- However, care must be taken that the workload of these primary care-based specialists does not prevent the maintenance of the valuable, generalist role. There is, therefore, a need to ensure more healthcare professionals receive the specialist training that they need to fulfil the roles expected of them in the future.
- The approach to configuring services can vary in different areas, depending on the skills available. Innovative solutions may be the best way to bridge the gap between current services and those required to fulfil patient expectations. Examples include the use of peripatetic specialist nurses to bridge the gap between primary and secondary care, and home care teams to provide personalised care packages in the community for patients with COPD.
- When considering how best to commission respiratory healthcare services, PCTs will need to assess the size of the problem and how care is currently provided, develop a service model that best meets local needs, implement the model and then evaluate the success of the approach, making any modifications that are necessary to bring further improvements.
- Cooperation with secondary care is vital. Hospital trusts also have to ensure that respiratory services are adequately developed to service the local community, providing facilities for the specialist care of acute respiratory disorders and adequate diagnostic facilities.

### 7.2 Education and training

- While many practices now have access to a nurse with specialist training in asthma care (and have seen consequent improvements in health outcomes in the asthma population), the skills base in COPD, spirometry, smoking cessation and allergy is woefully inadequate.
- If primary care is to fulfil the reasonable expectations of the majority of patients with COPD and allergy, each practice needs access to healthcare professionals across the primary care team with specialist education about these conditions and training in appropriate skills.
- PCTs should ensure that these multidisciplinary training needs are fulfilled as rapidly as practicable, with regular training updates – there may be scope for meeting this need by developing the role of the GP with a special clinical interest (GPSCI)<sup>30</sup>.
- The importance of patient education in chronic respiratory diseases must also be recognised and addressed.

### 7.3 Budget implications

- Treatment of respiratory conditions in primary care is predominantly medical, so that drug budgets can expect to rise as appropriate management is given to more patients at an earlier stage in diagnosis.
- However, it should be remembered that pharmaceutical products are part of the solution to rising healthcare costs, not part of the problem. Prompt use of smoking cessation products, together with appropriate support, is one of the most cost-effective of all healthcare interventions. Likewise, effective treatment for asthma or COPD that reduces the incidence of acute exacerbations may increase drug budgets but bring big savings in the need for costly hospitalisation, as well as benefits to patients in terms of improvements in quality of life.
- All PCTs need to appreciate that funding of education and medical interventions for respiratory care is an investment that can offset future NHS and societal costs arising from long-term ill health.
- Pulmonary rehabilitation is currently severely under-resourced, yet this can have long-term benefits by increasing functional ability of patients with COPD. All PCTs need to ensure that resources are invested in this important area, which may be integrated with cardiac exercise services or geriatric provisions, for maximum efficiency.

### 7.4 Bridging the gap between current service provision and reasonable patient expectations

- This report highlights the gaps that exist between the health services currently provided for patients with long-term respiratory diseases and those required to meet the reasonable expectations of these patients.
- Bridging this gap should bring benefits to:
  - patients, in terms of reduced mortality and morbidity
  - the NHS, in terms of reduced healthcare resource utilisation (e.g. unscheduled consultations, A&E visits)
  - society, in terms of reduced costs of lost working days.
- Those commissioning respiratory healthcare services have the opportunity to make a real impact. The Respiratory Alliance hopes that this opportunity will be firmly grasped.

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