Designed for People with Chronic Conditions

Service Development and Commissioning Directives

Chronic Respiratory Conditions

October 2007
# Designed for People with Chronic Conditions

## Service Development and Commissioning Directives

### Chronic Respiratory Conditions

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Foreword by Mrs Edwina Hart AM MBE, Minister for Health and Social Services

I am pleased to introduce the Service Development and Commissioning Directives for chronic 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.

Chronic 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 and Chronic Obstructive Pulmonary Disease 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 services.

Health and social care services are facing growing pressures making it increasingly difficult to keep pace with the numbers of people consulting health professionals with chronic respiratory problems, the 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 and Designed to Improve Health and the Management of Chronic Conditions in Wales: An Integrated Model and Framework for Action, this publication aims to ensure that the right services are provided in the right place, at the right time, and by the right person 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 help prevent chronic respiratory conditions and develop services fit for the future and capable of improving the health, well being and quality of life of people in Wales.

Mrs Edwina Hart AM
Minister for Health and Social Services
Executive Summary

Chronic respiratory conditions, which include asthma, Chronic Obstructive Pulmonary Disease (COPD) and respiratory failure, are the most common chronic conditions in the UK. The impact of living with these conditions can be profound affecting every aspect of life. These conditions contribute to high rates of emergency admissions to hospital, require appropriate healthcare interventions and advice, and often call for support from a wide range of social care and voluntary sector organisations to enable people to live as independently as possible in their own communities.

The growing demands for services for people living with chronic respiratory conditions are placing increasing pressures on our health and social care system in Wales. The Welsh Assembly Government is committed to ensure that service provision suitably matches the needs of the 21st Century and reshaping services appropriately for people living with chronic respiratory conditions is a key part of this process.

The Service Development and Commissioning Directives for Chronic Respiratory Conditions outline a vision for services in Wales which aim to:

- improve health and well being and minimise the risks of respiratory illness;
- reduce levels of morbidity and avoidable emergency admissions to hospital;
- provide the right services at the right time, in the right place and by the right person;
- support people’s independence in all areas of life.

This vision will be delivered through:

- the promotion of healthy lifestyles and relevant support;
- timely access to well trained professionals for assessment, diagnosis, and treatment;
- care pathways where a clear journey of care is planned and effectively supported;
• seamless care provided by integrated multidisciplinary teams working across the traditional boundaries of primary, secondary, and tertiary care, and social care and the voluntary sector;

• community based health care, social care and social support provided in a planned and integrated way by appropriate organisations.

The key elements of this approach which are crucial to improving respiratory health and services for people living with chronic respiratory conditions are:

• assessing need and reviewing service provision to inform commissioning decisions;

• developing well trained integrated multidisciplinary teams for managing respiratory conditions;

• ensuring early and accurate assessment, diagnosis and appropriate treatment and management of chronic respiratory conditions;

• encouraging people to stop smoking, especially those at risk or who have established chronic respiratory conditions;

• ensuring early and appropriate discharge from hospital supported by multidisciplinary teams which include the voluntary sector;

• delivering services through innovative workforce developments, harnessing the skills of specialists in the community and strengthening mainstream service provision;

• providing evidence based and effective rehabilitation, including pulmonary rehabilitation, in the community;

• strengthening the appropriate provision of domiciliary oxygen supported by assessment by qualified health professionals;

• ensuring access to diagnostic support in acute admitting units and non-invasive ventilation on respiratory units;

• strengthening research into respiratory care.

Key issues for improving care and support are highlighted throughout this document. A number of key actions are identified at the end of each chapter to ensure an equitable and consistent approach to service provision for people living with chronic respiratory conditions across Wales.
These Service Development and Commissioning Directives fit with the general principles of improving health and the management of chronic conditions as set out by the Welsh Assembly Government in *Designed to Improve Health and the Management of Chronic Conditions in Wales: An Integrated Model and Framework for Action*. This approach requires a whole systems focus and a change in approach working in partnership with all key stakeholders and crossing traditional organisational boundaries. Delivering the change will require concerted action by a wide range of organisations and will demand the commitment of key local decision makers in strengthening partnership planning, commissioning and using joint resources effectively.
Chapter 1: Setting the Scene

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 through preventative measures 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 integrated high quality patient-centred services. They will be provided as locally as possible and supported by 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 people living with chronic respiratory conditions are able to reach their full potential and live independent and fulfilled lives.

1.1 Introduction

1.1.1 Respiratory conditions which affect both the upper and lower respiratory tracts kill more than one in four of the United Kingdom population. The long term effects of respiratory illness are considerable and affect every aspect of daily life. Chronic respiratory conditions, which include asthma, Chronic Obstructive Pulmonary Disease (COPD) and respiratory failure, are the most common form of chronic illness in the UK and account for more deaths each year than coronary artery disease and non-respiratory cancer.

1.1.2 The prevalence of respiratory conditions in Wales calls for immediate action with rates of mortality for asthma and COPD for example well above the UK average. Welsh Health Surveys between 1995 and 1998 showed that the percentage of males reported having current respiratory illness, increased from 22.6% to 23.5% and during the same period the prevalence rates for women
increased from 20.7% to 22.7%. Some areas of Wales, notably the old industrial areas, reported prevalence rates as high as 28% in 1998 while other, more rural, areas were much lower at around 19%.

1.1.3 Admissions to hospitals resulting from respiratory infections are a significant issue in Wales. There were 147,750 admissions to hospital recorded between 1999 and 2004, with an average length of stay of six to seven days. The vast majority of those admissions were emergencies and there are indications that emergency medical admissions for respiratory conditions have been increasing in Wales with, for example, admissions from exacerbations of COPD rising at an average 3.75% per year between 1997/98 and 2005/06. Evidence also indicates the predominant conditions leading to emergency admissions were due to infections such as Community Acquired Pneumonia, with nearly half being caused by pneumococcal disease, influenza and exacerbations of COPD and asthma. This trend is expected to continue as the effects of smoking persist and as the population ages.

‘The long-term burden of respiratory illness imposes considerable personal discomfort’.

1.1.4 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 deprived old industrial heartlands than in more affluent areas. These inequalities in life chances need urgent redress.

‘Patients with severe COPD may become housebound, socially isolated, and depressed, with increasing dependence on carers, social and health services’.

1.1.5 Exacerbations of respiratory conditions have a significant impact on hospital bed usage. The majority of beds used in NHS Wales for respiratory disease are occupied by people over the age of 65 years who stay in hospital for at least 11 days. Evidence shows that the extreme elderly, over 80 years old, are the most dependent on hospital services with an average length of stay over two weeks, twice the average length of stay in hospitals overall.

Wales has 4,000 hospital admissions for asthma a year, in the case of adults, a rate nearly 30% higher than the rest of the UK - and of these hospital admissions, 75% could have been avoided.

Wales has 4,000 hospital admissions for asthma a year, in the case of adults, a rate nearly 30% higher than the rest of the UK - and of these hospital admissions, 75% could have been avoided.
There is great potential to reduce the admission rate for emergency care and enhance the ability to deal with epidemic disease by instituting preventative measures in primary and community care such as pneumococcal and influenza vaccinations and by supporting people with respiratory conditions in the community and helping people live independently in their homes wherever possible. For those people that are admitted to hospitals as an emergency there should be rapid access to appropriate emergency equipment, well trained professionals and staff, diagnostic facilities as well as effective mechanisms for discharge planning to enable appropriate rehabilitation and support in the community.

1.2 Background and scope

1.2.1 These service development and commissioning directives have been developed to address the challenges presented by chronic respiratory conditions in Wales. They underpin the planning, commissioning and delivery of services for people living with these conditions and aim to:

- promote positive lifestyle changes to help reduce the risks of illness, disability and premature death;
- reduce levels of morbidity and emergency admissions to hospital;
- ensure early and accurate assessment and diagnosis, access to high quality, integrated and patient-centred services;
- improve health and quality of life;
- 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;
- align health and social care services to provide the right services in the right place and at the right time.

1.2.2 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 and Designed to Improve Health and the Management of Chronic Conditions in Wales: An Integrated Model and Framework for Action. 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 improving the lives of people with these conditions in Wales.

1.2.3 These directives focus on services for adults in Wales, while fully acknowledging the All Wales Standards for Paediatric Respiratory Services\(^1\) and the wider work of the National Service Framework for Children, Young People and Maternity Services.\(^2\) The development and commissioning of respiratory services in Wales need to take account of these key documents and other relevant publications, particularly in relation to the transition of young people from paediatric to adult services.

1.2.4 This work has been compiled with the support of a multi-professional and multi-agency reference group (see Appendix 1). The group has taken account of the Respiratory Alliance recommendations in Bridging the Gap\(^3\) and benefited from the support of members of the Welsh Thoracic Society. The advice of patients, health and social care professionals, the voluntary sector and others that support people living with respiratory conditions has also been called upon to inform this work.

1.2.5 The Service Development and Commissioning Directives embrace the principles of equality of opportunity (Sections 77 of the Government of Wales Act 2006\(^4\)) and aim to improve service provision across health and social care to ensure that the right care and support is available, delivered at the right time, in the right place and by the right person. The planning and commissioning process should from the outset take account of equality legislation to ensure an effective approach to equality of opportunity in service design and delivery (see Appendix 2).

1.2.6 Sub groups have been involved in the production of this document and have drawn advice from the National Institute for Healthcare and Clinical Excellence (NICE), the British Thoracic Society (BTS) and the Scottish Intercollegiate Guidelines Network (SIGN). A number of key conditions were addressed in further detail by these groups including asthma, COPD, community-acquired pneumonia, cystic fibrosis and tuberculosis, and sleep disordered breathing. The outcomes of this work and further details on each of these conditions are available in a compendium resource complementing this document.
1.3 **Categories of Respiratory Conditions**

1.3.1 This document provides a framework for the prevention, assessment, diagnosis, treatment and management, of the most common respiratory conditions in Wales. It also focuses on approaches to help manage and support the independence of those living with a range of chronic respiratory conditions. Its principles and aims may be applied to all respiratory conditions and those which are not detailed in this document.

1.3.2 Table 1 provides details of the most common respiratory conditions in Wales. It sets out the key issues and solutions for consideration and also indicates where further information and guidance on the management and treatment of such conditions can be found to inform planning and commissioning decisions. Further information of the incidence, epidemiology, diagnosis, treatment and management of these respiratory conditions are contained in the compendium document informed by the specialist sub groups.
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<thead>
<tr>
<th>Key condition and characteristics</th>
<th>Current issues</th>
<th>Key solutions and recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Asthma</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Chronic inflammatory condition</td>
<td>• Affects 5.2 million people in the UK</td>
<td>• Achieving the standards of the Quality and Outcomes Framework of the General Medical Services Contract</td>
</tr>
<tr>
<td>• Affects children and adults</td>
<td>• 260,000 people treated annually in Wales</td>
<td>• Monitoring the overall quality of care</td>
</tr>
<tr>
<td>• Symptoms include wheezing and shortness of breath</td>
<td>• 69,000 hospital admissions resulting from poorly managed symptoms</td>
<td>• Care pathway and improved integration between health and social care services</td>
</tr>
<tr>
<td>• Hyper-responsive to brochoconstrictor stimuli</td>
<td>• Around 1,100 deaths each year in England and Wales</td>
<td>• Adherence to national clinical guidelines</td>
</tr>
<tr>
<td><strong>Key Guidelines:</strong></td>
<td></td>
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<tr>
<td><a href="http://www.enterpriseportal2.co.uk/filestore/bts/asthmaupdateNov05.pdf">http://www.enterpriseportal2.co.uk/filestore/bts/asthmaupdateNov05.pdf</a></td>
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<tr>
<td><strong>COPD</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Progressive and non reversible airflow obstruction</td>
<td>• Under and misdiagnosed</td>
<td>• Early detection in primary care and achieving the standards of the Quality and Outcomes Framework of the General Medical Services Contract</td>
</tr>
<tr>
<td>• Encompasses chronic bronchitis, emphysema and some cases of asthma</td>
<td>• Confusion with symptoms of asthma</td>
<td>• Expansion and strengthening of smoking cessation services in primary and secondary care settings</td>
</tr>
<tr>
<td>• Predominantly caused by smoking</td>
<td>• Inappropriate prescribing</td>
<td>• Delivery of health education, health promotion and self management programmes</td>
</tr>
<tr>
<td>• Increasing prevalence with age</td>
<td>• Over 30,000 deaths per year in the UK</td>
<td>• Multidisciplinary and multi-agency team based care including early discharge, pulmonary rehabilitation and palliative care</td>
</tr>
<tr>
<td><strong>Key guidelines:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Care pathway and improved integration between health and social care services</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Access to non invasive ventilation, long term ventilation and domiciliary oxygen therapy</td>
</tr>
<tr>
<td>Key condition and characteristics</td>
<td>Current issues</td>
<td>Key solutions and recommendations</td>
</tr>
<tr>
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</tr>
<tr>
<td><strong>Respiratory Infections</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Range from mild common colds to more serious bacterial and viral infections</td>
<td>• Increasing incidence of tuberculosis in the UK especially among migrant populations</td>
<td>• Increase the uptake of influenza and pneumococcal vaccinations through targeted vaccination programmes among the elderly and other high risk groups</td>
</tr>
<tr>
<td>• Include tuberculosis, community acquired pneumonia and influenza</td>
<td>• Emerging threats from new diseases such as SARS</td>
<td>• Active infection prevention, control and surveillance systems of respiratory infections across Wales particularly during winter months</td>
</tr>
<tr>
<td>• May require treatment in hospital and can be life threatening especially in the elderly, those with existing respiratory conditions and other health problems</td>
<td>• Annual threats of viral diseases including influenza and Respiratory Syncytial Virus (RSV) in winter months</td>
<td>• Provision of adequate assessment in primary care using validated early warning signs for viral and pneumococcal pneumonia</td>
</tr>
<tr>
<td><strong>Key Guidelines:</strong> <a href="http://www.cks.library.nhs.uk/">http://www.cks.library.nhs.uk/</a></td>
<td></td>
<td>• Adoption of Wales TB Programme</td>
</tr>
<tr>
<td><strong>Cystic Fibrosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Most common life limiting inherited/ genetic disease</td>
<td>• Most common life limiting inherited disease in Wales</td>
<td>• Robust screening arrangements for new born babies</td>
</tr>
<tr>
<td>• Requires two faulty genes to activate it</td>
<td>• 1 in 25 of the UK population (more than 2.3 million people) are carriers for the faulty gene</td>
<td>• Effective monitoring arrangements of patients and implement bi-annual review process by Cystic Fibrosis specialist</td>
</tr>
<tr>
<td>• Thick mucus in the lungs and digestive system makes it difficult to breathe and digest food</td>
<td>• Average age of death has risen to 31 in the UK</td>
<td>• Multidisciplinary and shared care arrangements</td>
</tr>
<tr>
<td>• High risk of bacterial chest infections</td>
<td></td>
<td>• Delivery of health education and self management programmes for carers</td>
</tr>
<tr>
<td><strong>Key Guidelines:</strong> <a href="http://www.cftrust.org.uk/aboutcf/publications/">http://www.cftrust.org.uk/aboutcf/publications/</a></td>
<td></td>
<td>• Adherence to national standards for long term ventilation</td>
</tr>
<tr>
<td>Key condition and characteristics</td>
<td>Current issues</td>
<td>Key solutions and recommendations</td>
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</tbody>
</table>
| Diffuse Parenchymal Lung Disease  | • Account for 15% of Chest Physicians workload in the UK  
  • Incidence increasing in the UK  
  • Shortage of Radiologists and Histopathologists with appropriate interest | • Multidisciplinary team based care  
  • Expansion and strengthening of smoking cessation services in primary and secondary care settings  
  • Access to immunosuppressive therapy  
  • Exploration of the development of a regional approach to specialist treatment with appropriate links to lung transplantation services  
  • Palliative care provision in the community |
| • 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 | | |
| Key Guidelines: | http://www.brit-thoracic.org.uk/ | |

| Chronic Respiratory Failure | • 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 | • Review of availability and access to diagnostic, assessment and NIV facilities across Wales  
  • Review of training and workforce development requirements with consideration of training for all junior medical, nursing and allied health professionals  
  • Access to non invasive ventilation supported by experienced staff in a dedicated setting  
  • Improved data collection and audit systems of non invasive ventilation services across Wales |
| • 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)  
  • High rates of mortality | | |
<p>| Key guidelines: | <a href="http://www.library.nhs.uk/respiratory/">http://www.library.nhs.uk/respiratory/</a> | |</p>
<table>
<thead>
<tr>
<th>Key condition and characteristics</th>
<th>Current issues</th>
<th>Key solutions and recommendations</th>
</tr>
</thead>
</table>
| **Obstructive Sleep Apnoea (OSA)** | • Prevalence of 2-4% of the population in the UK  
• Significantly affects quality of life  
• May contribute to cardiovascular disease and road traffic accidents  
• Disparate services across Wales | • Improved universal diagnostic services for OSA in Wales  
• Proactive programmes for the management of the major risk factors for OSA including obesity  
• Access to simple diagnostic facilities in acute admitting hospitals  
• Facilitate access to specialist regional centres backed by internationally defined research programmes funded through research and development programmes  
• Consideration of findings of National Public Health Service review of sleep apnoea services in Wales  
• Consideration of the forthcoming NICE Technology Appraisal of the evidence of the long term effectiveness of Continuous Positive Airways Pressure (CPAP)* |

*Key Guidelines: http://www.sign.ac.uk/guidelines/fulltext/73/index.html
1.5 **The Strategic Context**

1.5.1 Health and social care services in Wales face significant challenges and recent reports have indicated that the existing pattern of services cannot be sustained. The Review of Health and Social Services in Wales by Sir Derek Wanless\(^1\) and Sir Jeremy Beecham’s Review of Local Service Delivery\(^2\) have highlighted that new ways of working are needed to deliver health and social care services that are fit for purpose in Wales.

1.5.2 The Welsh Assembly Government is committed to achieving high standards across the public service, and its aims and expectations are set out in *Making the Connections*.\(^3\) This emphasises the need to design and operate services around the needs of the users, not the provider, taking into account all associated risks, and ensuring high quality, easily accessible and responsive services.

1.5.3 Improved 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 across 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. Local Service Boards and Regional Commissioning Units will play an increasingly important role in this context.

1.5.4 The agenda to improve health services has been set in Wales by *Designed for Life: Creating World Class Health and Social Care for Wales in the 21st Century*.\(^4\) Improving the management of chronic conditions is a key feature of this strategic approach and the service model for chronic conditions management is established in *Improve Health and the Management of Chronic Conditions in Wales: An integrated Model and Framework for Action*.\(^5\) The Service Development and Commissioning Directives are firmly rooted in this agenda and should be supported by developments in community services, Health, Social Care and Well Being Strategies and commissioning across Wales. This should ensure a consistent approach to improvements to the management of chronic conditions and the delivery of high standards of care.
1.5.5 This document supports the rebalancing of services and resources. It focuses on the development of community services to ensure care and support is provided safely as close to people’s homes as possible and to drive improvements in acute and specialist care. The commissioning and development of specialist multidisciplinary services supported by care pathways and strengthened partnerships with the voluntary sector and carers, is needed to effectively support and care for people with all chronic conditions including chronic respiratory conditions. People need to be informed and supported to take greater responsibility for their health and well-being wherever appropriate and to understand when to seek professional advice. Services should 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.

1.5.6 Respiratory conditions are a key priority, for all areas of Wales, however the specific commissioning and implementation of service change will depend on the assessment of local needs and existing patterns of service provision. Plans to implement the key actions in these commissioning directives will need to be considered by Local Health Boards and their local partners and should be taken into account in the development of local Health, Social Care and Well-Being Strategies which provide a co-ordinated response to all the policy objectives and requirements relating to health and social care services in the local area.

1.6 The Structure of the Document

1.6.1 These directives are built upon a strategic pathway of care, which underpins the patient journey where access to services, information and self-care cut 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.

Each chapter of this document addresses the key stages of the strategic pathway providing specific examples and case studies to illustrate the approach needed in Wales. Key actions are also presented at the end of each chapter.

1.6.2 While the needs of people with respiratory conditions may fluctuate over time it is important that services are fit for purpose and are able to respond appropriately and provide the right services at the right time and in the right place. Figure 2 illustrates the levels of care and the types of services required at each level for managing chronic conditions. Reducing the barriers between services at all levels and increasing integration should be a key part of future service models to ensure seamless services and continuity of care.
1.7 **Commissioning effective services**

1.7.1 Robust commissioning within agreed strategic frameworks is needed to ensure that services are evidenced-based, patient-centred, accessible, responsive to the needs of people living with respiratory conditions and cost effective. It is also important in ensuring that service delivery is monitored and strengthened by a continual cycle of review and improvement. The local intelligence acquired through the commissioning process should be used to plan long term and sustainable services and should inform the development of local Health, Social Care and Well-being Strategies. Solutions to the challenges that are presented at local, regional and national levels need to be agreed in partnership with service users and all key stakeholders responsible for supporting respiratory health and well being.

1.7.2 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 appropriate services that are aligned to need. Commissioners will need to audit
and review service provision making use of available data from social services, primary, secondary and tertiary 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.20

1.7.3 Local service users are an essential component in helping to determine how services can be best provided to meet their needs. Meaningful public and patient engagement will also need to be further encouraged to inform service developments for respiratory care.

Table 1 outlines the key issues for commissioners in developing effective and sustainable services for respiratory conditions in Wales.

Table 1: Commissioning Checklist for Respiratory Conditions

<table>
<thead>
<tr>
<th>Key Elements of commissioning</th>
<th>Key issues for chronic respiratory conditions</th>
</tr>
</thead>
</table>
| Assessment of service users needs | • Review of the epidemiology of respiratory conditions  
• Audit of current service provision in primary, secondary and social care |
| Preventative action and services | • Primary, secondary and tertiary prevention |
| Public and patient engagement | • Signposts guidance21 |
| National standards and good practice | • Healthcare Quality Improvement Plan22  
• National Institute for Clinical Excellence and Health care (NICE)  
• British Thoracic Society (BTS)  
• Scottish Intercollegiate Guidelines Network (SIGN) |
| Development of care pathways | • Integrated care pathways23  
• Map of Medicine24  
• Year of Care25 |
| Links with related service commissioning, provision and support | • Transition from child to adult  
• Primary care networks  
• Intermediate care services  
• Integrated commissioning arrangements between LHBs, NHS Trusts, Local Authority services, Health Commission Wales  
• Support of National Public Health Service  
• Support from Regional Commissioning Units |
| Demonstration of the development of services within all tiers of the chronic conditions model | • Health improvement and primary prevention  
• Primary care and community based services  
• Network based services  
• Case managed services |
<table>
<thead>
<tr>
<th>Key Elements of commissioning</th>
<th>Key issues for chronic respiratory conditions</th>
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<tr>
<td>Population stratification</td>
<td>• Risk stratification tools</td>
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<tr>
<td>Workforce implications and planning</td>
<td>• Designed for Work</td>
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<tr>
<td></td>
<td>• Agenda for Change</td>
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<td>• Timescales for delivery and service change</td>
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<td>Monitoring and evaluation of services</td>
<td>• Local action plan</td>
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<td>• SaFF targets</td>
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<td>• Balanced scorecard</td>
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Using this checklist, commissioning must drive improvements in quality and performance. The process must remodel services where needed, tackle unacceptable practice, and improve quality, reflecting national quality standards.26

<table>
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<th>Setting the Scene</th>
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<tr>
<td><strong>Key Actions</strong></td>
<td><strong>By Who</strong></td>
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<tr>
<td><strong>Needs assessment</strong></td>
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<tr>
<td>By March 2008 population needs will be assessed and services reviewed for respiratory conditions to inform the planning and commissioning of services as part of the needs assessment process for local Health, Social Care and Well Being Strategies.</td>
<td>Local Health Boards (LHBs)</td>
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<td>National Public Health Service (NPHS)</td>
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<td>Social Services</td>
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<td>Health Commission Wales (HCW)</td>
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<td><strong>Local Action Plans</strong></td>
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<tr>
<td>By March 2008 Local Respiratory Action Plans will be developed to improve respiratory services ensuring the implementation of these Directives and supported by local service advisory groups and meaningful public and patient engagement.</td>
<td>LHBs</td>
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<td><strong>Monitoring and Evaluation</strong></td>
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<tr>
<td>By March 2008 mechanisms to monitor and evaluate the implementation of these directives will be identified.</td>
<td>Welsh Assembly Government</td>
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Chapter 2: Prevention - Reducing the risks

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

2.1 Background

2.1.1 A number of factors contribute to the development and progression of chronic respiratory illness. They include poor and damp housing conditions, environmental conditions and the most significant are smoking, respiratory infections and obesity. Co-ordinated preventive action is needed to reduce the risks of developing respiratory conditions. The responsibility for this is wide ranging and includes the general public, patients and their carers, employers, Local Authority departments, health and social care staff and other professionals such as teachers and school nurses.

2.1.2 Treatment and management interventions are needed to help maintain the well-being and respiratory function of people with established conditions. Effective and integrated support mechanisms from health, social care and the voluntary sector are 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

‘Primordial Prevention’ - Preventing the onset of chronic conditions by focusing on the wider determinants of health including lifestyle choices, individual behaviour and environmental factors (Chapter 2).

Primary Prevention - Limiting the incidence of chronic conditions by controlling the causes and risk factors at population levels or through targeted approaches aimed at people with high risk factors (Chapters 2).

Secondary Prevention - Slowing or halting the progression of chronic 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).
2.2 Awareness of causes

2.2.1 Raising awareness of the causes associated with the development of respiratory conditions can help to prevent their onset and minimise their impact. 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.

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

**The general public:** Health promotion information and campaigns contribute to a better understanding of how to prevent and manage respiratory illness. A whole population approach should include information on obesity, healthy diet, exercise, the dangers of smoking, and the impact of the environment and the workplace on respiratory health. The responsibility for education and information, in this context, is wide and includes the Welsh Assembly Government, the health and social care community, educational establishments, the voluntary sector, other public sector organisations and the private sector.

**The Patient:** Good quality information can improve outcomes for individuals and help them become active partners in their care by making informed positive lifestyle changes. Information should be provided from a variety of sources, including statutory and voluntary organisations, to help people understand more about their conditions and how to manage them safely and effectively. Interventions including coaching and self management courses should be made available locally to help people learn new skills and ways of coping with the day to day management of their condition and their lives. They should be informed about initiatives such as the Expert Patients Programme and condition specific courses, delivered by the voluntary sector, such as the *Breathe Easy* initiative.
Health and Social Care Professionals: Information and advice on managing respiratory conditions should be an integral part of the education and training of all healthcare providers. In addition to treatment and management, 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 and how to live as independently as possible in the community.

2.3 Smoking

2.3.1 Smoking is the greatest single 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.

2.3.2 Smoking also damages the health of non-smokers. In 1998 the UK Scientific Committee on Tobacco and Health issued a report which concluded that exposure to second-hand smoke causes lung cancer and heart disease in adult non-smokers and pre-maturity, respiratory disease, cot death, middle ear disease and asthmatic attacks in children.30

"Parental smoking doubles the chances of smoking uptake by children."31

2.3.3 Existing local health-promotion campaigns and programmes of smoking cessation should be strengthened to help create a smoke-free Wales. Messages to help prevent the uptake of smoking need to be provided to all age groups, in order to reduce the risks of COPD and other respiratory conditions. The Welsh Assembly Government is committed to reducing the levels of smoking within the population. The Smoke Free Premises etc (Wales) Regulations 2007,32 which came into force in April 2007 banned smoking in all enclosed public spaces in Wales and are a significant step in reducing the risks associated with exposure to second hand smoke and encouraging people not to smoke.

2.3.4 Smoking cessation reduces the risk of smoking-related respiratory illness and death within a relatively short period of time after quitting. The onset of disease is prevented in those who give up at an early stage, the course of disease is modified and the progression of lung function loss slowed in those with more advanced airways dysfunction.33
Smoking cessation interventions are effective and should be incorporated into the routine practice of medicine in healthcare systems.\textsuperscript{13}

2.3.5 Providing motivational support to smokers, who wish to quit, significantly increases the rates of quitting.\textsuperscript{34} The All Wales Smoking Cessation Service (AWSCS) is a community-based service delivered and managed by the National Public Health Service (NPHS). It provides a standardised withdrawal-oriented treatment model and provides data to LHBs and Trusts to ensure that the links with primary and secondary care are established. All primary and secondary care health professionals are encouraged to provide interventions and referrals.

2.3.6 It is important to ensure early diagnosis of respiratory conditions ensure that appropriate health interventions are introduced to reduce the risks of further damage to the lungs. It is essential to encourage people who smoke and have been diagnosed with a respiratory conditions, particularly COPD, to quit smoking, in order to help slow down the progression of the disease.

2.4 Respiratory Infections

2.4.1 Respiratory conditions caused or exacerbated by infections account for a significant level of morbidity and mortality in Wales, the impact of which is felt by individuals and families and across primary, secondary and social care services.

2.4.2 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.

2.4.3 The increasing cases and survivors of tuberculosis, HIV/AIDS infections and people requiring long term immunosuppressive therapy, require effective prevention and control policies, particularly in our hospital settings. The threat of a human pandemic that may arise from mixing avian influenza in birds and human influenza and the recent experience with Severe Acute Respiratory Syndrome (SARS) in the Far East and Canada have exposed the vulnerability of modern health care systems to infectious disease, and demonstrate the need to plan for any future human pandemic.
2.4.4 The impact of respiratory infections can be reduced by effective use of vaccines, and by the appropriate prescribing of antibiotics to reduce morbidity associated with rising 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 people living with chronic conditions, the immunocompromised, and the elderly are covered by the annual influenza and pneumococcal immunisation programmes to help reduce serious illness, hospital admissions and deaths caused by infections and their often-attendant complications.

2.4.5 Steps continue to be taken by the NPHS Communicable Disease Surveillance Centre and the Welsh Assembly Government to develop yet further the control and surveillance of respiratory infections in Wales. National policy and guidance on arrangements for the influenza and pneumococcal immunisation programmes together with the identification of clinical risk groups are contained within Welsh Health Circulars (2007) 037[9] and (2005) 034.36 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 (HOWIS) intranet web site.37 It is important that the requirements for communicable disease surveillance should be considered at the design stage of all information technology developments for healthcare.

2.4.6 Guidelines are being developed by the NPHS TB Programme Group for the notification, prevention, and diagnosis and treatment of tuberculosis. 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 guidelines will also be expected to set up appropriate systems in which to audit and measure compliance.

2.5 Healthy Lifestyles

2.5.1 A healthy, active lifestyle is important to help preserve and strengthen respiratory function. Primary and secondary prevention strategies are important to help prevent the onset and limit the progression of chronic respiratory conditions and can help sustain quality of life for those living with these conditions.
2.5.2 Obesity coupled with sedentary lifestyles has a marked impact on respiratory function. People who are obese have an increased risk of health problems including high blood pressure and cardiovascular disease, as well as a susceptibility to obstructive sleep apnoea. This condition, which is defined as five or more obstructed breathing events per hour during sleep, increases the risks of cardiovascular disease and adds to the risks of road traffic accidents, and injury at work as a result of excessive somnolence.

2.5.3 A balanced and healthy diet has many benefits for health and well-being. Recent evidence has highlighted an association between the increase in asthma and obesity in children in Wales. Losing weight for obese asthmatics is effective in improving asthma control and the daily consumption of fruit and vegetables in infancy is associated with lower levels of asthma in school-age children. These findings indicate the potential of encouraging healthy eating for those most at risk of developing respiratory conditions - particularly infants, smokers, and ex-smokers.

2.5.4 Exercise pays an essential role in strengthening and maintaining respiratory function. Exercise referral schemes can play an important role in encouraging exercise as both preventative and rehabilitative measures. They provide a targeted approach to enable people who either have health problems or are at significant risk of developing them, to receive support in becoming more active. They also provide an opportunity for health professionals and exercise professionals to work together and are a model for a more integrated and patient-centred approach to health improvement. Commissioners should take account of plans which are being made in Wales to develop and evaluate national exercise referral schemes to help ensure an effective and standardised approach to these schemes.

2.5.5 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 improving 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.
2.6 The Environment

2.6.1 Good air quality is essential for respiratory health and quality of life. The health effects of air pollution have been subject to intense study in recent years and will be subject to further scientific interest. Evidence suggests that high concentrations of air pollutants in the atmosphere may exacerbate symptoms of some respiratory conditions. People with respiratory conditions should be made aware that their symptoms may get worse during periods of high air pollution based on seasonal changes and other factors, and advice should be given on actions to take to prevent exacerbations of their conditions.

2.6.2 Plans to target people at the highest risk of respiratory exacerbations from respiratory infections and seasonal changes in weather should also be considered. Opportunities to use existing data and systems for monitoring service demands should be explored, as well as considering approaches 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 approach. 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’.

2.6.3 Occupational exposure to certain dusts, fumes, irritant gases and vapours can 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. Prior exposure to asbestos can lead to the development of thoracic conditions in particular pleural thickening and malignancies such as mesothelioma and lung cancer. It is important that organisations take account of the control of respiratory sensitisers at work, covered by the Control of Substance Hazardous to Health regulations (COSH 2002).

2.6.4 The Welsh Assembly Government’s Corporate Health Standard is the national mark of quality in workplace health and well being. This programme provides support to organisations to help them 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.
### Prevention: Reducing the risks

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<th>Key Actions</th>
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<tr>
<td><strong>Primary and secondary prevention measures</strong></td>
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<td>By September 2008 appropriate and evidence-based primary and secondary prevention measures for chronic respiratory conditions will be established as part of mainstream service provision.</td>
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<td>Social Services</td>
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<td>Voluntary Sector</td>
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<td>Annual influenza and pneumococcal immunisation targets will be met across Wales ensuring immunisation of high risk categories, people living with chronic respiratory conditions, the immunocompromised and older people.</td>
<td>LHBs</td>
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<td>NPHS</td>
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<td>NHS Trusts</td>
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<td>Smoking cessation services will be made easily accessible to all across primary and secondary care with access to the All Wales Smoking Cessation Service facilitated for people with chronic respiratory conditions and those in high risk categories.</td>
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<td>Welsh Assembly Government</td>
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<td>LHBs</td>
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<td><strong>Infection control</strong></td>
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<td>By September 2008 infection prevention, control and surveillance systems will be strengthened across Wales and supported by robust audit systems and automated data collection mechanisms.</td>
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<td>Informing Healthcare</td>
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<td>On an annual basis NHS commissioners will ensure that TB services are meeting nationally agreed standards of care through appropriate audit mechanisms.</td>
<td>LHBs</td>
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<td>NHS Trusts</td>
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<td>NPHS</td>
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<td><strong>Information</strong></td>
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<tr>
<td>By December 2008 appropriate health promotion information and advice on respiratory health will be made easily available to the general public and specifically targeted at people with chronic respiratory conditions and those in other high risk categories.</td>
<td>Welsh Assembly Government</td>
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<td>Voluntary Sector</td>
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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.

3.1 Background

3.1.1 There is considerable scope to improve the diagnosis, treatment and management of respiratory conditions in Wales. The current configuration of services reflects historical developments and is not necessarily reflective of the present needs of the population or delivered in the most effective and evidence-based way. Care that is planned, co-ordinated and integrated across all health and social care sectors should be strengthened to help limit the impact of respiratory conditions on individuals and services. Early identification and intervention can have long-term benefits for people with respiratory conditions, for health and social care services in terms of resource utilisation, and for society as a whole.

3.1.2 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 the amelioration of the disease process and its consequences and further deterioration of lung function. Local advisory groups should play a key role in shaping services to meet local needs.

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.

3.1.3 The effective management of chronic respiratory conditions should take a holistic approach by helping people learn how to cope with the physical, psychological, social and wider aspects of the condition in their everyday lives.
3.1.4 Local multidisciplinary teams are central to ensuring an holistic approach to care for people with chronic respiratory conditions. 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 that can help support individuals to live as independently as possible.

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

3.2 Access to assessment and diagnostic support

3.2.1 Timely and accurate assessment and diagnosis of respiratory illness is the first stage to ensuring that respiratory health is preserved, treated and managed as quickly and effectively as possible. The future configuration of services will need to benefit from improved access to diagnostic services that span primary, secondary and tertiary care.

3.2.2 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 play an important role in the initial assessment of an individual’s respiratory health, as a number of conditions can be diagnosed, and managed, in a primary care setting. Improved access, strengthened by appropriate training of healthcare professionals is needed for spirometry testing, oximetry, and chest radiographs in primary care.

3.2.3 It is important that primary care professionals are supported in this process by specialist respiratory physicians as part of a multi-disciplinary approach to health care. More specialist diagnostic support facilities such as thoracic imaging, high quality chest radiographs, computer tomography, bronchoscopy, polysomnography, thoracoscopy for pleural disease and oxygen assessments should be available for more complex respiratory conditions in secondary care settings. This must be supported by appropriate training.
3.2.4 Those conditions that are difficult to assess and diagnose such as Diffuse Parenchymal Lung Disease (DPLD), sleep disordered breathing and more rare respiratory conditions such as Cystic Fibrosis and interstitial lung disease, require specialist diagnostic support from tertiary services. Commissioning arrangements for specialist respiratory services will need to be strengthened to incorporate provision for such conditions. To take this forward in line with NHS Commissioning guidance, LHBs, Regional Commissioning Units and specialist commissioners should build capacity and call upon expertise and professional advice from a range of appropriate sources including clinical networks.

3.2.5 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.

3.3 Primary care services

3.3.1 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, relevant diagnostic procedures and treatments, and pharmacological and non-pharmacological interventions.

3.3.2 To improve outcomes for individuals with common respiratory conditions, by providing accurate and timely assessment, diagnosis, treatment and management, general practices should ensure access to GPs, nurses and other members of the extended primary care team with specialist education in respiratory conditions and training in appropriate skills. Commissioner should be aware of opportunities to utilise the skills of respiratory specialists as part of a multidisciplinary approach. Respiratory Specialist Registrars can for example be trained to support early discharge from hospital, domiciliary oxygen provision, and pulmonary rehabilitation in the community. Respiratory physiotherapy can also be effectively provided in the community by appropriately trained health professionals ensuring rehabilitation is provided as close to people's homes as possible.

A seamless approach to the management of people with chronic respiratory conditions in the community can be achieved when primary and secondary care services are effectively integrated.
3.3.3 The Quality and Outcomes Framework (QOF) is a key component of the General Medical Services contract for general practices which rewards practices for the provision of quality health care, and helps to support further improvements in the delivery of clinical care. The QOF includes key clinical and organisational indicators for Chronic Obstructive Pulmonary Disease, Asthma and Smoking Cessation, with indicators for the maintenance of records and management of cases. Achieving the highest levels of care against the QOF criteria ensures improved assessment and diagnosis, treatment and ongoing management of these respiratory conditions. The utilisation of data collected through QOF should also be used 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

3.3.4 LHB commissioners should aim to obtain maximum benefit from General Medical Services (GMS) by utilising the QOF and the other provisions of primary care contracts including the development of effective local enhanced services.

3.4 Multi-disciplinary team-based care

3.4.1 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.50 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.51 As models of respiratory care are developed across Wales it is important that the people with chronic respiratory conditions have access to a multi-disciplinary team that has defined and overlapping roles.

3.4.2 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, respiratory nurses, 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.

3.4.3 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.

3.4.4 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 such as minority ethnic communities and asylum seekers who may find it more difficult to access appropriate services. The location and design of services 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 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.7

3.5 Emergency, secondary and specialist care

3.5.1 Rapid emergency response to life threatening situations is essential. The role of the Welsh Ambulance Services NHS Trust in this respect is vital and clear targets have been set for improving response times to life threatening and serious emergencies.

3.5.2 Recognition of the special requirements of people with chronic respiratory conditions is of crucial importance for ambulance services when responding to respiratory emergencies. Prescribed oxygen is one area in particular that must be accounted for in an emergency situation and it is essential that emergency personnel are aware of the dangers of the over-use of oxygen in patients who are sensitive and rendered unconscious by the use of oxygen.

3.5.3 The Ambulance Service also has a key role to play in the partnership approach to change the pattern of services to fulfil the wish of people to remain in or return to their homes wherever possible. One of the principles of the Delivering Emergency Care Services Strategy (DECS) is to provide services as
close to people’s homes as it is safe to do so. It is recognised that delivering safe services locally will require appropriate expertise and training and will require the development of the capacity of the Ambulance Service NHS Trust as set out in its Modernisation Plan.52

3.5.4 If admitted to hospital it is essential that people with respiratory conditions 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.

3.5.5 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 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.’

3.5.6 Twenty-four hour access to facilities for acute respiratory support, including non-invasive ventilation (NIV) and emergency oxygen provision, is imperative for people with respiratory conditions admitted to hospital as an emergency, and should be available at all acute admitting medical units. Evidence indicates that NIV reduces the length of hospital stay, avoids admission to intensive care or therapy units, avoids the risk of ventilator pneumonia, and reduces morbidity and mortality. The training of staff to utilise the benefits of simple diagnostic facilities and administer appropriate life-saving emergency interventions in acute emergency settings is vitally important.

3.5.7 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 consultant. 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 to hospital 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.

3.5.8 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.

3.6 Pulmonary Rehabilitation

3.6.1 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.\textsuperscript{51} It improves the quality of life for people with lung disease whose exercise capability and lifestyle is adversely affected by chronic breathlessness.\textsuperscript{54, 55} This includes people with a diagnosis of COPD, chronic asthma, pulmonary fibrosis, and bronchiectasis.

3.6.2 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. The configuration of the rehabilitation service may vary in each locality, in some areas resources from chronic conditions management teams can be used and primary care can take a key role as part of a multidisciplinary approach.\textsuperscript{56} Commissioners should evaluate which model of pulmonary rehabilitation will be most suitable for their local area.

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

- Respiratory nurse
- Medical Practitioner
- Physiotherapist
- Occupational Therapist
- Dietician
- Social Worker
- Pharmacist
- Psychology input
- Voluntary Sector support e.g. Breathe Easy Groups (British Lung Foundation)
- Primary care professionals
3.6.3 Trials have 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 appropriate. Participation in pulmonary rehabilitation has also been shown to reduce length of stay in hospital for those admitted to hospital with exacerbations of their condition.

**Success of rehabilitation programmes is attributed to the multi-professional team.**

3.6.4 The benefits of pulmonary rehabilitation are reported to be improvements in exercise-tolerance, health status, dyspnoea, and a reduction in usage of health services. 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. Importantly it has also been reported that these benefits are independent of age or the severity of the condition.

**Case Studies in Wales**

A community based pulmonary rehabilitation programme was set up in 2006 by Newport Local Health Board, Gwent NHS Trust and Newport City Council. Accessed via referral from Consultants, Specialist Nurses and in some cases directly from GPs, the programme successfully assists appropriate patients with COPD to proactively manage their condition.

The programme is underpinned by NICE guidance. It involves a structured six week exercise course, provided at Newport City Council’s International Sports Village facility, and is supported by education and advice from appropriate health professionals and fitness instructors. Family members, friends or other carers are encouraged to attend the exercise sessions to offer encouragement and importantly to help support continued safe exercise following the end of the programme.

The service is an illustration of effective multi-agency working to ensure service users are able to receive appropriate rehabilitation in a first class community facility. Users of the service have reported significant improvements in their health, general well being and quality of life.

3.6.5 It is important that rehabilitation programmes are 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.

### 3.7 Palliative and end of life care

3.7.1 Evidence indicates that people with progressive, life-limiting chronic 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 or end of life care services. Access to palliative care and end of life services for people with end-stage respiratory disease should be available for the individual, their families and carers and provided in appropriate settings with the agreement of the individual and their family and/or other carers. This must be multi-disciplinary in nature and managed within current guidelines including the NICE guidance on supportive and palliative care, All Wales Standards for Palliative Care Services and the all Wales care pathway for the last days of life. The development of services should also take account of forthcoming plans for improving end of life care across Wales.

*The provision of effective respiratory care across primary, secondary and tertiary services relies upon strong core elements of service provision. The following core elements should be strengthened in respiratory care in Wales:*

### 3.8 Adherence to national guidelines

3.8.1 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 is provided at appendix 3.

### 3.9 Care pathways

3.9.1 The effective coordination of the 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 people involved in caring for and supporting people with respiratory conditions are working to agreed goals and within defined areas of responsibility. The level of detail in a pathway can range from relatively simple high-level route maps that service users should follow, to a highly detailed evidence-based guide for a specific intervention or sets of interventions. The common aim of any pathway should be to ensure that patients are treated in the right way, at the right time and by the right person.

3.9.2 A number of tools have been developed to help structure care pathways including the concept of the ‘Year of Care’ and the ‘Map of Medicine’. Integrated Care Pathways (ICPs) provide a good example of how care can be structured. ICPs determine locally agreed practice, based on guidelines and evidence where available, for a specific patient or 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.

‘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.’

3.9.3 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.

3.9.4 Commissioners and planners will need to determine how care pathways should best be developed building upon the work driven by the National Leadership and Innovation Agency for Healthcare (NLIAH).

3.10 Oxygen Therapy

3.10.1 Provision of domiciliary oxygen, including long term oxygen therapy, short burst oxygen therapy and ambulatory oxygen improves the quality of life for people living with acute chronic respiratory conditions such as COPD and Cystic Fibrosis and plays an important role in helping them to live as independently as possible at home. This therapy has clear benefits for appropriately assessed 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.
3.10.2 New arrangements have been introduced to improve the provision of oxygen therapy services in Wales. Prescription of the therapy is now authorised following assessment by specialist teams to ensure that prescribing is in line with guidance produced by the British Thoracic Society.

**Case Studies in Wales**

Local Health Boards have implemented the new contract for domiciliary oxygen across Wales. 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 the individual need of the patient and, where appropriate, is delivered direct to patients’ home, with expert advice and support available 24 hours a day, 7 days a week.

### 3.11 Access to information and advice

3.11.1 People with a chronic respiratory condition can experience a great deal of uncertainty and anxiety regarding the future, both during assessment and later. Health professionals need to support people with these conditions, being sensitive to their concerns and changing needs by providing advice, relevant links and information resources.

3.11.2 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. These issues are further addressed in Chapter 4.

*The provision of respiratory services can be strengthened by exploring the opportunities to provide seamless care for people with respiratory conditions. Developments that should be explored include:*

### 3.12 Integrated Services

3.12.1 Integrating services more effectively is crucial to the future of health and social care in Wales. The Community Services Framework outlines some key approaches which can help to ensure that services are effective and meet all value for money challenges:
• Specifically tailored arrangements for service co-ordination, such as local networks for the care of COPD, can promote more effective service collaboration around the user. Improved joint planning and utilising the provisions of the Health Act Flexibilities can improve co-ordination and allow secondary care specialists, primary care clinicians and social services to work as a single team within a defined area.

• Opportunities to use shared service locations such as a Resource Centre or an existing or redeveloped community hospital site should also be explored by commissioners as a way of bringing together a number of services.

• The Local development of primary care networks or clusters can also ensure that the fullest range of specialist, diagnostic and therapeutic services is available locally.

### 3.13 Workforce Development

3.13.1 Modernising service delivery will require workforce planning and development. This will call for the development of appropriate new roles at various levels, the development of skills and competencies, innovative practice, and working across traditional organisational and professional boundaries. Commissioners of services will need to work in partnership with the Welsh Assembly, the National Leadership and Innovation Agency for Healthcare (NLIAH), the Workforce Development Education and Contracting Unit and the Welsh Deanery to take this forward within the context of Designed to Work: A workforce strategy to deliver Designed for Life.\(^2\)

3.13.2 Nurses, respiratory technicians, physiotherapists, dieticians and other health professionals can be appropriately trained at various levels to take increasing responsibility for managing chronic respiratory conditions, within a multi-disciplinary team and in accordance with locally defined protocols and care pathways.

3.13.3 Services for people with respiratory conditions in Wales can also benefit from the growing number of specialist nurses, 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.\(^2\)
3.13.4 Supplementary prescribing in Wales has allowed registered nurses and pharmacists to prescribe medicine as part of an agreed patient-specific clinical management plan and has led to a safer, more efficient and patient-friendly system of repeat prescribing. Independent prescribing, introduced in Wales in 2007, will help expand the clinical roles of nurses and pharmacists to support improved management of chronic conditions and the modernisation of service configuration in line with the vision set out in Designed for Life.

3.14 Specialists in the community

3.14.1 Health professionals with specialist interests, training and qualifications can play an important role as part of the multidisciplinary team in supporting people with chronic respiratory conditions in the community. They include GPs and nurses with a special interest in respiratory conditions and specialist respiratory nurses. Supported by training, quality assurance measures, the support and clinical leadership of secondary care specialists, all 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. These roles are also important for ensuring continuity of care, particularly following discharge from hospital, and can help to bridge primary, secondary and social care services.

3.14.2 There is also increasing interest in Wales in the training and development of Specialist Registrars in the community. As part of a multidisciplinary team the Respiratory Specialist Registrar can play a key role in supporting early discharge from hospital, domiciliary oxygen therapy and pulmonary rehabilitation programmes. As part of the development of effective service models for respiratory care, commissioners should explore all opportunities for appropriate outreach from secondary care specialists into the community in accordance with national guidelines and consistent with plans to rebalance local services.

3.14.3 As part of local workforce development plans, commissioners will ensure that the full range of opportunities to extend the role of specialists in the community are explored to ensure increasing support and continuity of care in the community in line with Agenda for Change.

3.15 Regional, Clinical and Commissioning Networks

3.15.1 Arrangements to provide services for respiratory conditions are made at local and regional levels. Each Local Health Board in Wales is well placed to work with
their local partner organisations including NHS Trusts, Local Authorities and the voluntary sector - to provide services which help to meet local needs.

3.15.2 For some conditions, a regional or national approach is 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. Local Service Boards and Regional Commissioning Units will have an important role in this context. The Commissioning of services should take account of NHS Commissioning Guidance published in 2007 (WHC (2007)023).

3.15.3 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 play an important role in ensuring that regional plans are developed to appropriately address these significant threats to respiratory health.

<table>
<thead>
<tr>
<th>Diagnosis, Treatment and Management</th>
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<tbody>
<tr>
<td><strong>Key Actions</strong></td>
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<tr>
<td><strong>Multidisciplinary Teams</strong></td>
</tr>
</tbody>
</table>
| By April 2008 a programme of joint training and educational sessions will be established to support the development of integrated respiratory multidisciplinary teams. | LHBs
NHS Trusts
Social Services
National Leadership and Innovation Agency for Healthcare (NLIAH)
Welsh Deanery |
| By June 2008 Integrated multidisciplinary teams for assessing and managing chronic respiratory conditions will be established across Wales. | LHBs
NHS Trusts
Social Services
NLIAH |
| Healthcare organisations must ensure that respiratory multidisciplinary teams deliver appropriate healthcare standards across Wales. | LHBs
NHS Trusts
Healthcare Inspectorate Wales
Welsh Assembly Government |
## Diagnosis, Treatment and Management

<table>
<thead>
<tr>
<th>Key Actions</th>
<th>By Who</th>
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<tbody>
<tr>
<td><strong>Care Pathways</strong></td>
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</tbody>
</table>
| By June 2008 care pathways will be established for chronic respiratory      | NLIAH
| conditions including asthma, COPD, cystic fibrosis, obstructive sleep       | LHBs
| apnoea and respiratory infections.                                           | NHS Trusts
|                                                                             | HCW
|                                                                             | Social Services      |
| By September 2008 local referral protocols will be established for          | LHBs
| respiratory conditions supporting care pathways and ensuring timely and    | NHS Trusts
| appropriate access to primary, secondary and tertiary health care services. | HCW
|                                                                             | NLIAH                |
| By December 2008 'End of Life' care pathways will be established for        | LHBs
| people with chronic progressive and end stage respiratory conditions in    | NHS Trusts
| line with emerging guidelines and local palliative care strategies.         | HCW
|                                                                             | Social Services
|                                                                             | Voluntary sector
|                                                                             | Independent sector   |
| **Assessment and Diagnosis**                                               |                      |
| By September 2008 a programme of training will be established for primary  | LHBs
| healthcare teams and other members of multidisciplinary teams as           | NHS Trusts
| appropriate to deliver simple diagnostic services for respiratory          |                      |
| conditions including spirometry testing and pulse oximetry.                |                      |
| NHS Commissioners will ensure that new and emerging technologies are        | LHBs
| utilised to facilitate early assessment and diagnosis of chronic            | NHS Trusts
| respiratory conditions in primary, secondary and tertiary care.             | Informing Healthcare  |
| By September 2009 specialist diagnostic facilities will be available in    | LHBs
| Wales supported by appropriate training.                                    | HCW
|                                                                             | NHS Trusts          |
## Diagnosis, Treatment and Management

### Key Actions

<table>
<thead>
<tr>
<th>Medical Emergencies</th>
<th>By Who</th>
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<tbody>
<tr>
<td>Responses to respiratory emergencies will be improved in line with modernisation plans for the Welsh Ambulance Service.</td>
<td>Welsh Ambulance Services NHS Trust LHBs NHS Trusts</td>
</tr>
<tr>
<td>By April 2008 essential life-saving equipment and simple diagnostic facilities for respiratory emergencies will be made available at all emergency admitting facilities across Wales supported by relevant training for medical and nursing staff. This must include access to non-invasive ventilation services and emergency oxygen provision.</td>
<td>LHBs NHS Trusts</td>
</tr>
<tr>
<td>By July 2008 all emergency admitting facilities will ensure prompt access to respiratory specialists for acute severe respiratory emergencies.</td>
<td>LHBs NHS Trusts</td>
</tr>
</tbody>
</table>

### Primary and Community Services

| LHB commissioners will utilise the provisions of the General Medical Services Contract to help ensure the maximum achievement of quality indicators for asthma, COPD, and smoking cessation. | LHBs |
| By September 2008 all patients with chronic respiratory conditions including asthma and COPD will have individual care plans in place developed by health professionals and the patient. | Primary Care Teams Respiratory Multidisciplinary Teams LHBs |
| By September 2008 rehabilitation programmes, including pulmonary rehabilitation, will be available to support people with chronic respiratory conditions in the community in line with National and Professional guidance. | LHBs NHS Trusts Local Authorities Voluntary Sector |
## Diagnosis, Treatment and Management

<table>
<thead>
<tr>
<th>Key Actions</th>
<th>By Who</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicines prescribed for chronic respiratory conditions by GPs and multidisciplinary teams will be reviewed and monitored within National guidelines.</td>
<td>LHBs</td>
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<tr>
<td></td>
<td>NHS Trusts</td>
</tr>
<tr>
<td></td>
<td>Welsh Assembly (AWMSG)</td>
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<tr>
<td><strong>Specialist Services</strong></td>
<td>LHBs</td>
</tr>
<tr>
<td>By April 2009 services will be made available in Wales for appropriate, evidence-based and cost effective services for complex respiratory conditions, including DPLD and cystic fibrosis and those conditions requiring specialised care and support, including long term ventilation.</td>
<td>NHS Trusts</td>
</tr>
<tr>
<td></td>
<td>Regional Commissioning Units</td>
</tr>
<tr>
<td></td>
<td>HCW</td>
</tr>
<tr>
<td><strong>Workforce Development</strong></td>
<td>Welsh Assembly</td>
</tr>
<tr>
<td>By March 2009 plans to develop the workforce to support the implementation of these Directives will be integrated into local workforce plans.</td>
<td>LHBs</td>
</tr>
<tr>
<td></td>
<td>NHS Trusts</td>
</tr>
<tr>
<td></td>
<td>Welsh Deanery</td>
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<td></td>
<td>Local Authorities</td>
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</table>
Chapter 4: Facilitating and Managing Independence

Aim - To ensure that people with chronic 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.

4.1  Introduction

4.1.1  The chronic and potentially debilitating nature of respiratory conditions can have a major impact on the lives of individuals and their families. Empowering and enabling individuals to share responsibility for managing their condition and providing the necessary support in all areas of their lives, will be beneficial for the individual and will also help to ensure that health and social care services are more efficiently utilised.

4.1.2  The core service elements and interventions highlighted in chapter three help to maximise independence, and will not be covered in detail in this chapter. For example, pulmonary rehabilitation as part of the ongoing management of respiratory conditions which helps people gain and maintain independence, and treatments such as long term oxygen therapy in people’s homes help people to live as independently as possible in the community.

4.1.3  Integrated, individual care-planning across health, 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.

4.2  Social Model of Disability

4.2.1  The Welsh Assembly Government has adopted the social model of disability as the basis for all its work on disability. The social model recognises that disadvantage and social exclusion often stem from the barriers in society rather than from an individual’s impairments. All service commissioners and planners should understand and implement the model when planning their services. They should be aware that people with chronic respiratory conditions often have impairments that may be hidden from view (including fatigue and anxiety) and that the severity of symptoms of the condition may fluctuate significantly from one day to the next.
4.3 Improving quality of life

4.3.1 Although it is unlikely that individuals with chronic respiratory conditions will be cured, much can be done to improve quality of life and support independence by ensuring:

- flexible and responsive services that are multi-disciplinary and seamless;
- training, information and advice on positive lifestyle options and self-management strategies;
- accessible employment or appropriate social security support, training and education;
- fully accessible buildings, transport, housing, leisure facilities and pursuits;
- clear roles between all appropriate agencies offering advice and support to enable people to fulfil their potential.

4.4 Social Inclusion, Care and Support

4.4.1 Chronic 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.

4.4.2 Living with chronic respiratory conditions has 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 chronic 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, 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.74

4.4.3 With appropriate support, chronic 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 advice, and an understanding and flexible approach from employers and employees can increase opportunities for gaining, regaining or remaining in employment. Access to appropriate treatment and support as outlined in chapter 3 enables individuals to take control of their own symptoms and, for those of working age, able to work, to be proactive in managing their work routines.

4.4.4 People living with respiratory conditions, and their family and other carers, should be in receipt of the benefits, support and advice they are entitled to. 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/

4.4.5 The National Association of Citizens Advice Bureaux (NACAB) Better Advice: Better Health initiative is a comprehensive provision of advice services for GP practices, covering the whole of Wales. The service has become part of the mainstream service allowing GPs to refer patients requiring benefits advice and social care services to expert advisers from NACAB.

4.5 Self Management

4.5.1 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 and to emergency admissions to acute hospital care when this could be avoidable and preventable.

4.5.2 To support independence and self-management, individuals need to be able to:

- recognise symptoms and understand the benefits of safe and effective exercise, correct diet and smoking cessation;
- develop or enhance existing skills and techniques to help look after themselves;
- recognise when professional advice is required and other support is needed;
- understand when their conditions can be safely managed by themselves.
4.5.3 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 relevant information and advice. Sources of information can be accessed through a number of routes including web-based advice and a 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.75

4.5.4 Self management programmes including the Expert Patients Programme have been found to bring about a reduction in hospital admissions and visits to Accident and Emergency Departments.76 Research also indicates that disease specific self management interventions for respiratory conditions, provided by trained health professionals, can improve health status as well as significantly reducing the utilisation of health care services.77 Planners and commissioners of services should consider interventions such as the Expert Patients Programme, which focuses on teaching self management skills, and condition specific programmes like the British Lung Foundation’s ‘Breathe Easy’ initiative.78

**Case Studies in Wales**
Breathe Easy groups are part of a network of patient support groups organised and supported by the British Lung Foundation. Meeting usually on a monthly basis, they offer an opportunity to get together with others who are in similar circumstances. In addition to providing vital access to peer support, they can also offer information and education about respiratory conditions. A member of the Breathe Easy group in Bridgend said “Breathe Easy can overcome the sense of being alone with a chronic disease. I’ve made friends who fully understand my situation. In return I find it a pleasure to join in activities which allow us to promote greater awareness of lung disease”.

4.5.5 Individuals whose conditions are controlled by medication should be educated and provided with correct information to ensure the full benefits of compliance are realised. Community pharmacists can play an important role in supporting the management of medicines to help people self-manage. Under the new Pharmacy Contract, community pharmacists can play a significantly increased role in the management of chronic conditions.
4.6  **Home Care and Personal Assistance**

4.6.1  People with chronic respiratory conditions including COPD and acute asthma will need assistance with personal care and domestic activities at some stage. This can be on a short-term basis or part of a longer term programme, based upon a joint health and social services assessment of individual's needs. Services should be responsive and flexible to attend to the different nature of respiratory conditions and individual requirements.

4.6.2  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 should be built into joint assessments including the Unified Assessment Process for people with respiratory conditions.

4.6.3  ‘Direct Payments’ by social services provide a good example of how this can be achieved. Evidence supports the view that direct payment schemes offer improved quality of life for disabled people. The Direct Payment option may not be suitable for all people with chronic respiratory conditions, but it is important that guidance is available to support those who are able to take up this option.

4.6.4  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. Their role should be addressed through integrated planning and commissioning processes.

4.7  **Aids and Adaptations**

4.7.1  Timely provision of aids and adaptations can have an important impact on independence for a person living with a chronic respiratory condition. This provision is currently provided by a range of organisations including health services, social services and the voluntary sector. It is important that the support and advice of the Occupational Therapist facilitates this process and ensures links are made with appropriate local authority departments including housing.

4.7.2  Consistency in the provision of aids and adaptations across Wales will be encouraged by the development of integrated health and local authority equipment services. These services are more responsive to the needs of individuals, ensure cost-effectiveness through greater purchasing power, and provide a consistent, seamless service for individuals with respiratory conditions.
4.7.3 Both telecare and telehealth services 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 delivering such services or developing them in partnership with the voluntary sector and other stakeholders. A new telehealth website contains information about related activities currently in progress across Wales. Further information about telehealth and telecare is available at http://www.wales.nhs.uk/

4.8 Supporting unpaid carers

4.8.1 Many people living with a chronic respiratory condition are supported in the management of their condition 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, often resulting in ill health and discrimination.

4.8.2 It is essential that unpaid carers have access to support and information if their contribution to the effective rehabilitation and management of respiratory conditions is to be maximised. Carers need to be offered choices about whether or not they wish to take on a caring role and if so, be offered appropriate support, information and courses that can help them learn how to cope, manage their own health and well being, and keep on caring. A number of voluntary sector organisations provide free information and support to carers. The Expert Patients Programme also offers the ‘Looking After Me’ course which helps carers to manage their own lives whilst being a carer.80

4.8.3 Carers need to be treated as partners in care and be involved in all aspects of care planning, including hospital admissions and discharge arrangements, and support in the community. Multidisciplinary teams involved in an individual’s treatment and care need to know about care arrangements at home. The development of protocols could help to support active engagement with carers in care planning by specifying what steps should be taken to involve carers in all relevant aspects of care planning. This should cover the provision of appropriate information and signposting carers towards sources of support, including carers’ assessments, voluntary organisations and support groups and training courses.
4.8.4 Assessments for care services under the Unified Assessment Process include a section on the role of any carer who provides or intends to provide “regular and substantial” care. This should trigger the requirement of the Carers Equal Opportunities Act 2006 that carers should be informed of their right to a separate assessment of their needs. This assessment must 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, and take into consideration the work, education/learning and leisure needs of the carer.

4.9 Hospital Discharge

4.9.1 Respiratory conditions are a major reason for admission to hospital. Length of stay in a hospital bed for respiratory conditions is greater than the average length of stay for other health conditions, which places considerable pressure on secondary health care services. 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.

4.9.2 It is essential that robust discharge procedures are in place to facilitate a return to home life when clinically appropriate. The interface between hospital 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 enabling discharge, reducing subsequent morbidity and avoiding readmission to hospital for the same complaint.40 Readmission to hospital 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. This needs considerable attention in Wales.

4.9.3 The principles of hospital discharge planning as outlined in Welsh Health Circular 2005 (035)41 should be applied to all people admitted to hospital with an exacerbation of a chronic respiratory condition. Planning for early and appropriate discharge should begin at admission to hospital or earlier, if applicable, with assessment by appropriate members of the multi-disciplinary team to facilitate early discharge and ensure seamless provision of appropriate services to support a return to home life. Early and assisted discharge and step-down schemes, supported by co-ordinated rehabilitation programmes provide a useful solution to facilitating early and appropriate discharge. They can be an important
component of care for some people admitted with exacerbations of chronic respiratory conditions such as COPD. They require increased medical, nursing and social support in the community and should be extended across Wales. Good communication within the multidisciplinary team and with the patient is essential to ensure positive outcomes for the individual and efficient provision of services.

**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 requires 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.

4.9.4 Effective medicines management is also a key feature of the discharge planning process. Pharmacological interventions should support the individual needs of each patient and 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.82
### Facilitating and Managing Independence

<table>
<thead>
<tr>
<th>Key Actions</th>
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<tbody>
<tr>
<td><strong>Self Management</strong></td>
<td></td>
</tr>
<tr>
<td>By July 2008 individual care plans will include a category for self management ensuring access to the Expert Patients Programme courses for people with chronic respiratory conditions.</td>
<td>LHBs, NHS Trusts, Expert Patients Programme, Voluntary Sector</td>
</tr>
<tr>
<td><strong>Information</strong></td>
<td></td>
</tr>
<tr>
<td>By September 2008 appropriate information and support on chronic respiratory conditions will be widely available signposting services provided by the voluntary sector and local user-led self-help groups.</td>
<td>LHBs, NHS Trusts, NPHS, Voluntary Sector</td>
</tr>
<tr>
<td><strong>Hospital Discharge</strong></td>
<td></td>
</tr>
<tr>
<td>By April 2008 integrated plans will be in place ensuring joint discharge planning and assisted hospital discharge/step down schemes for people with chronic respiratory conditions.</td>
<td>LHBs, NHS Trusts, Social Services, Voluntary Sector</td>
</tr>
<tr>
<td><strong>Aids and Adaptations</strong></td>
<td></td>
</tr>
<tr>
<td>By September 2008 joint processes will be in place ensuring an assessment of the daily living needs of people with chronic respiratory conditions at high risk of emergency admissions to hospital and the provision of appropriate equipment and/or housing adaptations.</td>
<td>LHBs, Social Services, Voluntary Sector</td>
</tr>
<tr>
<td><strong>Supporting Carers</strong></td>
<td></td>
</tr>
<tr>
<td>By March 2009 opportunities for respite for carers of people with chronic respiratory conditions will be maximised in line with existing guidance.</td>
<td>LHBs, Social Services, Voluntary Sector</td>
</tr>
<tr>
<td>By March 2009 unpaid carers will be actively involved in joint care planning arrangements to help them look after themselves and the person living with a chronic respiratory condition.</td>
<td>LHBs, Social Services, Voluntary Sector</td>
</tr>
</tbody>
</table>
Appendix 1

Membership of the Implementation and Planning Group

Dr Tim Baker  
Chair, Consultant Respiratory Physician
Mrs Helen Howson  
Welsh Assembly Government
Mr Ross Gregory  
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Mrs Sue Davies  
Welsh Therapies Advisory Committee
Mrs Jenny Harries  
Welsh Pharmaceutical Committee
Dr David Phillips  
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Appendix 2

Key Equality Legislation

The equality agenda is underpinned by a large body of legislation, including:

- The Equal Pay Act 1970
- The Sex Discrimination Act 1975
- The Race Relations Act 1976
- The Disability Discrimination Act 1995
- The Human Rights Act 1998
- The Race Relations (Amendment) Act 2000
- The Employment Equality (Sexual Orientation) Regulations 2003
- The Employment Equality (Religion and Belief) Regulations 2003
- The Gender Recognition Act 2004
- The Disability Discrimination Act 2005
- The Equality Act 2006
- Carers (Equal Opportunities) Act 2004
Appendix 3

Key sources of Clinical Guidance

National Institute for Health and Clinical Excellence (NICE): Accessible at: http://www.nice.org.uk/


Scottish Intercollegiate Guidelines Network: Accessible at: http://www.sign.ac.uk/

Cystic Fibrosis Trust. Accessible at: http://www.cftrust.org.uk/

National Library for Health - Clinical Knowledge Summaries: Accessible at: http://www.cks.library.nhs.uk/

NHS Library: Respiratory Conditions: Accessible at: http://www.library.nhs.uk/
Appendix 4

References


4. Op Cit

5. Patient Episode Database Wales (PEDW)


11 Welsh Assembly Government, National Service Framework for Children, Young People and Maternity Services: Accessible at:


13 Government of Wales Act 2006, ISBN 0 10 543206 7 Available at:


15 The Review of Health and Social Care in Wales: A Report of the Project Team advised by Sir Derek Wanless (June 2003) Available at:


20 See http://www.rcplondon.ac.uk/college/ceeu/ceeu_copd_home.htm


24 Further information at: http://www.mapofmedicine.com/

25 Further information at: http://www.dur.ac.uk/ccmd/yoc/


28 Further information at: http://www.eppwales.org/

29 Further information at: www.lunguk.org


32 http://www.smokingbanwales.co.uk/english/


Further information at: http://www.Howis.nhs.uk/immunisation


Doul and Burr 2006

BTS Asthma guideline accessible at: http://www.brit-thoracic.org.uk/asthma-guideline-download.html


http://www.cmo.wales.gov.uk/content/work/physical-activity/exercise-referral-guide-e.pdf#search=%22Exercise%20Referral%20in%20Wales%22

http://new.wales.gov.uk/topics/health/professionals/ocmo/?lang=en

Food and Well Being: Reducing inequalities through a nutrition strategy for Wales (2003), Food Standards Agency Wales, Welsh Assembly Government

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


See: http://www.metoffice.com/health/features/copd.html


http://www.hse.gov.uk/pubns/indg95.pdf

NICE Clinical Guideline 12 Management of COPD in adults in primary and secondary care

Cystic Fibrosis Trust, Accessible at: http://www.cftrust.org.uk

Welsh Ambulance Services NHS Trust (2007), Time to make a difference: Transforming Ambulance Services in Wales


62 Nice guidance on supportive and palliative care for adults with cancer: Available at: http://guidance.nice.org.uk/csgsp

63 All Wales Standards for Palliative Care Services: Children and Young People’s Specialised Healthcare Services (2005)


65 NPA 1998


67 Johnson, Pathways of Care, Chap 2, (Blackwell Science: 1997)

NICE Management of Chronic Obstructive Pulmonary Disease in Adults in Primary and Secondary Care February 2004

Accessible at: http://www.brit-thoracic.org.uk/

Ref: Community Services Framework

Designed to Work: A workforce strategy to deliver Designed for Life, July 2006, Welsh Assembly Government

Therapies for Modernisation, Welsh Assembly Government 2005


http://www.asthma.org.uk/how_we_help/schools_early_years/index.html

Expert Patients Programme Post-Course Analysis, January 2005, Department of Health


Accessible at: www.lunguk.org


http://www.expertpatients.nhs.uk/carers.shtml
