19th October 2006

Dear colleague

SERVICE DEVELOPMENT AND COMMISSIONING DIRECTIVES: RESPIRATORY CONDITIONS

I am pleased to enclose a copy of the Service Development and Commissioning Directives for Respiratory Conditions which the Minister for Health and Social Services has approved for consultation.

This is part of a series of publications to support the redesign of care for chronic conditions as outlined in Designed for Life and is part of the Welsh Assembly Government’s integrated approach to tackle chronic conditions in Wales.

In line with Designed for Life this publication aims to ensure that the right services are provided in the right place and at the right time by refocusing services and resources to meet local needs. Care pathways for the effective treatment and management of these conditions will become the bedrock of service provision, supported by timely assessment and accurate diagnosis. The provision of services by integrated multidisciplinary and multi-agency teams will also become a key feature of managing these conditions across primary, secondary and social care where individuals will be supported to understand more about their condition and given increasing confidence to self-manage wherever appropriate.

Using these directives, commissioners and planners will deliver the important changes needed to develop services fit for the future and capable of improving the health, well being and quality of life of people living with respiratory conditions in Wales.
The consultation period will run for three months and to support this process a number of key questions have been outlined in the attached proforma. I look forward to receiving your comments and would be grateful if all responses could be sent to Rick Thomas, Strategy Unit, Department of Health and Social Services, Welsh Assembly Government, Cathays Park, Cardiff, CF10 3NQ by 12th January 2006. All responses may be published in line with our normal policy on consultation.

Helen Howson  
Strategy Unit - Uned Strategaeth  
Department of Health and Social Services - Adran lechyd a Gwasanaethau Cymdeithasol
Designed for People with Chronic Conditions

Service Development and Commissioning Directives

Respiratory Conditions
Designed for People with Chronic Conditions

Service Development and Commissioning Directives

Respiratory Conditions

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Foreword by Dr Brian Gibbons, Minister for Health and Social Services

I am pleased to introduce the Service Development and Commissioning Directives for respiratory conditions. This is part of a series of key documents that establish the direction we need to be working towards to help remodel services to improve the health and well being of people living with chronic conditions in Wales.

Respiratory conditions affect a large proportion of the population. They are life long conditions and have a dramatic effect on physical, psychological and social aspects of everyday life. Conditions such as asthma, Chronic Obstructive Pulmonary Disease, and Cystic Fibrosis are a leading cause of death and daily disability affecting all areas of life including employment, education and social relationships. These conditions account for a high proportion of emergency admissions to hospital and call for increasing levels of support from health and social care professionals.

Health and social care services are facing a growing number of pressures making it increasingly difficult to keep pace with the numbers of people consulting health professionals with chronic respiratory problems, rising demands for prescriptions, increasing needs to support daily living, and the resources needed to tackle these conditions. The current pattern of services has to change to meet these challenges and those presented by a growing number of older people in our society.

In line with Designed for Life this publication aims to ensure that the right services are provided in the right place and at the right time by refocusing services and resources to meet local needs. Care pathways for the effective treatment and management of these conditions will become the bedrock of service provision, supported by timely assessment and accurate diagnosis. The provision of services by integrated multidisciplinary and multi-agency teams will also become a key feature of managing these conditions across primary, secondary and social care where individuals will be supported to understand more about their condition and given increasing confidence to self-manage wherever appropriate.

Using these directives, commissioners and planners will deliver the important changes needed to develop services fit for the future and capable of improving the health, well being and quality of life of people living with respiratory conditions in Wales.

Dr. Brian Gibbons AM
Minister for Health and Social Services
Vision
Wales will have World class healthcare and social services in a healthy, dynamic country by 2015. The risks associated with developing chronic respiratory conditions will be minimised and respiratory health preserved. People with these conditions will be well informed, supported to take greater responsibility for their health and well-being where appropriate, able to self-manage and understand when to seek professional advice.

Services for people with respiratory conditions will be designed for a healthier population that have access to high quality patient-centred health and social care services. They will be locally provided and supported by specialist integrated multidisciplinary services and clear patient pathways of care. Early assessment and diagnosis will be made and access to specialist and secondary care services will occur as part of a plan agreed between the patient and health and social care professionals where all relevant agencies understand the role they have to play in managing a person’s condition. Effective support in the community will ensure that the people with chronic respiratory conditions are able to reach their full potential, maximise their independence and live fulfilled lives.

Introduction
The purpose of this document is to set out the key actions to improve the health and quality of life of people with respiratory conditions, promote the positive lifestyle changes needed to help prevent the onset of these chronic disorders wherever possible and to ensure that health and social care services provide the right services in the right place, and at the right time. These directives underpin the planning, commissioning and delivery of services for people with respiratory conditions in Wales.

The document is part of a series of strategic publications for redesigning the care of chronic conditions as outlined by Designed for Life: Creating World Class Health and Social Care for Wales in the 21st Century. It is aimed at the health and social care community – planners, commissioners, and providers of services – as well as people living with respiratory conditions, the voluntary sector, carers and wider support networks. All play important roles in contributing to improvements to the lives of people with these conditions in Wales.

These directives predominately focus on services for the adult population in Wales while fully acknowledging the All Wales Standards for Paediatric Respiratory Services and the wider work of the National Service Framework for Children, Young People and Maternity Services. The development and commissioning of respiratory services in Wales will need to take account of these key documents and other relevant publications.

This work has been compiled with the support of a multi-professional and multi-agency reference group. The group has put the needs of people with
respiratory conditions at the centre of this document and has called upon the advice of patients, health and social care professionals, the voluntary sector and others that support people with respiratory conditions. The report has benefited from the support of members of the Welsh Thoracic Society, leading health professionals in the field of respiratory medicine and people with respiratory conditions or caring for others with those conditions.

Sub groups have been involved in leading the production of this document and were able to draw advice from the National Institute for Clinical Excellence (NICE), the British Thoracic Society (BTS) and the Scottish Intercollegiate Network (SIGN). The document has also taken account of the recommendations of the Respiratory Alliance in the publication *Bridging the Gap*.\(^5\) COPD, Asthma, Community-acquired pneumonia, Cystic Fibrosis and Tuberculosis were addressed in detail by these groups.

**Why is this document needed?**

Respiratory diseases kill more than one in four of the United Kingdom population. They are the most common form of chronic illnesses and account for more deaths each year than coronary artery disease and non-respiratory cancer.\(^6\)

The long term effects of respiratory illness on people with these conditions are considerable and affect every aspect of daily life.

‘The long-term burden of respiratory illness imposes considerable personal discomfort’.\(^7\)

The Welsh Health Surveys of the 1990s revealed that, in males, between 1995 and 1998 the percentage of those surveyed who reported having current respiratory illness increased from 22.6% in 1995 to 23.5% in 1998, while during the same period for women the point prevalence rates were 20.7% and 22.7%. Across Wales some areas of the principality, notably our old industrial areas, reported rates as high as 28% in 1998, while other areas, particularly the more rural, were much lower, at 19%.\(^8\)

With the decline in occupationally acquired lung disease such as pneumoconiosis, the greatest contributor to premature death and morbidity from respiratory disease and carcinoma of the lung is cigarette smoking. This is still more prevalent in our deprived old industrial heartlands than in more affluent areas. These inequalities in life chances need urgent redress.

Admissions to Welsh hospitals resulting from respiratory infections are a significant factor requiring attention. During the period 1999 to 2004 – a time when only one small outbreak of influenza was witnessed – there were 147,750 admissions to hospital for respiratory infections, with an average length of stay of between six and seven days. The vast majority of those admissions, some 135,000, were emergencies.
The predominant conditions leading to emergency admissions during the period 1999-2004 were due to infections such as Community Acquired Pneumonia, with nearly half being caused by pneumococcal disease, influenza and exacerbations of COPD and asthma. There is great potential to reduce the need for emergency admissions to hospital by instituting preventative measures in primary and community care such as pneumococcal and influenza vaccinations. Ensuring adequate support structures are in place for people with respiratory conditions should also help people to live independently in their homes and reduce the need for emergency care.

‘Patients with severe COPD may become housebound, socially isolated, and depressed, with increasing dependence on carers, social and health services.’ (Bridging the Gap, The Respiratory Alliance, 2003)

Exacerbations of respiratory conditions have a significant impact on hospital bed usage. The majority of beds used in the NHS in Wales on a daily basis for respiratory disease are occupied by individuals over the age of 65 years, with the extreme elderly being the most dependent on hospital services.

Evidence shows that older people over the age of 65 years are admitted to hospital with respiratory disease for at least 11 days. Over the age of 80 years the average length rises to above two weeks, twice the average length of stay in our hospitals overall. Reducing this admission rate and supporting people in the community will dramatically improve the use of valuable hospital beds and enhance our ability to deal with epidemic disease.

Categories of Respiratory Conditions
This document addresses the key respiratory conditions which present the most problems to individuals and health and social care services in Wales. Table 1 provides further details of those conditions, sets out the key issues, and also indicates where further valuable information and guidance on the management and treatment of such conditions can be found to inform planning and commissioning decisions.

These key categories were addressed by a number of sub groups in detail to inform the production the respiratory service development and commissioning directives. Specific papers were completed by each sub group containing details of the incidence, epidemiology, diagnosis, treatment and management of these key respiratory conditions. The papers are available as a compilation resource document to complement these directives. The resource document offers an opportunity for commissioners and planners of services to focus on specific individual respiratory conditions in greater detail.
### Table 1: Summary of key categories of respiratory conditions

<table>
<thead>
<tr>
<th>Condition</th>
<th>Current problems</th>
<th>Key Solutions</th>
<th>Key Recommendations</th>
</tr>
</thead>
</table>
| **Chronic Obstructive Pulmonary Disease (COPD)** | - Progressive and non-reversible airflow obstruction  
- Encompasses chronic bronchitis, emphysema and some cases of asthma  
- Predominantly caused by smoking  
- Increasing prevalence with age | - Under and misdiagnosed  
- Confusion with symptoms of asthma  
- Inappropriate prescribing  
- Over 30,000 deaths per year in the UK | - Reducing smoking in public places and increasing smoking cessation activities  
- Health education/promotion and self management programmes  
- Improved early identification and detection  
- Integrated care pathway across primary and secondary care  
- Interventions from multidisciplinary health care team including palliative care  
- Development of Pulmonary Rehabilitation Provision of Non-Invasive Ventilation (NIV), Long Term Ventilation (LTV) and domiciliary oxygen therapy | - Continued unification of smoking cessation services by the All Wales Smoking Cessation Service (NPHS and LHBs)  
- Banning smoking in public places (Welsh Assembly Government)  
- Delivery of health education, health promotion and self management programmes (LHBs and Local Authorities)  
- Strengthening Multidisciplinary and multi-agency team based care including palliative care (LHBs, Trusts)  
- Development of care pathway (LHBs Trusts)  
- Achieve standards of the Quality and Outcomes Framework (GP practices)  
- Consideration of guidance and standards for Long Term ventilation (LHBs, Trusts, HCW) |
| **Asthma** | - Chronic inflammatory condition  
- Affects children and adults  
- Symptoms include wheezing and shortness of breath  
- Hyper-responsive to brochoconstrictor stimuli | - Affects 5.2 million people in the UK  
- 220,000 people treated annually in Wales  
- 69,000 hospital admissions resulting from poorly managed symptoms  
- Around 1,100 deaths each year in England and Wales | - Improved quality of care through individual patient management plans, patient registers in GP practices, and adoption of National Guidelines  
- Increased skills in primary care  
- Better integration between Primary and Secondary care  
- Improved audit systems  
- Condition specific education programmes and Expert Patient Programme | - Achieve standards of the Quality and Outcomes Framework (GP practices)  
- Development of local registers and audit mechanisms to monitor patients (GP practices)  
- Monitoring of overall quality of care (LHBs)  
- Development of care pathway  
- Ensuring adherence to national clinical guidelines (LHBs and Trusts)  
- Delivery of health education and self management programmes (LHBs and Trusts) |
| **Respiratory Infections** | - Range from mild common colds to more serious bacterial and viral infections  
- Conditions include tuberculosis, community acquired pneumonia, and influenza  
- May require treatment in hospital and can be life threatening especially in the elderly, those with existing respiratory and other health problems | - Increasing incidence of tuberculosis in the UK especially among migrant populations  
- Emerging threats from new diseases such as SARS  
- Annual threats of viral diseases including influenza and Respiratory Syncytial Virus (RSV) in winter months | - Targeted vaccination programmes  
- Active infection prevention, control and surveillance systems in Wales  
- Assessment of patients in primary care using validated early warning signs for viral and pneumococcal pneumonia | - Increase the uptake of influenza and pneumococcal vaccinations among the elderly and other high risk groups (LHBs and NPHS)  
- Improve surveillance of respiratory infections during winter months (NPHS)  
- Adopt TB Programme (LHBs, Trusts, GPs) |
| **Cystic Fibrosis** | - Most common lethal inherited/genetic disease  
- Requires two faulty genes to active it | - Most common life limiting inherited disease in Wales  
- 1 in 25 of the UK population  
- Screening arrangements for new born babies  
- Improved integration and shared care | - Establishing effective monitoring arrangements of patients (LHBs, Trusts, GPs)  
- Improving multidisciplinary team care approach | |
<table>
<thead>
<tr>
<th>Condition</th>
<th>Current problems</th>
<th>Key Solutions</th>
<th>Key Action required</th>
</tr>
</thead>
</table>
| **Diffuse Parenchymal Lung Disease (DPLD)** | - A generic term to describe a disparate group of over 150 conditions affecting small airways  
- Some conditions are self limiting, or regress when exposure to causative agent ceases.  
- A number of conditions result in progressive pulmonary fibrosis, hypoxia and death from respiratory failure | - Account for 15% of Chest Physicians workload in the UK  
- Incidence increasing in the UK  
- Shortage of Radiologists and Histopathologists with appropriate interest | - Diagnosis requires a multidisciplinary approach including Radiologists, Chest Physicians, Histopathologists and Thoracic Surgeon  
- Lung transplantation  
- Immunosuppressive therapy  
- Palliative Care | - Strengthening smoking cessation services (LHBs, NPHS)  
- Strengthening Multidisciplinary team based care including palliative care (LHBs, Trusts)  
- Exploring the development of a regional approach to treatment with link to transplant centre (LHBs, Trusts) |
| **Obstructive Sleep Apnoea** | - Disordered breathing while asleep  
- Increased risk of hypertension and diabetes | - Prevalence of 2-4% of the population in the UK  
- Disparate services across Wales | - Improved basic diagnosis  
- Access to appropriate diagnostic facilities in acute admitting medical units  
- Access to CPAP machines  
- Access to specialist centres | - Consideration of findings of review of sleep apnoea services (NPHS, HCW) |
| **Chronic Respiratory Failure** | - Impaired gas exchange leads to reduced oxygen tension in the blood (type 1) and may also increase in carbon dioxide level (type 2)  
- May be acute (e.g. in exacerbations of COPD) or chronic (e.g. Neuromuscular disorders and COPD)  
- Has high rates of mortality | - Variable care across Wales  
- Non-invasive ventilation (NIV) not available at all District General Hospitals in Wales  
- Few NIV facilities which increases the need for intubation and ventilation  
- Inadequate monitoring of oxygen requirements | - Availability of facilities for medical assessment and monitoring of oxygen requirements  
- Access to NIV delivered in a dedicated setting by experienced staff 24 hours a day  
- Improved data collection and audit systems of NIV services across Wales  
- Introduction of training for all junior medical, nursing and allied health professional staff | - Review of availability and access to diagnostic, assessment and NIV facilities across Wales (LHBs, Trusts)  
- Review of training requirements (Welsh Assembly, LHBs, Trusts) |
The Strategic Context
Health and social care services in Wales face major challenges, and changes are needed to the existing pattern of services to help meet the increasing demands on those services. New ways of working which are evidence-based, flexible, rooted in a cycle of evaluation and continual improvement, and which encourage innovation across organisational boundaries are needed to deliver patient-centred care that is fit for purpose in Wales. Strategic level partnership working across all key agencies is needed to agree common goals, avoid duplication and support the sustainable development of effective and responsive services.

The way ahead has been set out inDesigned for Life: Creating World Class Health and Social Care for Wales in the 21st Century. This aims to move the focus from acute illness to prevention and the early intervention of health problems, and to integrate services into community settings and closer to people’s homes where appropriate. It aims to engage patients, service users, health and social care professionals, planners and commissioners of services, and the wider general public, to ensure that services are well planned, effectively coordinated, and responsive to people’s needs.

The commissioning and development of specialist, integrated multidisciplinary services supported by care pathways and partnerships with the voluntary sector and carers, is needed to strengthen the management of chronic conditions. People need to be informed and supported to take greater responsibility for their health and well-being where appropriate and to understand when to seek professional advice. Services need to be patient-centred and more accessible in the community, with access to secondary care services occurring as part of an agreed care pathway where all relevant agencies understand the role they have to play in managing a person’s chronic conditions.

Key Principles and Aims
This document focuses on the needs of people with respiratory conditions in Wales and aims to:

- Maintain respiratory health and well-being in order to reduce the risks of illness, disability and premature death.

- Ensure early and accurate assessment and diagnosis, access to high quality, integrated and patient-centred services for the treatment and management of respiratory conditions.

- Ensure that people with respiratory conditions are partners in decision-making relating to treatments, services and support, and are empowered and supported to maximise their independence in all areas of life.
The Structure of the Document
These directives are built upon a strategic pathway of care, which underpins the patient journey where access to services, information and self-management cuts across each component (Figure 1).

Fig 1. Strategic pathway of care

The pathway of care applies to those people who:

a. are generally well and able to live fairly independent lives
b. have more significant care needs
c. have long term conditions
d. need emergency treatment or rapid access to social care
e. need elective care
f. require social care

Commissioning effective services
Strong commissioning is needed to improve respiratory health and ensure that services that are patient-centred, effective, accessible, and responsive to the needs of people with these conditions. Strengthening the commissioning process is needed to ensure that effective service developments are underpinned by local need and a continual cycle of review and improvement. Welsh solutions need to be developed in partnership with service users and adopted to meet the local challenges presented by chronic respiratory conditions. This will ensure that services are responsive to local needs as well as contributing to the delivery of the vision of rapid improvements in health and quality of life in Wales.

Key components for commissioning
- Review of the epidemiology of respiratory conditions
- Audit of current service provision in primary, secondary and social care
- Assessment of service users needs
- Joint planning to integrate services
Assessing the demands on services, the patterns of disease, and the needs of people with respiratory conditions including those from vulnerable and disadvantaged groups, will be a necessary starting point for commissioning services that are aligned to need. Commissioners will need to audit and review service provision by making use of available data from primary and secondary care, the voluntary sector, the British Thoracic Society’s annual audits, and the National COPD Resources and Outcomes Project (NCROP) undertaken by the Royal College of Physicians.\textsuperscript{10}

Local service users are an essential component in helping to determine how services can be best provided to meet their needs. Public and patient involvement will also need to be further encouraged to inform service developments for respiratory care.
<table>
<thead>
<tr>
<th>Setting the scene</th>
<th>Key Actions</th>
<th>By</th>
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<tbody>
<tr>
<td></td>
<td>With support from the National Public Health Service for Wales (NPHS), commissioners will assess population needs, audit and review services and utilise that intelligence to plan and commission services for people with respiratory conditions.</td>
<td>December 2007</td>
</tr>
<tr>
<td></td>
<td>Planners and commissioners of local respiratory services will engage with service users, families and carers to assist in the design, development, monitoring and evaluation of services.</td>
<td>December 2007</td>
</tr>
<tr>
<td></td>
<td>LHBs will establish an action plan to improve the provision of services for respiratory conditions and to ensure implementation of these directives.</td>
<td>March 2008</td>
</tr>
<tr>
<td></td>
<td>The Welsh Assembly Government will establish a mechanism to monitor and evaluate the implementation of these directives.</td>
<td>March 2008</td>
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</table>
Chapter 2: Prevention – Reducing the risks

Aim – To maintain respiratory health and well-being in order to reduce illness, disability and premature death

Background
A number of factors contribute to the development and progression of respiratory illness. The most significant are smoking, respiratory infections and obesity.

Coordinated preventive action is needed to reduce the risks of developing respiratory conditions. The responsibility for this is wide ranging and includes the public, patients and their carers, employers, health and social care staff and other professionals such as teachers and school nurses.

Treatment and management interventions, including pharmacological treatments, self care and self management, as well as social care support in the community are needed to help maintain the well-being and respiratory function of people with established conditions. Effective and integrated support mechanisms from healthcare, social care and the voluntary sector are also essential to help improve the quality of life of individuals, maintain their independence and reduce the risk of avoidable emergency admissions to hospital and premature death.

Types of prevention
The key types of prevention referred to in this document are:

**Primary Prevention** – Preventing the onset of respiratory conditions by focusing on the wider determinants of health including lifestyle choices, individual behaviour and environmental factors (Chapter 2)

**Secondary Prevention** – Slowing or halting the progression of respiratory conditions through early detection, accurate diagnosis, treatment and management, and effective follow up (Chapter 3)

**Tertiary Prevention** – Reducing personal disability and maintaining quality of life and independence by focusing on rehabilitation and appropriate support in the community (Chapter 4)

Awareness of causes
Raising awareness of the causes associated with the development of respiratory conditions can help to prevent and minimise the impact of those disorders. Effective communication and the availability of relevant and high quality information and evidence based interventions are needed to:

- Identify the causes of respiratory problems
Help identify the early symptoms of respiratory disorders
Understand the impact of those conditions on people’s lives
Identify tools and techniques for effective self care and self management
Understand when self management is safe and effective
Inform people when to seek professional advice

Information on respiratory conditions should be appropriately targeted and is important at three levels:

- **The general public:** Health-promotion information and campaigns should educate the public and contribute to a better understanding of how to prevent and manage respiratory illness. A whole population approach can help to educate the public to minimise the risks associated with the development of respiratory illness. This should include information on obesity, healthy diet, exercise, the dangers of smoking, and the impact of the environment and the work place on respiratory health.

- **The Patient:** A variety of resources should inform and educate patients about their condition and the wider implications of living with that condition. Interventions or courses should be made available locally to help people learn new ways of coping better with the day to day management of their condition and their lives. Good quality information should be provided from a variety of sources including statutory and voluntary sector organisations to help people understand more about their conditions and how manage them safely and effectively. Good quality information can improve outcomes for individuals with respiratory conditions and help them become active partners in their care.

- **Health and Social Care Professionals:** Communicating advice on managing respiratory conditions should be an integral part of the education and training of all healthcare providers. Health professionals need to understand the most effective ways to manage the risks associated with the development of respiratory conditions. In addition to the treatment and management of respiratory conditions, health and social care professionals have an important role to play in helping people with respiratory conditions understand how to minimise the risks of further complications to their conditions and how to live as independently as possible in the community.

The responsibility for education and information, in this context, is wide. It should include the Welsh Assembly Government, the health and social care community, educational establishments, the voluntary sector, other public sector organisations, and the private sector. The general public, and people living with respiratory conditions, also have individual responsibilities to for their health and well-being and need advice and information about how to make positive lifestyle changes. People with respiratory conditions may lack the skills and appropriate techniques that are conducive to effective self management and self care. They should therefore be made aware of initiatives like the Expert Patient Programme and condition specific courses delivered by the voluntary sector such as the Breath Easy initiative.
Smoking
Smoking is the greatest preventable cause of illness, disability and premature death in Wales. Half of smokers are expected to die from a smoking related disease. Most are expected to die from one of three main diseases caused by smoking – lung cancer, chronic obstructive lung disorder (bronchitis and emphysema) and coronary heart disease.

Smoking also damages the health of non-smokers. In 1998 the UK Government appointed Scientific Committee on Tobacco and Health issued a major report which concluded that exposure to second-hand smoke causes lung cancer and heart disease in adult non-smokers and respiratory disease, cot death, middle ear disease and asthmatic attacks in children.12

‘Parental smoking doubles the chances of smoking uptake by children.’13

Stopping smoking has many health benefits for individuals and those around them. It reduces the risk of smoking-related respiratory illness and death within a relatively short period after quitting. Providing motivational support to smokers who wish to quit has been demonstrated to be effective in significantly increasing the rates of quitting.14

Early diagnosis of respiratory conditions, particularly COPD, can help to ensure that appropriate health interventions are introduced to help reduce the risks of further damage to the lungs. It is essential to encourage people diagnosed with COPD and who smoke to quit smoking, in order to help slow down the progression of the disease. It is also important that messages to help prevent the uptake of smoking are provided to all age groups, in order to reduce the risks of COPD.

Smoking cessation is the most important intervention in modifying the course of disease, preventing onset in those who give up at an early stage and slowing the rate of progression of loss of lung function in those with more advanced airways dysfunction.15

‘Smoking cessation interventions are effective and should be incorporated into the routine practice of medicine in healthcare systems.’16

Smoking cessation services should be provided by primary and secondary care services in Wales. General Practitioners, secondary care respiratory health professionals, dentists and other health professionals should provide the motivation and support to help people stop smoking across the care pathway. Community pharmacists should also play an important role in supporting people to quit smoking through the provision of advice on healthy lifestyles and by signposting people to further support and advice.

The All Wales Smoking Cessation Service (AWSCS) was established in 2003. It is a community-based service delivered and managed by the National
Public Health Service (NPHS) through a Service Level Agreement with the Welsh Assembly Government. It provides a standardised withdrawal-orientated treatment model with clients accessing sessions outside working hours. The AWSCS also provides data to LHBs and Trusts to ensure that the links with primary and secondary care are established and GPs, dentists, pharmacists and other health professionals are encouraged to provide interventions and referrals.

Health and Social Care bodies should continue to build upon existing local health-promotion campaigns and programmes of smoking cessation to help create a smoke-free Wales.

The Welsh Assembly Government is committed to banning smoking in public places. The Health Bill which completed its consideration by Parliament early in 2006, devolves powers to the National Assembly for Wales to make regulations for a ban on smoking in enclosed public places in Wales. Regulations will be issued which cover issues such as exemptions to the ban on smoking in enclosed public places and workplaces, the no-smoking signage requirements and arrangements for enforcement of the ban. The new law is expected to come into force by summer 2007.

**Respiratory Infections**

Respiratory disease caused or exacerbated by infections accounts for a significant level of morbidity and mortality in Wales, the impact of which is felt across primary, secondary and social care.

During the winter months increased demand is placed on the NHS. Influenza is an important contributor to the excess mortality that occurs every winter. It carries an increased risk of serious illness such as Community Acquired Pneumonia, which can result in admission to hospital and deaths in the most vulnerable in society – particularly those with chronic conditions, the immunocompromised and the elderly.

Increasing demands are being placed on the healthcare sector from the rise in infections. The increasing cases of tuberculosis, HIV/AIDS infections, the increasing number of people surviving following chemo or radio therapy, and people requiring long term immunosuppressive therapy demand effective prevention and control policies, particularly in our hospital settings. The current human pandemic threat that may arise from the mixing of avian influenza in birds and human influenza is a timely reminder of how vulnerable we are to epidemic infectious disease. Recent experience with Severe Acute Respiratory Syndrome (SARS) in the Far East and Canada has also exposed the vulnerability of modern health care systems to contagious disease and has provided valuable lessons to help us plan for the next human pandemic, whenever that should be.

The impact of respiratory infections can be reduced by more effective use of vaccines, and by reducing the inappropriate prescribing of antibiotics to help reduce the morbidity associated with the rise in drug resistance. Not all respiratory tract infections are preventable but attention to detail in infection prevention, control and surveillance is crucial for future respiratory health and
well-being in Wales. It is essential that patients with chronic conditions, the immunocompromised, and the elderly, are covered by the annual influenza and pneumococcal immunisation programmes to help reduce serious illness, hospital admission and deaths caused by infections and their often-attendant complications.

A number of steps have been taken to address the control and surveillance of respiratory infections. Guidance on arrangements for the influenza and pneumococcal immunisation programmes is contained within Welsh Health Circulars (2005) 34 and (2005) 65. Algorithms for influenza and influenza-like symptoms are also available to health professionals in the Green Book – accessible via the Health of Wales Information Service web site.\textsuperscript{18}

Guidelines have also been developed by the NPHS TB Programme Group for the surveillance, diagnosis and management of TB cases. NHS organisations will be expected to adopt these guidelines. This will require collaboration within and between organisations and integration into policy at a local level. NHS Trusts, LHBs, GP practices and Health Protection Teams in adopting these standards will also be expected to set up appropriate systems in which to audit and measure compliance.

**Healthy Diet**

A balanced and healthy diet has many benefits for health and well-being. Reports indicate variable evidence of the links between diet and respiratory conditions,\textsuperscript{19,20,21} but one recent study has shown that the daily consumption of fruit and vegetables in infancy is significantly associated with lower levels of asthma in school-age children.\textsuperscript{22} While these findings require further confirmation they indicate the importance of targeted health promotion campaigns to increase the intake of fruit and vegetables for those most at risk of developing respiratory conditions – particularly infants, smokers, and ex-smokers.

Recent evidence has highlighted an association between the increase in asthma and obesity in children in Wales.\textsuperscript{23} The importance of losing weight for obese asthmatics has also been demonstrated to be effective in improving asthma control.\textsuperscript{24}

Obesity coupled with sedentary lifestyles has a marked impact on respiratory function. People who are obese have an increased risk of a number of health problems including high blood pressure, cardiovascular disease and, in terms of respiratory function, are susceptible to obstructive sleep apnoea. This condition, which is defined as five or more obstructed breathing events per hour during sleep,\textsuperscript{25} adds to the risks of road traffic accidents and injury at work as a result of excessive somnolence. As the prevalence of obesity continues to rise it is likely that the number of people with obstructive sleep apnoea will increase over coming years.

The Welsh Assembly Government supports the integration of nutrition and physical activity policies and programmes, where appropriate, recognising the fact that the effects of diet and physical activity on health often interact. A number of existing strategies and initiatives recognise the importance of work
to improve nutrition and levels of physical activity, particularly among children and young people and it is important that these key messages continue to be built upon 26 27.

The Environment
Good air quality is essential for good respiratory health and quality of life. The health effects of air pollution have been subject to intense study in recent years. Evidence suggests that high concentrations of air pollutants in the atmosphere may exacerbate symptoms for those suffering from some respiratory conditions, although the health effects of air pollution will be subject to further scientific interest for some years to come. 28 Interventions should be made where appropriate to ensure that people with respiratory conditions are made aware that their symptoms may get worse during periods when air pollution is high, and that advice can be given to individuals on actions that can be taken to help prevent exacerbations of their conditions.

Similarly there is scope for developing plans to target people at the highest risk of respiratory exacerbations from respiratory infections and seasonal changes in weather. Opportunities to use existing data and systems for monitoring service demands should be explored, as well as considering innovative approaches and models linking respiratory health to environmental conditions. The current work that the Met Office is taking forward on COPD health forecasting and anticipatory health care provides a good example of this. 29 An early evaluation of this scheme concluded that ‘the predictability of week to week variation in risk of COPD admission offers the basis for improving the management of COPD patients through forecast-responsive care pathways’ 30.

Occupational exposure to certain dusts, fumes, irritant gases and vapours can also lead to the development of some respiratory conditions. Occupational factors are known to contribute to the development of asthma, and there are reports which suggest COPD is made worse by some working environments. Additionally, it is predicted that prior exposure to asbestos will lead to an increased number of thoracic conditions.

Health and safety is a non-devolved issue and remains with the Health and Safety Executive. The control of respiratory sensitisers at work is covered by Control of Substance Hazardous to Health regulations (COSH 2002) 31.

The Welsh Assembly Governments Corporate Health Standard is the national mark of quality in workplace health and well being. This programme provides support to organisations to help them to improve the health and well being of their employees. The Corporate Health Standard is endorsed and supported by the Health and Safety Executive and covers a broad range of workplace health issues including occupational health.

Pulmonary Rehabilitation
Pulmonary rehabilitation plays an important role in reducing disability in people with lung disease and COPD and improving their quality of life while diminishing the health care burden. 32 This type of intervention can reduce the overall cost of lung disease and is an important measure which can help to
reduce the need for admission to hospital while reducing the length of hospital stays when admission is necessary (see chapter 4).
<table>
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<tr>
<th>Prevention: reducing the Risks</th>
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<tr>
<td><strong>Key Actions</strong></td>
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<tr>
<td>Commissioners supported by the National Public Health Service for Wales (NPHS) will ensure that evidenced-based primary and secondary prevention measures addressing local needs are integral to services and care pathways for people with respiratory conditions.</td>
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LHBs will work in partnership with the NPHS to ensure that smoking cessation services are accessible to all, with key targets for people with established respiratory conditions.

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LHBs in partnership with relevant other organisations, will ensure that appropriate information, advice, and support are provided to the general public and targeted at those with chronic respiratory conditions.

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LHBs in partnership with the voluntary sector and relevant organisations will ensure self management courses are accessible to people with respiratory conditions.

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LHBs in partnership with the NPHS will ensure infection prevention, control and surveillance systems are in place across Wales and that appropriate audit systems are established.

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Chapter 3 - Diagnosis, Treatment and Management

Aim – To ensure early and accurate diagnosis and access to high quality, integrated and patient-centred services for respiratory conditions

Background
The diagnosis, management, and treatment of respiratory conditions cut across the organisational boundaries of primary, secondary, tertiary and social care. Coordination between appropriate health and social care professionals is key to addressing the burden placed upon patients and health and social care services by respiratory conditions.

There is considerable scope to improve the diagnosis, treatment and management of respiratory conditions in Wales. Care that is planned, coordinated and integrated across the health and social care sectors should be strengthened to help limit the impact of respiratory conditions on individuals and services. Early intervention can have long-term benefits for people with these conditions, health and social care services in terms of resource utilisation, and for society as a whole.

CORE SERVICE ELEMENTS
The provision of effective respiratory care relies upon strong core elements of service provision. The following core elements should be strengthened in respiratory care in Wales:

i. Adherence to national guidelines
There are a wide range of nationally recognised guidelines which provide evidence of good practice and recommendations on service delivery for respiratory health care. NICE guidelines, British Thoracic Society guidance, and the Scottish Intercollegiate Network (SIGN) guidelines are key sources of information which should guide the development and provision of services. It is important that the assessment, diagnosis, treatment and management of respiratory conditions consistently adhere to guidance which is both evidence based and supported by key professional bodies. A list of the main sources of clinical guidance are provided in appendix A.

ii. Care pathways
The effective coordination of treatment and management of respiratory conditions by a multidisciplinary team should be achieved through locally agreed protocols and guidelines which support clear pathways of care. This should ensure a consistent approach to patient care which is focused on the individual and which ensures that all health and other professionals involved in caring for and supporting people with respiratory conditions are working to agreed goals and within defined areas of responsibility.

Integrated Care Pathways (ICPs) provide one example of how care can be structured. ICPs determine locally agreed practice, based on guidelines and evidence where available, for a specific patient/client group. They form all or
part of the clinical record, document the care given and enable the evaluation of outcomes allowing for continuous quality improvements to be made.\(^{33, 34}\)

### ‘An Integrated Care Pathway amalgamates all the anticipated elements of care and treatment of all members of the multidisciplinary team, for a patient or client of a particular case-type or grouping within an agreed time frame, for the achievement of agreed outcomes.’\(^{35}\)

A number of examples of ICPs for respiratory conditions can be found in the National Library for Health located at [http://libraries.nelh.nhs.uk/pathways](http://libraries.nelh.nhs.uk/pathways).

### iii. The organisation of care

Comprehensive treatment and management needs to have a range of integrated components which include public and patient education, community social support services, and good primary, secondary and tertiary care.

### Services should be effectively coordinated by integrated multidisciplinary and multi-professional teams supported by shared care arrangements, locally agreed referral protocols, and clear pathways of care.

The development of individual patient care plans supported by condition specific patient education and life skills training, which promote safe and effective self-management are also important aspects of managing respiratory conditions.

The art of good management lies in the identification of individual needs and the development of knowledge of the condition, the skills to manage it, and ensuring access to care, supported by the most appropriate services. For this to be most effective, the individual needs to be at the heart of the process and fully engaged in decision making. Treatment and management also requires knowledge of conditions and their consequences, and an appreciation of the appropriate resources which can help support individuals live as independently as possible.

Prompt and appropriate treatment interventions to address the amelioration of the disease process and its consequences are necessary to limit the progression of respiratory disease. The effective management of chronic respiratory conditions should take a holistic approach by helping people learn to cope with the physical, psychological, social and wider aspects of the condition in their everyday lives. Local multidisciplinary teams are central to ensuring a holistic approach to care for people with chronic respiratory conditions.

The way services are organised is important to the outcomes for people with respiratory conditions. Well organised services should ensure that people with these conditions have access to the right professional to ensure early diagnosis and the prompt initiation of treatment and management interventions to limit further deterioration of lung function. Informing people about their condition to help them confidently self manage is also an important
component of the health and social care continuum which allows people to take greater control over their lives. Commissioners of health services should ensure that the key components of care are brought together effectively.

iv. Access to assessment and diagnostic support
Timely and accurate assessment and diagnosis of respiratory illness is the first key stage to ensuring that respiratory health is preserved, treated and managed as quickly and effectively as possible.

Members of the primary care team including GPs, practice nurses, and pharmacists are usually the first point of contact for people with respiratory conditions. They should play an important role in the initial assessment of an individual’s respiratory health. Making a clear and accurate diagnosis is a crucial part of the patient journey which can help to preserve respiratory health and reduce the risks of deterioration of respiratory function. Healthcare professionals in primary care require training and access to assessment and diagnostic services to help make an accurate diagnosis. It is also important that primary care professionals are supported in this process by specialist respiratory physicians as part of a multi-disciplinary approach to health care.

A number of respiratory conditions can be diagnosed and managed in a primary care setting. The appropriate equipment, recruitment and training to enable accurate interpretation of results are needed to enable this to take place. More complex conditions that are difficult to assess and diagnose such as Diffuse Parenchymal Lung Disease (DPLD) and more rare respiratory conditions such as Cystic Fibrosis and interstitial lung disease, require specialist diagnostic support from tertiary services. The provision of tertiary diagnostic services will rest upon commissioning and planning decisions at local and regional levels and it is vital that those decisions are underpinned by a clear understanding of the needs of people with respiratory conditions.

The future configuration of services will benefit from improved access to diagnostic services that span primary, secondary and tertiary care. Improved access, strengthened by appropriate training of healthcare professionals is needed for spirometry testing, oximetry, and chest radiographs in primary care. More specialist diagnostic support facilities such as thoracic imaging, high quality chest radiographs, computer tomography, bronchoscopy, polysomnography, and oxygen assessments should be available for more complex respiratory conditions in secondary care settings.

The provision of assessment and diagnostic services that are seamless between primary, secondary and tertiary care settings should be achieved through the development of effective referral protocols between primary and secondary care, strengthening clinical leadership across multi-disciplinary teams to ensure learning and innovation. The development of direct access schemes to more specialised diagnostic services should also be considered as part of the commissioning process.
v. Multi-disciplinary team-based care

There is evidence that multi-disciplinary care benefits people with respiratory conditions. NICE guidelines recommend in particular that care and support for people with COPD should be provided by a multidisciplinary team\textsuperscript{36}. There is evidence that care coordinated by a specialist multidisciplinary team can improve outcomes for high risk patients and for rarer conditions such as Cystic Fibrosis\textsuperscript{37}. People with chronic respiratory conditions should have access to a multi-disciplinary team that has defined and overlapping roles.

Early assessment, diagnosis, treatment and management of respiratory conditions should be delivered by a multidisciplinary and multi-agency team of health and social care professionals. This team should include respiratory physicians, respiratory technicians, GPs, psychologists, occupational therapists, physiotherapists, extended scope practitioners, pharmacists, social workers, dieticians, self management trainers and other professionals that can complement packages of care. These professionals cover all care settings from primary to tertiary care, and a well organised multi-disciplinary team should ensure that services are provided on a multi-agency basis across the whole system of health and social care.

Multi-disciplinary care teams that are integrated across health and social care should help to bridge the gap between primary and secondary care. This model of care also presents opportunities to ensure that care is shared and provided in a timely way, in the most appropriate setting and, by reaching out into the community, as near to the patient’s home as possible.

Multi-disciplinary teams should facilitate access to a wide range of support in the community, including physical, emotional, social and practical support as well as appropriate therapies and rehabilitation. This is particularly important for older people and disadvantaged groups who may find it more difficult to get access to appropriate services. The location and design of clinics is also important to ensure that the needs of people with a range of physical impairments associated with respiratory disorders, including mobility difficulties, are effectively met. The provision of peripatetic outreach respiratory care and domiciliary home care support teams to provide personal packages of care in the community can help to overcome barriers to accessing services where evidence suggests that this is effective\textsuperscript{38}.

vi. Primary care services

Respiratory conditions take up a considerable amount of time in primary care. All GPs should have a general knowledge of and training in managing respiratory illness, the relevant diagnostic procedures and treatments, and pharmacological and non-pharmacological interventions.

General practices should have access to GPs and nurses and other members of the extended primary care team with specialist education about respiratory conditions and training in appropriate skills\textsuperscript{39}. This should improve the outcomes for individuals with common respiratory conditions by helping to provide accurate assessment, diagnosis and timely treatment and management interventions.
‘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.’ (Bridging the Gap, The Respiratory Alliance, 2003)

The Quality and Outcomes Framework (QOF) is a key component of the General Medical Services contract for general practices which aims to improve quality of health care in primary care. The QOF rewards practices for the provision of quality health care, and helps to support further improvements in the delivery of clinical care. While participation by practices in the QOF is on a voluntary basis, the QOF measures the achievements of practices against a range of evidence-based clinical indicators, and against a range of indicators covering practice organisation and management developed to improve quality of care.

The QOF includes key indicators for Chronic Obstructive Pulmonary Disease, Asthma and Smoking Cessation. These indicators reward practices for maintaining records or registers, the initial management, and ongoing management. Achieving the highest levels of care against the QOF criteria will help to drive up quality of care in primary care, ensuring improved assessment and diagnosis, treatment and ongoing management of these respiratory conditions. The utilisation of data collected through QOF should also help to inform and improve the management of high risk individuals as well as providing key information to inform local commissioning decisions.

Further information on the QOF indicators for respiratory conditions can be found at: http://www.wales.nhs.uk/sites3/home.cfm?orgid=480

vii. Secondary and specialist care
Specialist respiratory physicians play an important role in diagnosing and treating complex respiratory conditions. Respiratory conditions that are difficult to diagnose and manage and which need intensive support require expertise based upon the relevant training, qualifications and experience found in the secondary care sector. As a key part of the multidisciplinary respiratory team, respiratory consultants should also provide clinical leadership and direction for other members of the team. The multidisciplinary team has a key role to play in ensuring that specialist respiratory health professionals have the capacity to attend to the most complex respiratory conditions.

‘Respiratory services should be adequately developed to service the local community, providing facilities for the specialist care of acute respiratory disorders and adequate diagnostic facilities.’

People with complex respiratory conditions may require long term contact with specialist services, while some may only require limited contact and follow-up appointments with a respiratory physician. Opportunities to manage these chronic conditions in community settings, where clinically appropriate, should be maximised by strengthening the role of multi-disciplinary team-working,
and shared care arrangements between primary and secondary care health professionals.

**Strategies aimed at preventing admissions and instituting supportive environments in the community to allow early and supported hospital discharge would dramatically improve the availability of beds for unplanned episodes of care.**

It is important that packages of care receive regular periodic review. Specialists in respiratory health should play a leading role in developing care pathways and supporting members of the multi-disciplinary team to coordinate the package of care. They also have a key role in directing change in management and treatment when required. Specialist departments can also play a key role in supporting patient education and leading in the management of complex therapeutic regimens.

**Case studies in Wales**

The Pontypridd and Rhondda Early Discharge Scheme was set up in April 2001 to facilitate early discharge from hospital following a mild to moderate exacerbation of COPD. The service supports some 150 patients a year and allows people to be appropriately discharged into the community and supported in their own homes. The service depends on cooperation between secondary, primary, and social care services and requires a strong multidisciplinary and multi-agency team approach with well established arrangements across health and social care settings.

The scheme is highly valued by patients, carers and health professionals. It has safely and effectively reduced the average length of stay in hospital to 2.2 days and is estimated to save nearly 1300 bed days.

This model of care has been successfully adopted in other areas of Wales including Wrexham, Bangor, Neath/Port Talbot, and Swansea.

**viii. In-patient and out-patient care**

It is essential that people with respiratory conditions that are admitted to hospital should benefit from access to a respiratory specialist and members of the respiratory multi-disciplinary team which can advise other health professionals on their respiratory needs.

Twenty-four hour access to facilities for acute respiratory support, including non-invasive ventilation, is also imperative for people with respiratory conditions admitted to hospital as an emergency. The training of staff to administer such therapy on an emergency basis is also vitally important.

Evidence indicates that people with progressive, life-limiting respiratory conditions such as COPD, have a poor quality of life, high levels of anxiety, unmet symptoms, and inadequate access to psychological support and palliative care services. Access to palliative care services for people with
end-stage respiratory disease should also be available for the individual, their families and carers at all stages of their illness and in all appropriate settings. This should be multi-disciplinary in nature and managed within current guidelines\(^43\).

ix. Pulmonary Rehabilitation

Pulmonary rehabilitation is defined by NICE as a multi-disciplinary programme of care for people with chronic respiratory impairment that is individually tailored and designed to optimise the individual’s physical and social performance, and their autonomy\(^44\). It can benefit all people with lung disease whose lifestyle is adversely affected by chronic breathlessness\(^45\). This includes people with a diagnosis of COPD, chronic asthma, pulmonary fibrosis, and bronchiectasis.

Pulmonary rehabilitation should be a truly multi-professional and multidisciplinary approach comprising of a number of mutually-supportive interventions including physical training, physiotherapy, dietetics, occupational therapy, psychology, education, smoking cessation, social support and life skills advice and training.

**Pulmonary rehabilitation should be supported by an appropriately trained and resourced team which can include:** -

- Respiratory nurse
- Physiotherapist
- Dietician
- Pharmacist
- Voluntary Sector support e.g. Breath Easy Groups (British Lung Foundation)
- Medical Practitioner
- Occupational Therapist
- Social Worker
- Psychology input

Evidence indicates that pulmonary rehabilitation is an effective multi-disciplinary intervention which, when provided to people with COPD whose exercise capability is limited, can have beneficial outcomes\(^46\). Trials have also indicated that this approach is cost-effective and can be provided in different settings, including in-patient and out-patient settings and on an outreach basis in people’s homes where possible. There is also potential for primary care to take a key role in pulmonary rehabilitation as part of a multidisciplinary approach which has been investigated further in recent studies\(^47\).

**Success of rehabilitation programmes is attributed to the multi-professional team.**\(^48\)

The benefits of pulmonary rehabilitation are reported to be improvements in exercise-tolerance, health status, dyspnoea, and a reduction in usage of health services\(^49\). It has been reported that one third of patients may retain significant improvements in health status following a 4-12 week rehabilitation programme for up to two years after the programme has ended\(^50\). Importantly it has also been reported that these benefits are independent of age or the severity of the condition\(^51\).
Rehabilitation programmes should be sensitive to the limitations that the individual may have as result of their respiratory condition which include difficulties travelling. Transportation is a key issue for realising the benefits of pulmonary rehabilitation and these issues should be addressed by commissioners and service providers on a multi-agency basis at the design stage of rehabilitation programmes.

x. Oxygen Therapy
The provision of domiciliary oxygen, including long term oxygen therapy, short burst oxygen therapy and ambulatory oxygen can play an important role in helping people with respiratory conditions such as COPD and Cystic Fibrosis to live at home as independently as possible. This therapy has clear benefits for appropriately selected patients and it is important that guidance is adhered to when prescribing this intervention. NICE guidance has specified which indications of COPD should require long term oxygen therapy. New arrangements have been introduced to improve the provision of oxygen therapy services in Wales. A single contract covers the supply of oxygen facilities, including the installation of oxygen concentrators, and prescription of the therapy is now authorised following assessment by specialist teams. This approach is supported by evidence that specialist assessment will ensure the appropriate prescribing of oxygen therapy in line with guidance produced by the British Thoracic Society. The new service is in line with the vision set out in Designed for Life, which aims to treat people in the most effective and appropriate way and setting.

Case Studies in Wales
Local Health Boards have worked hard on the implementation of the new contract for domiciliary oxygen. An example of good practice can be found in the Blaenau Gwent LHB area. Patients are assessed in accordance with protocols agreed by the Welsh Thoracic Society and the most up to date equipment is made available to those who need it through the NHS. This is tailored to individual patients' needs and, where appropriate, is delivered direct to patients' home, with expert advice and support available 24 hours a day, 7 days a week.

xi. Access to information and advice
People with a chronic respiratory condition can experience a great deal of uncertainty and anxiety regarding the future, both during assessment and at the point of diagnosis. Health professionals need to support people with these conditions during this period, being sensitive to their concerns and providing advice, relevant links and information resources.

Signposting by health professionals to relevant help lines, self management courses, voluntary sector organisations such as the British Lung Foundation and Asthma UK Cymru, and other sources of information can help to support people during assessment and following diagnosis.

It should also be recognised that the needs of individuals may change over time, as personal circumstances, or the condition and its impact on the individual, also change. It is important to ensure that effective information and
DEVELOPMENTAL AREAS
The provision of respiratory services should be strengthened by exploring the opportunities to provide seamless care for people with respiratory conditions. Developments that should be explored include:

i. GPs with Special Interests
Supported by training, quality assurance measures, the support and clinical leadership of secondary care specialists, GPs with a special interest (GPwSI) in respiratory health can be more actively involved in the management of more complex conditions as part of the multidisciplinary team. The GPwSI in respiratory health can bring real and sustainable benefits to patients and the NHS in Wales by extending the range of specialist respiratory care delivered within primary care and community settings. By working as part of multidisciplinary team, focusing on care pathways, and keeping the needs of the patient at the heart of service design, the GPwSI in respiratory health can play an important role in helping to integrate healthcare across primary and secondary care. With the support of multidisciplinary team the GPwSI should also help to relieve pressure on secondary care services and ensure that patients are treated and supported in managing their condition as close to home as possible.

Further information and guidance on the development of GPwSI services can be found in Welsh Health Circular (2005)047.54

ii. Specialist GP clinics
Specialist clinics can be established in primary care settings to complement the work of more traditional hospital specialists. These clinics, led by GPwSIs and supported by respiratory specialists can accept referrals from other GP practices in accordance with locally agreed guidelines. This approach to service provision aims to improve access to care particularly for conditions associated with long waiting times. The development of specialist clinics should take account of local needs, agreed models of service provision, care pathways and the need for specialist clinical leadership as part of a multidisciplinary team approach.

iii. Extended health professional roles
Workforce requirements across the NHS have fuelled an increasing interest in extending the scope and role of health professionals in primary and secondary care settings, including those that support the management of chronic conditions. Nurses, respiratory technicians, physiotherapists, dieticians and other health professionals involved in respiratory care can be trained to take greater responsibility for managing people’s respiratory conditions within a multi-disciplinary team and in accordance with locally defined care pathways.

Services for people with respiratory conditions in Wales should benefit from the growing number of clinical specialists, extended scope practitioners, and consultant therapists, as well as a greater variety of skilled administrative and
clinical support worker roles. The need for the development of extended scope therapists is clearly set out in the Therapies Strategy for Wales.55

Extended scope practitioners can help to free consultant time in clinics and help to reduce waiting times for clinic appointments56.

Supplementary prescribing in Wales has proved to be a successful development allowing trained nurses and pharmacists to prescribe medicine as part of a patient-specific clinical management plan agreed with an independent prescriber. This has produced a safer, more efficient and patient-friendly system of repeat prescribing. Independent prescribing will be introduced in Wales in 2007 and will help expand the clinical roles of nurses and pharmacists to support the better management of chronic conditions and unscheduled care, as well as the modernisation of service configuration in line with the vision set out in Designed for Life.

The development of Medical Care Practitioners, also known as Physician Assistants, is also being addressed by the Welsh Assembly. Evidence from recent pilot studies have indicated that these roles make a positive impact on the workload of primary care teams and contribute to improvements in accessing primary care services57. These health professionals are responsible for delivering treatment and care in a primary care setting within the medical model under defined levels of General Practice supervision. They can also support multidisciplinary team approaches to healthcare and help to bridge the gap between primary and secondary care services. These developments should play an advanced role in diagnosis, physical examination, prescribing (subject to necessary legislation), the development of personal care plans, health promotion, and patient education. These roles will also help to support General Medical Practice and secondary care departments in assessing, diagnosing, treating, and managing respiratory conditions.

iv. Regional, Clinical and Commissioning Networks
Arrangements to provide services for respiratory conditions can be made at local and regional levels. Each Local Health Board in Wales is well placed to work with their local partner organisations which include NHS Trusts, Local Authorities and the voluntary sector – to provide services which help to meet local needs.

For some conditions, a regional approach may be more realistic in terms of planning and funding. A regional approach to the provision of specialist respiratory services would be beneficial for a number of specialist conditions to ensure equity of service provision across Wales. Regionally based services should be commissioned by one leading commissioning body with the full support and involvement of the relevant service providers and health professionals. Services for obstructive sleep apnoea provide a good example of an area that would benefit from regionally developed services.

Emergency plans to ensure that Wales is adequately prepared to cope with the potential pressures on acute facilities associated with pandemic flu or Severe Acute Respiratory Syndrome (SARS) should also benefit from a
regional approach. LHBs in partnership with NHS Trusts, the National Public Health Service, and the Welsh Assembly, should play an important role in ensuring that regional plans are developed to appropriately address these significant threats to respiratory health.

Networks can also help to strengthen commissioning and clinical leadership across Wales, improving communication and the sharing of good practice. The development of regional networks for respiratory health should play an important role in ensuring that quality services are consistently provided across Wales.
## Diagnosis, Treatment and management

### Key Actions

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<th>Action</th>
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<tr>
<td>LHBs will ensure that person-centred, integrated, and multidisciplinary teams for managing respiratory conditions in the community are in place.</td>
<td>March 2008</td>
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<tr>
<td>LHBs in partnership with NLIAH and NHS Trusts will ensure the development of Care Pathways and local referral protocols between primary, secondary and tertiary care services for people with respiratory conditions.</td>
<td>March 2009</td>
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<tr>
<td>Commissioning arrangements should include signposting guidelines for health professionals and other community personnel in contact with people at risk of developing respiratory conditions.</td>
<td>January 2008</td>
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<tr>
<td>NLIAH and NHS Regional Offices will support LHBs and where appropriate Health Commission Wales to develop Regional respiratory health networks for specialised disorders, including sleep apnoea, DPLD and cystic fibrosis.</td>
<td>April 2009</td>
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<tr>
<td>Commissioning arrangements will be made by LHBs to provide appropriate joint educational and development sessions to support the development of respiratory multi-disciplinary teams.</td>
<td>September 2008</td>
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<tr>
<td>Commissioning arrangements will include the training of appropriate health professionals and community workers in prevention and recognition of respiratory illness in people at risk including smokers.</td>
<td>March 2009</td>
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<tr>
<td>LHBs and NHS Trusts will ensure regular periodic monitoring of medicines prescribed for respiratory disorders by GPs and hospital-based specialist teams within national guidelines.</td>
<td>March 2008</td>
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<tr>
<td>Health Commission Wales and LHBs will work with Informing Healthcare to ensure that modern technologies are fully utilised to facilitate early assessment and diagnosis of respiratory conditions.</td>
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Status: Consultation Document  
32 October 2006
Chapter 4- Facilitating and Managing Independence

Aim – To ensure that people with respiratory conditions are empowered and supported to maximise their independence in all areas of life and are partners in decision-making relating to treatments and services

Introduction
Supporting people with respiratory conditions and wherever possible enabling them to take greater responsibility for managing their condition is beneficial for the individual and health and social care services.

There are a number of areas where interventions can help to maximise independence. Treatments such as Long Term Oxygen Therapy in people’s homes and Ambulatory Oxygen Therapy can help people with respiratory conditions to live as independently as possible in the community. Pulmonary Rehabilitation is also a key part of the ongoing management of respiratory conditions such as COPD which can help people to cope with the day to day aspects of living with these conditions. Interventions by a multidisciplinary team should also be a key aspect of supporting people in returning to their home life following hospital discharge.

Increasing self efficacy in using appropriate self management techniques and making best use of the disease specific information available can help individuals improve their quality of life and support their independence in addition to the clinical interventions.

Carer support and respite care for family members that provide full-time care for their family member is also necessary to ensure that independence is maximised. Integrated, individual care-planning across health and social care and the voluntary sector should play a key role in supporting the independence of people with chronic respiratory conditions and their families and carers. Carers play an important role in supporting people with chronic conditions and need to be offered choices about support and the courses available that can help them to learn how to cope, manage their own health and well being, and keep on caring. ‘Looking after me’ courses provide an example of the type of support that is available to teach carers to better cope with their lives.

Social Inclusion, Care and Support
Respiratory conditions have an impact on an individual’s access to a wide range of opportunities including education, employment, housing and benefits. The impact can be even greater for disadvantaged groups who encounter additional barriers to accessing these opportunities.

With appropriate support, respiratory conditions should not act as a barrier to employment or a successful career for many people living with these conditions. Timely access to support services, including rapid access to appropriate health and rehabilitation services, self-management and disability
employment advisors, and an understanding and flexible approach from employers and employees can increase opportunities to gaining, regaining or remaining in employment. Access to appropriate treatment and support enables individuals to take control of their own symptoms and to be proactive in managing their work routines.

Living with respiratory conditions can have significant implications for children and young people, ranging from physical, emotional and social development, to education, employment, play, leisure and relationships. These conditions can also impact significantly on parents and other members of a family. A range of appropriate services may be necessary to enable a child with respiratory conditions including asthma and Cystic Fibrosis to fulfil his or her potential, and to maximise health and well-being: paediatric services, paediatric respiratory services and a range of health professions, provision of information, training and advice on exercise and self-management, provision of aids and adaptations, and accessible and flexible education.

The key issues regarding paediatric respiratory conditions are addressed in further detail by the All Wales Standards for Paediatric Respiratory Services. It is important that all those living with respiratory conditions, are in receipt of the benefits, support and advice they are entitled to. Many people do not claim their full entitlement. Advice on services and benefits is available from the Department of Work and Pensions (DWP), advisory bodies, local authorities, and voluntary organisations working with and supplying DWP. Further information is available at http://www.dwp.gov.uk/

Better Advice, Better Health is probably the most comprehensive introduction of advice services into GP practices that has ever taken place in the UK. It covers the whole of Wales, deprived and affluent areas alike, with many GP practices across Wales now providing this service. The Assembly provides recurrent funding to the National Association of Citizens Advice Bureau (NACAB) for the Better Advice: Better Health initiative. The service has now become part of the mainstream service in Wales and allows GPs to refer patients requiring benefits advice and social care services to expert advisers from the NACAB. The primary objectives are:

(a) to improve the uptake of unclaimed benefits;
(b) to improve income levels for poorer people; and
(c) to reduce the time GPs spend resolving non-medical enquiries.

**Self Management**
People need to be able to recognise the symptoms of respiratory conditions and understand the benefits of safe and effective exercise, correct diet and smoking cessation. They need to develop or enhance existing skills and techniques to help them look after themselves and live their lives to the fullest. They need to be able to recognise when professional advice is required, and understand when their conditions can be safely controlled by themselves or self-managed. Information and advice needs to made available to the general population and should be targeted at and provided to people with diagnosed respiratory conditions.
Enabling a person to manage their own conditions, where appropriate, is needed to help minimise the risks of respiratory exacerbations and to help reduce the need for emergency admissions to acute hospital care when this is avoidable and preventable. Self management programmes including the Expert Patient Programme have been found to bring about a small reduction in hospital admissions and visits to Accident and Emergency Departments. Research also indicates that disease specific self management interventions for respiratory conditions, in particular support for people with COPD provided by a trained health professional can significantly reduce the utilisation of health care services and improve health status.

Information can help to empower people with respiratory conditions to manage their conditions more effectively and can enable carers and others that have regular contact with them to understand their conditions. It is important to ensure that the self management of respiratory conditions is supported by the relevant information and advice.

Sources of information can be accessed through a number of routes including web-based advice and through the wide variety of leaflets developed by patient groups and professional bodies. Guidance on helping pupils control their asthma and creating a safe environment for pupils with asthma in schools, recently developed by Asthma UK, provide a good example of this.

Individuals whose conditions are controlled by medication should also be educated and provided with the correct information to ensure the full benefits of compliance. Community pharmacists can play an important role in supporting the management of medicines to help people self-manage.

People with chronic respiratory conditions will often experience a number of symptoms that are caused by their condition including pain, fatigue, anxiety, anger and frustration. Some individuals may need training in techniques to deal with these symptoms, which if not managed appropriately can lead to deterioration or exacerbation of their respiratory condition. It is important that planners and commissioners of services take account of interventions such as the Expert Patient Programme which focuses on teaching self management skills and that they also support condition specific initiatives like the British Lung Foundation’s ‘Breath Easy’ initiative.

Home Care and Personal Assistance
People with chronic respiratory conditions such as COPD will need assistance with personal care and domestic activities at some stage. This can be on a short-term basis, as part of a patient discharge plan coordinated by health and social services. It can also form part of a longer-term programme of care based upon the individual’s specific needs.

For people who need personal assistance, services should be responsive and flexible to take into account the nature of the different types of respiratory conditions. It is crucial that service users have control over the care and assistance they receive, so that they can tailor it to fit how they may feel from...
day to day. These considerations need to be built into the Unified Assessment Process for people with respiratory conditions.

Domiciliary care staff and formal carers not only play an important role in supporting the daily activities of people with physically and socially restricting chronic conditions but also in promoting independence and personal responsibility for health and supported self care.

‘Direct Payments’ by social services provide a good example of how this can be achieved and research and evaluations support the view that direct payment schemes offer improved quality of life for disabled people\(^6\). While the Direct Payment option may not be suitable for all people with respiratory conditions, it is important that support and guidance is available to enable people with chronic respiratory disorders who may decide to take up this option if they chose to do so.

**Aids and Adaptations**

Timely provision of aids and adaptations can have a major impact on independence for a person with respiratory conditions. This provision, together with information and appropriate support, is currently provided by a range of organisations including health services, social services and the voluntary sector. Adaptations should be provided as quickly as possible with the support and advice of the Occupational Therapist playing a key part in this process and ensuring links are made with appropriate Local Authority departments including housing.

The introduction of Telecare and telehealth services supports the Assembly Government’s strategic direction for Health and Social Services throughout Wales. They both play an important role in managing the health of older people and those with chronic conditions within their own homes. Many authorities in Wales are either already delivering such services or developing them in partnership with the voluntary sector and other stakeholders. A new Telehealth website has been developed and contains information about this and related activities currently in progress across Wales. Further information about telehealth and telecare is available at [http://www.wales.nhs.uk/](http://www.wales.nhs.uk/)

It is important to ensure consistency in the provision of aids and adaptations across Wales. The development of integrated health and Local Authority equipment services should allow services to be more responsive to the needs of individuals, ensure cost-effectiveness through greater purchasing power, and should provide a consistent, seamless service which meets the needs of the individual with respiratory conditions.

**Supporting carers**

Many people with a chronic respiratory condition are supported in the management of their conditions by partners, family members and friends. Where the respiratory condition is severe, people within these support networks become carers.

Carers experience many of the social disadvantages faced by people with respiratory conditions. These include loss of income and work opportunities,
isolation, stress and fatigue. It is essential that carers have access to support and information if their contribution to the effective rehabilitation and management of respiratory conditions is to be most beneficial for the person with the respiratory condition.

Multidisciplinary teams involved in an individual’s treatment and care need to know about care arrangements at home. Assessments for care services under the Unified Assessment Process should include a section on the role of any carer who provides or intends to provide “regular and substantial” care. This assessment will look at the willingness and ability of the carer to provide all or part of the care needs of the person with the respiratory condition.

Carers who provide day to day support for somebody with a respiratory condition may benefit greatly from knowing more about the condition and may feel the need for some support themselves. A number of voluntary sector organisations provide free information and support to carers. The Expert Patient Programme also offers the ‘Looking After Me’ course which helps carers to self manage their own lives whilst being a carer.

**Hospital Discharge**
Respiratory conditions are a major reason for admission to hospital. Evidence shows that admissions to hospital from respiratory infections such as influenza are particularly marked in the winter months among the most vulnerable, such as the older population. Length of stay in a hospital bed for respiratory conditions is also greater than the average length of stay for other health conditions, which places considerable pressure on secondary health care.

It is essential that robust discharge procedures are in place to facilitate a return to home life when clinically appropriate. This is needed to support the individual patient and relieve pressures on hospital wards.

All hospital Trusts have discharge policies and many are joint with local authority social services but the provision of discharge services varies from one area to another. The interface between hospital services and community services should be seamless and continuity of care needs to be maintained for the patient. Integrated health and social care plans to facilitate early and appropriate discharge from hospital are a key factor in both enabling discharge and helping to avoid the need for readmission to hospital for the same complaint. Readmission for COPD is a particular problem and reports highlight that people with COPD are often involved in a ‘revolving door’ situation of admission and readmission to hospital on an emergency basis. The use of action plans or individual patient plans at discharge from hospital can reduce subsequent morbidity and the need for hospital admission.

Effective medicines management should also be a key feature of the discharge planning process. Pharmacological interventions should support the individual needs of each patient and should be planned to help reduce the need for further emergency care. Guidance on discharge planning and medicines management has been produced by the Royal Pharmaceutical
Society of Great Britain to help maximise good practice and to minimise the risks associated with medicines during the transfer and discharge process\textsuperscript{66}.

Discharge planning should begin at admission or earlier, if applicable, with assessment by appropriate members of the multi-disciplinary team to facilitate early discharge. Early discharge and step-down schemes supported by coordinated rehabilitation programmes can provide a useful solution to facilitating early and appropriate discharge. These should be extended across Wales. Good communication within the multidisciplinary team and across health and social care settings is essential to ensure the seamless provision of appropriate services to support a return to home life. Placing the patient at the centre of this process is also essential to ensure positive outcomes for the individual and services.
<table>
<thead>
<tr>
<th>Facilitating and Managing Independence</th>
<th>By</th>
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<tbody>
<tr>
<td><strong>Key Actions</strong></td>
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<tr>
<td>LHBs will ensure that local, user-led self-help groups and support mechanisms for people with respiratory conditions, and their families and carers are established as an integral part of service design.</td>
<td>December 2007</td>
</tr>
<tr>
<td>LHBs in partnership with NLIAH, the Expert Patient Programme Wales and the voluntary sector will support the development of self-management programmes and associated training for managing chronic respiratory conditions.</td>
<td>March 2008</td>
</tr>
<tr>
<td>The Welsh Assembly will support LHBs, NHS Trusts and Local Authorities to develop integrated equipment services to include support for people with chronic respiratory conditions.</td>
<td>December 2007</td>
</tr>
<tr>
<td>The Welsh Assembly will work with the appropriate bodies including the voluntary sector to ensure signposting information is available for people with chronic respiratory conditions and their carers.</td>
<td>March 2008</td>
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4 http://www.wales.nhs.uk/sites3/docopen.cfm?orgid=441&ID=46873&2F23AEC4-48A6-4EC9-A5FC4551728ABC0E
8 WHS 1998
10 See http://www.rcplondon.ac.uk/college/ceeu/ceeu_copd_home.htm
11 www.lunguk.org
17 http://www.smokingbanwales.co.uk/english/
18 See http://www.Howis.nhs.uk/immunisation
23 Doul and Burr 2006
24 BTS Asthma guideline
26 Food and Well Being: Reducing inequalities through a nutrition strategy for Wales (2003), Food Standards Agency Wales, Welsh Assembly Government
27 Food and Fitness -Promoting Healthy Eating and Physical Activity for Children and Young People in Wales: A 5 Year Implementation Plan (2006) Welsh Assembly Government
29 See: http://www.metoffice.com/health/features/copd.html
31 http://www.hse.gov.uk/pubns/indg95.pdf
32 British Thoracic Society Guidelines on Pulmonary Rehabilitation 2004
33 NPA 1998
35 Johnson, Pathways of Care, Chap 2, (Blackwell Science: 1997)
36 NICE Clinical Guideline 12 Management of COPD in adults in primary and secondary care
37 Cystic Fibrosis Trust http://www.cftrust.org.uk
38 Respiratory Alliance (2003) Bridging the Gap Cookham, Direct Publishing

Status: Consultation Document 40 October 2006
The following key questions are provided to help structure responses to the consultation on the Service Development and Commissioning Directives for Respiratory Conditions. More detailed information about the content of this document is available at the following locations: http://www.wales.gov.uk and http://wales.nhs.uk

Please return your response by Friday 12th January 2007 to:-

Rick Thomas
Strategy Unit
Department of Health and Social Services
Welsh Assembly Government
Cathays Park
Cardiff
CF10 3NQ

rick.thomas@wales.gsi.gov.uk

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Your Details
If you are responding on behalf of an organisation or group please give the name of the organisation here and your contact details below.

Name of organisation or group .................................................................

Contact Details
Name ........................................
Address ......................................
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Post Code ...................................
Tel ...........................................
e-mail .....................................
Questions

1. Are you satisfied with the scope and vision of the Service Development and Commissioning Directives for Respiratory Conditions?

☐ yes ☐ no

Comments

2. Do you agree that the Directives are helpful in setting out the actions needed to help modernise and improve health and social care services for people with respiratory conditions in Wales?

☐ yes ☐ no

Comments

3. Is the document comprehensive, accurate, and applicable to the key issues that face people with respiratory conditions, service providers, planners and commissioners in Wales?

☐ yes ☐ no

Comments
4. Does the document provide clear guidance to service planners, commissioners, service providers and health professionals?

☐ yes  ☐ no

Comments

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5. Have any key issues that affect people living with respiratory conditions been missed in the document?

☐ yes  ☐ no

Comments

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6. Do you have any further comments to make on the document?

Comments

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