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# Together for Health – A Respiratory Health Delivery Plan

A Delivery Plan up to 2017 for the NHS and its partners

Date of Issue: 29 April 2014

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#### Mark Drakeford AM, Minister for Health and Social Services

#### **Ministerial Foreword**

Respiratory disease is the cause in one in seven of all deaths in Wales; the third largest cause of death for both women and men in Wales. At the same time, one in seven adults in Wales reports being treated for a respiratory condition.

As with a number of other health conditions, lifestyle factors can increase the risk of getting a respiratory disease. Whilst diet and weight are contributory factors, smoking continues to be the main risk factor. The Welsh Government will continue to take legislative action to reduce the incidence of smoking. At the same time we will continue to help make people aware of these risks in their own lives, and encourage individuals to take responsibility for the actions which they can take to shape their own health, and reduce the risks of respiratory disease.

The prudent healthcare approach means that we all have to be jointly involved in avoiding avoidable harm. Respiratory health is a vivid example of this principle because, through a combination of collective and individual action, so much can be done to prevent harm from occurring.

To achieve the best possible outcomes for patients with a respiratory condition each individual needs to be fully involved in their care; be that a child and their family managing a new diagnosis of asthma, or an elderly patient with a terminal diagnosis considering options for palliative care. Patient education and co-production of care needs to be part of the patient's care pathway to achieve the best for the patient.

This Plan will be supported by a separate children and young peoples' section, addressing the specific needs of this group of people. This will be published this summer.

Respiratory health covers a range of conditions. This plan sets out the main actions needed to be implemented to improve healthcare outcomes for patients. It seeks to ensure that these improvements are delivered to all the people of Wales; wherever they live and whatever their socio-economic situation

### Foreword from Simon Dean, Acting Chief Executive of NHS Wales

This Respiratory Health Delivery Plan sets out a compelling vision for success. It challenges organisations to plan and deliver high quality services in partnership. I want to see continuous improvement integrated into everyday working. Our measures of success must focus more on public health outcomes, the quality of our services and the individual's experience.

I commit Local Health Boards and NHS Trusts, working together with their partners, to plan and deliver safe, sustainable, high quality respiratory care for their populations. I will support them in this endeavour, holding Local Health Boards to account on the outcomes they deliver for their populations and their contribution to the overall health of the people of Wales.

To deliver long term, sustainable improvements to respiratory care services in Wales will be a challenge for the NHS and its partners. It is a challenge we must and will meet.

#### 1. INTRODUCTION

This Respiratory Health Delivery Plan provides a framework for action by Local Health Boards (LHBs) and NHS Trusts. It sets out the Welsh Government's expectations of the NHS in Wales to tackle lung diseases in adults and young people wherever they live in Wales and whatever their circumstances. The Respiratory Health Delivery Plan sets out how the NHS will deliver on its responsibility to meet the needs of people at risk of developing, or affected by, a wide variety of acute and chronic lung conditions. This is a significant challenge, for individuals and their carers and the Welsh NHS.

To sustain and continue developing high quality health care for the people of Wales, there needs to be increased levels of personal responsibility for lifestyle choices which influence people's risk of acquiring chronic conditions, or impacts the benefit of possible treatment. The Welsh Government issued a Public Health White Paper on 2 April 2014 to take forward our proposals to support improvements in lifestyle changes. The people of Wales need to fully engage in this debate if they are to help us achieve a healthier country, served by an effective and sustainable health service.

#### This plan establishes:

- The population outcomes we expect
- The outcomes from NHS care we expect
- How success will be measured and the level of performance we expect
- Themes for action by the NHS, together with its partners

#### 2. STRATEGIC CONTEXT

The Welsh Government's Programme for Government and its 5-year NHS Plan, *Together for Health*, introduced an ambitious programme for health in Wales so that:

- Health will be better for everyone
- Access to care and patient experience will be better
- Better service safety and quality will improve health outcomes

Achieving Excellence: The Quality Delivery Plan for the NHS in Wales for 2012-16 describes a journey to consistent excellence in service. It outlines actions for quality assurance and improvement. We commit to a quality-driven NHS that provides services that are safe, effective, accessible and affordable, and that come with an excellent user experience.

This Plan identifies what this means for the delivery of measurable excellence in respiratory health services for patients with common respiratory conditions that have not been addressed elsewhere. For example, lung cancer services have been addressed in the *Cancer Delivery Plan (2012*).

As patients may have a chronic respiratory condition as one of a number of comorbidities, LHBs need to consider the Chronic Conditions Management Model and Framework when developing local respiratory plans.

This plan also considers the need to develop services in Primary and Community settings. LHBs should take account of the principles detailed within the Setting the Direction: Primary & Community Services Strategic Delivery Programme when

developing such services. Much of the ongoing care and support for people with long term conditions can be provided by primary and community care at or close to home. The Welsh Government plan Delivering Local Health Care, published in June 2013, brings a renewed focus to the need for rapid change and improvement in primary and community care settings. Health Boards and their local government, third and independent sector partners must work together through locality networks to assess local community and individual need, and plan, co-ordinate and deliver local integrated health and social care designed to meet that need.

#### 3. OUR VISION

The Programme for Government states the overall population outcomes we want to achieve: better health for all and reduced inequalities in health. Reducing the impact of respiratory conditions on the lives of people in Wales will contribute significantly to these outcomes.

For our population we want:

- People of all ages to be encouraged to value good lung health, to be aware of the dangers of smoking and, take personal responsibility for their lifestyle choices to reduce the risk of acquiring a respiratory condition and maximise the benefit of any treatment
- Where problems with lung health occur, individuals can expect early and accurate diagnosis and effective treatment so the quality of their life can be optimised

Our aim is for Wales to have low incidence for lung disease and improved health care outcomes. We will use the following indicators to measure success:

- A reduction in prevalence of smoking as per the Tobacco Control Action Plan for Wales
- Incidence of Chronic Obstructive Pulmonary Disease (COPD) per 100,000 population
- Unscheduled hospital admissions for both asthma and COPD per 100,000 population
- Disease and age group specific mortality rates under age 75 per 100,000 population

#### 4. OUR DRIVERS

Health Statistics Wales 2013 makes clear the magnitude of respiratory conditions nationally. One in seven adults (14%) in Wales reports being treated for a respiratory condition and respiratory diseases cause one in seven (15%) of all deaths in Wales. Moreover, the *Welsh Health Survey 2012*, which includes lifestyle information, reveals a smoking prevalence in Wales of 23% and a prevalence of overweight and obese adults of 59%. Both smoking and obesity are major contributory factors to the levels of

respiratory disease. Improving the respiratory health of the population in Wales is a major challenge for health care providers and a key opportunity to improve the lives of patients and their families.

Improvements in respiratory heath care have not been achieved equally for all people and substantial differences in service provision can be found between communities. Levels of respiratory disease in areas of social deprivation are of particular concern and improved outcomes in respiratory health also need to be delivered equitably.

Local Health Boards need to focus their activity on providing services which make the most effective use of resources, whilst measurably impacting upon the quality of life for areas of population with particularly poor lung health.

#### **5. OUR JOURNEY SO FAR**

A wide diversity of respiratory diseases are part of the significant challenge of improving respiratory health in Wales. Better information on smoking and the incidence, prevalence and outcomes of common conditions such as Chronic Obstructive Pulmonary Disease (COPD), bronchiectasis, asthma and sleep-disordered breathing has defined the scale of the problem. Some progress has already been made in addressing smoking cessation. A ban on smoking in public places in Wales was introduced in 2007. Provision of good quality primary-care spirometry and oximetry and the delivery services required to support patients have enabled improvement; e.g. oxygen services and some pulmonary rehabilitation multidisciplinary teams are now established throughout Wales.

We acknowledge that much still needs to be done to deliver comprehensive respiratory services in Wales. The progress we have made has been much assisted by the detailed information from national guidelines and advice from the Respiratory Medicine National Specialist Advisory Group, with its provision of data and service reviews.

#### 6. WHAT DO WE WANT TO ACHIEVE?

This Delivery Plan establishes outcomes needed to improve respiratory health care in Wales. It sets out high level actions to support their effective delivery in the following areas:

#### 1. Preventing poor respiratory health

People to be aware how to live healthy lifestyles, make healthy choices and minimise their risk of poor respiratory health and understand the consequences of not doing so

#### 2. Detecting respiratory disease quickly

Respiratory disease to be detected quickly where it does occur

#### 3. Delivering fast, effective treatment and care

People to receive prompt, effective treatment and care for their respiratory condition so that they have the best chance of optimising their quality of life and improving survival, reciprocated by patients taking

responsibility for lifestyle choices that positively contribute to their treatment and care

#### 4. Supporting people living with lung disease

People to be placed at the heart of respiratory health care with their individual needs identified and met so that they feel well supported, informed and able to manage the effects of poor lung health

#### 5. Improving Information

Patients, health professionals and service planners will have access to appropriate information to help them make informed decisions about care and treatment. The public, the NHS, the third sector and the Welsh Government will have access to information on the outcomes of NHS Care

#### 6. Targeting research

The Welsh Government and NHS Wales continues to promote the research base and ensure appropriate access to clinical trials which can lead to better outcomes for patients

Each Local Health Board is required to develop local delivery plans setting out how they plan to achieve the respiratory health care outcomes established in this document.

### **6.1 Preventing Respiratory Disease**

Health education and disease prevention strategies should inform everyday life style choices. We need to motivate people to be aware of, and take action to minimise their risk of premature respiratory disease through healthy lifestyle choices. In particular, reducing smoking will have the greatest impact. Appropriate vaccination programs (e.g. influenza) need to be further encouraged amongst target populations. Drug-induced lung disease should be identified quickly and information about causes disseminated widely amongst health professionals. This support and advice needs to be reciprocated by people taking personal responsibility for their lifestyle choices; having been made aware of the possible consequence those choices may have on the benefits of any future care that they may receive.

The Welsh Government, Local Health Boards, Public Health Wales, the third sector, Community Pharmacy and other partners need to work collaboratively to increase public awareness and encourage and support at-risk populations to adopt healthier lifestyles to address personal diet and weight issues. LHBs must fully implement all levels of the All Wales Obesity Pathway. Relevant partners need to work with the Health and Safety Executive to ensure that there are continued improvements to working conditions in areas of industry and agriculture which involve exposure of individual's lungs to the adverse effects of hazardous compounds.

#### **SMOKING**

#### **OUTCOMES:**

 Reduction in the prevalence of adult smoking to 20% by 2016 and 16% by 2020

#### **ACTIONS:**

#### Welsh Government will:

 Work collaboratively with a broad range of organisations to reduce the uptake and prevalence of smoking in young people and adults; and monitor and review progress against actions in the Tobacco Control Action Plan for Wales (2011)

#### Local Health Boards and Public Health Wales will:

- Work with a broad range of partners (including community pharmacists, GPs, secondary care, Local Government and the third sector) to deliver local strategies and services to prevent smoking, offer support for those wishing to quit, and achieve the Tier 1 target on smoking cessation
- Work together to regularly review, plan and deliver the smoking cessation programmes recommended in the Tobacco Control Action Plan for Wales (2011) ensuring appropriate data collection for monitoring success
- Ensure smoking cessation services comply with best practice
- Ensure sufficient capacity and workforce to be able to deliver the actions and outcomes of the Tobacco Control Action Plan for Wales (2011)

#### **VACCINATION PROGRAM**

#### OUTCOME:

• Ensure >75% of target populations receive appropriate vaccinations

#### **ACTIONS:**

#### Welsh Government will:

• In partnership with Public Health Wales promote active awareness campaigns and take-up rates for immunisation programs

#### **Local Health Boards will:**

Raise awareness and implement local immunisation policies

### 6.2 Detecting Lung Disease Early

The benefits of prompt diagnosis of lung disease are significant, particularly in such conditions as asthma, COPD, sleep-disordered breathing, occupational lung diseases and a wide range of interstitial lung diseases. There is a need for greater public awareness of the symptoms of such lung diseases, of the risks posed by smoking and by any delay in diagnosing smoking-related lung conditions such as lung cancer and COPD.

Local public health analyses should model the expected prevalence of lung diseases, ensuring that local systems are identifying effectively lung diseases and that primary care Quality Outcomes Framework (QOF) registers are complete. Local Health Boards should consider the development of guidance or sharing of good practice to ensure that case-finding is systematic and effectively identifies those groups at risk in all settings. Consideration should also be given to the identification of risk in those who do not attend NHS services.

People with symptoms, abnormal tests or screening results should have these addressed locally and/or where appropriate, should be referred for further assessment and management when lung disease is suspected or confirmed.

Spirometry, oxygen saturation measurement and chest radiology are important investigations widely available in both primary and secondary care practice. They can be used to identify at-risk groups within case-finding strategies which can be most effectively undertaken in local community settings.

#### **OUTCOMES:**

- People over-35 who smoke are offered spirometry and signposted to smoking cessation support and made aware of the consequences of continuing to smoke on their health and possible future treatment
- At-risk groups who present with persistent respiratory symptoms receive appropriate diagnostic tests and are signposted to support and treatment as required

#### **ACTIONS:**

#### The Welsh Government will:

- Work with Local Health Boards and Public Health Wales, to encourage integrated services that will lead to appropriate access to services to improve diagnostics and improved take-up of preventative management
- Consider the inclusion of lung function and obstructive sleep apnoeahypopnoea syndrome diagnostics within the referral to treatment time targets (RTT) as part of the 2014/15 review of RTT

#### **Local Health Boards will:**

- Identify at-risk groups
- Offer at-risk groups who present with persistent respiratory symptoms appropriate diagnostic tests (e.g. chest X-rays and spirometry), delivered by appropriately trained staff
- Offer spirometry to the over-35 age group who smoke, delivered by Association for Respiratory Technology and Physiology (ARTP) accredited staff within primary and secondary care
- Validate and improve reporting and interpretation of spirometry results

### 6.3 Delivering Fast, Effective Care

Conditions affecting respiratory health are numerous, varied and often complex, requiring a multidisciplinary approach to management offered by many different providers. We have identified five lung conditions where improvements in the delivery of effective care can result in high impact changes to the people of Wales's respiratory health. These are: Asthma; Chronic Obstructive Pulmonary Disease (COPD) and Bronchiectasis; Interstitial Lung Disease; Sleep-Disordered Breathing; and Acute Respiratory Care.

#### **Asthma & Allergy**

Asthma is a condition that can affect people of any age. It is an important factor in repeated respiratory infections in children and causes breathlessness in adults. If undiagnosed or inadequately treated it can in the short-term lead to potentially life-threatening exacerbations and in the long-term to irreversible damage to the lungs. Once a diagnosis of asthma has been achieved, information about asthma which is relevant, easy to understand and in an accessible format should be provided. Those diagnosed should all be provided with an individual asthma management plan including relevant contacts and what to do in the event that their asthma becomes uncontrolled, including training in inhaler technique to support effective self management strategies for the condition.

All patients with asthma will receive treatment appropriate to the severity of their illness, supported by consistent, high quality prescribing across Wales.

#### Chronic Obstructive Pulmonary Disease (COPD) and Bronchiectasis

COPD is a chronic progressive disease of the airways associated with high morbidity and mortality. It is largely managed in primary care but exacerbations of symptoms often result in acute admission to hospital. Patient support groups can improve quality of life for patients living with COPD. Secondary care is involved with providing

increasingly more complex interventions such as domiciliary ventilation and assessment for referral to thoracic surgery. As the disease progresses, accessing palliative care services can improve the quality of life of patients with advanced disease.

Adherence to evidence-based guidelines, regular review in primary care, self-management initiatives, long-term oxygen therapy and pulmonary rehabilitation programmes (PRP) can all improve quality of life and reduce hospital admission. Non-invasive ventilation is cost effective and improves outcomes for selected patients. Optimisation and full integration of COPD care following discharge from hospital improves life for the patient and reduces re-admission rates.

**Bronchiectasis** is a condition characterised by chronic sputum production and a propensity to develop frequent lung infections, often requiring hospital admission. There is often pre-existing COPD. People with a suspected diagnosis of bronchiectasis should have the diagnosis confirmed by chest CT (computed tomography). Physiotherapy has a major role in its management, helping to reduce infections and hospital admissions.

#### **Interstitial Lung Diseases (ILDs)**

ILDs comprise a large number (over 150) of diverse conditions which primarily affect the lung's smallest airways and alveolar air sacs. Whilst the cause of some ILDs is unknown, there is an overlap with occupational and environmental lung diseases such as Coal and Slate workers' pneumoconiosis, asbestosis and Farmer's lung. It is known that some ILDs are caused by cigarette smoke and others may occur as a reaction to medication and yet others occur in association with diseases such as rheumatoid arthritis. Finally, ILDs need to be distinguished from other lung conditions which they sometimes mimic.

Idiopathic pulmonary fibrosis (IPF), the commonest ILD, has shown a greatly increased prevalence over the past 20 years, with Wales having one of the highest incidence rates of IPF in the UK<sup>1</sup>. The median survival for IPF is just three years – a prognosis that is worse than many cancers. Lung transplantation is the only treatment proven to improve survival in some forms of ILD.

#### **Sleep Disordered Breathing**

The obstructive sleep apnoea-hypopnoea syndrome (OSAHS) is common, affecting around 4-6% of middle-aged adults. If left untreated, OSAHS causes daytime sleepiness, impaired vigilance and cognitive functioning, reduced quality of life and is associated with an increased risk of road traffic accidents. The latter risk is particularly important for professional drivers of HGVs and public transport vehicles. Severe OSAHS, in particular, is associated with many other chronic cardiovascular diseases such as stroke and hypertension. Early diagnosis and a prudent approach to treatment should form the basis for OSAHS interventions, ranging from lifestyle advice for mild

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<sup>&</sup>lt;sup>1</sup> UK incidence for IPF is 7.94/100,000. The incidence rate for Wales is 8.22/100,000 for Wales, making it the fourth highest adjusted rate compared with other Heath Authorities in the UK.

symptomatic OSAHS to Continuous Positive Airway Pressure (CPAP) therapy and home bi-level ventilation for moderate to severe cases<sup>2</sup>.

#### **Acute respiratory illness**

Acute respiratory illnesses are common and include community-acquired pneumonia, acute exacerbations of COPD, asthma attacks and a number of less common conditions. Together these represent a major demand on primary and hospital care. There is the potential to develop admission-avoidance initiatives aimed at treating people successfully in the community and at home. Moreover, there are various early assessment and discharge schemes that can be utilised to reduce delays in effective treatment and subsequently the length of hospital stay, thus optimising the use of hospital beds and reducing the considerable costs of such conditions.

#### **OUTCOMES:**

- Where appropriate, patients are able to access care in the community, closer to home
- All people affected by a respiratory conditions to receive information about their condition, which is easy to access, relevant and easy to understand
- Patients are motivated and supported in managing their condition, thereby reducing the need for unscheduled attendances to hospital
- People diagnosed with ILD to be managed through a Multi Disciplinary Team (MDT) that works to national guidelines
- Patients have access to prompt diagnosis and treatment, achieved by maintaining compliance with patient referrals for treatment targets (RTT)

#### **ACTIONS:**

The Welsh Government will:

 Work with Health Boards and Public Health Wales to encourage integrated services that will lead to more rapid access to, and take-up of, asthma treatment and on-going care in the community

#### **Local Health Boards will:**

 Develop enhanced discharge and follow-up schemes to facilitate, when appropriate, quicker discharge from hospital and community support to reduce risk of re-admissions

<sup>&</sup>lt;sup>2</sup> The established treatment for moderate to severe OSAHS, which is cost-effective, is overnight home Continuous Positive Airway Pressure (CPAP) therapy and overnight home bi-level ventilation for moderate to severe sleep disordered breathing associated with complicating co-morbidity. CPAP should only be available as a treatment option for people with mild symptomatic OSAHS if lifestyle advice and other relevant treatment options have been unsuccessful or are considered inappropriate.

- Provide patients, and carers, with relevant, appropriate and adequate information about their respiratory conditions and allergic disorders
- Audit data on treatment steps, concordance with treatment and asthma self-management plans to support the development of improved service delivery
- All patients attending hospital with acute asthma to have a discharge letter delivered to the GP within 24 hours, or by the next working day
- Ensure the implementation of NICE guidelines for COPD in both primary and secondary care services through a defined pathway of care
- Develop recognised MDT-led Pulmonary Rehabilitation Programs (PRP) that address local needs and responds to the recommendations of National Clinical Audit<sup>3</sup>
- Patients with MRC breathless score of 3 or greater are referred to pulmonary rehabilitation (PR)
- Develop PRPs for patients admitted with acute exacerbations
- Ensure that adequate levels of physiotherapy services are established to provide and teach the breathing and lung drainage techniques that are essential to patients with bronchiectasis
- Ensure that, as with lung cancer, patients with ILDs are managed through a MDT framework and have access to specialist nursing support for appropriate conditions
- Ensure that pathways for the investigation of sleep-disordered breathing are established to assess and treat patients with OSAHS within established RTT
- Undertake a population needs assessment and review current levels of service for sleep-disordered breathing against the recommendations of the Strategy Document for Sleep Disordered Breathing Services in Wales 2010⁴
- Develop initiatives with community leads to promote the management of acute respiratory conditions in the patient's home and intermediate care, where appropriate
- Develop pathways to address acute conditions across an enhanced primary-secondary care interface and to manage them where appropriate in the community setting

<sup>&</sup>lt;sup>3</sup> The National COPD Audit Programme will include pulmonary rehabilitation snapshot audits.

<sup>&</sup>lt;sup>4</sup> Strategy Document for Sleep Disordered Breathing Services in Wales 2010 was issued jointly to LHBs by the Welsh Government and the Respiratory National Specialist Advisory Group in February 2011.

 Develop local hospital and community pathways to improve and facilitate the patient's journey from admission to returning home or to an intermediate care facility

### 6.4 Supporting People Living with Lung disease

Education is key to improving awareness of respiratory disorders and associated symptoms, helping achieve an earlier diagnosis and improved self-management. Having confident and informed respiratory patients at the centre of the decision-making processes will allow them to take ownership of their conditions leading to fewer unplanned primary care consultations, reductions in visits to outpatient departments, reduced hospital admissions and reduced length of stays in hospital.

Individuals with chronic lung disease benefit greatly from a multidisciplinary approach to care and gain the most benefit from this care if delivered in the community, closer to home. This ensures that individuals have two key elements of care: physical and psychological support. These are important, when living with such chronic disease, to help the individual cope with distressing symptoms such as breathlessness, as well as ensuring that respiratory infections are treated earlier to prevent worsening structural damage to the lungs. Professionals involved in supporting individuals with respiratory conditions should be trained in techniques which build self-sufficiency in their clients and address health related behaviours such as smoking and obesity. Pulmonary rehabilitation provides many aspects of this care and should be available locally for all patients with chronic lung disease, with further support accessible through the National Exercise Referral Scheme (NERS) Respiratory Disease Pathway, designed to increase the long-term adherence in physical activity of patients.

Patients with advanced disease need prompt access to effective palliative end of life care as set out in the Welsh Government's *End of Life Delivery Plan*.

#### **OUTCOMES:**

- All patients with chronic respiratory conditions to have an agreed selfmanagement plan
- Increase the proportion of qualifying patients who have accessed support groups and palliative care services
- All respiratory patients receive relevant key measurements for their condition annually as set out in NICE and British Thoracic Society treatment guidelines
- Increased number of advanced directives of patients with advanced chronic lung disease
- All patients with advanced disease to be offered palliative and end-of-life support

#### **ACTIONS:**

#### Local Health Boards will:

- Ensure that all people with chronic respiratory conditions have a personalised self-management plan in place within three months of diagnosis
- Ensure that all respiratory patients have the necessary key measurements taken annually to identify early decline in disease and facilitate appropriate interventions
- Support the development of, and encourage referral to, patient groups such as Breathe Easy
- Ensure adequate and equitable access to palliative care services, including respite care, for patients with respiratory disease in the endstages of their illness
- Utilise appropriate referral to the NERS scheme to support people with respiratory conditions increase their long-term adherence to physical activity

## **6.5 Improving Information**

There are five categories of information required from NHS Wales:

- Patients need clear information, easy to understand and which allows them to
  make decisions about their care and treatment, and which makes clear to
  consequences for their treatment or outcomes if positive steps in selfmanagement are not undertaken. Information should be provided at the point of
  diagnosis and may include a self-management plan. It should be in the language
  of choice of the patient and should be updated or added-to as their disease
  progresses.
- Health professionals need information on the respiratory health needs of their local population and how well the NHS is operating. Information should be accessible in both primary and secondary care to facilitate seamless care.
- Clinicians should provide clear and thorough notes and timely transfer of care information, thus ensuring that information is of high-quality and supports optimal levels of care for patients.
- Service planners need information for the clinical management of patients in order to drive continuous improvements to services. This requires the recording of both clinical and performance data by Local Health Boards.

• The public, NHS Wales, the third sector and Welsh Government need information on the identified outcomes that result from NHS care.

These data sets need to link better across all providers with more real time data on clinical outcomes in order to support effective clinical care.

#### **ACTIONS:**

#### Welsh Government to:

- Work with NHS Wales Informatics Service (NWIS) to develop IT systems which enable the sharing of patient information and data between primary and secondary care
- Evaluate and respond to health board service reviews, especially where inequities in service delivery and outcomes between health boards exist

#### **Public Health Wales and StatsWales to:**

 Provide Local Health Boards with information to facilitate planning for respiratory services and analyses of trends in clinical outcomes and provision of services in primary and secondary care

#### **Local Health Boards to:**

- Record and use information provided by Public Health Wales and Welsh Government sources to guide service review and development
- Ensure outcome data and information from local and primary care services are collected and used to facilitate development and transparently published
- To use data and information collected so as to reflect service provision and outcomes and to report such progress annually
- Report progress against local delivery plan milestones on their website

### 6.6 Targeting Research

The Welsh Government supports patient-focused clinical and more basic scientific research through the NISCHR funded Registered Research Group 'Lung Research Wales / Ymchwil yr Ysgyfaint Cymru'. This aims to foster a formal infrastructure for respiratory clinicians and academics to collaborate and to increase grant-funding capture.

Working together with NHS Local Health Boards and academic institutions, Lung Research Wales / Ymchwil yr Ysgyfaint Cymru has the following specific aims:

- 1. To develop a robust infrastructure to support and promote research into respiratory disease in Wales
- 2. To enable groups of respiratory researchers across Wales to contribute to and /or initiate:
  - Major UK-wide trials funded by major grant-awarding bodies (e.g. MRC, Welcome Trust, NIHR etc)
  - Multicentre clinical trials sponsored by pharmaceutical companies via the UK Clinical Network Respiratory Specialist Group
  - Smaller trials with basic scientific or translational themes which will benefit from recruitment from a wider population
- 3. To promote and facilitate good communication and collaboration between multiinstitutional research groups in Wales

#### OUTCOMES:

- An increased number of respiratory trials run within Wales
- An increased number of respiratory patients recruited to clinical trials

#### **ACTIONS:**

- Welsh Government and its partners, working with stakeholder researchers, to lead and co-ordinate development and co-operation through a respiratory framework
- Encourage more respiratory patients to participate in research activity

#### 7. WORKING TOGETHER

Services and support need to be integrated so that the people using the services feel their care is provided by one team and quality of care is consistent and good. This can be achieved by all partners working collaboratively.

The Welsh Government is responsible for strategic leadership through setting the health outcomes it expects for the people of Wales. It holds the NHS to account on how well it delivers the outcomes we want. The lines of accountability are via the Chairmen of the Local Health Boards and NHS Trusts to the Minister for Health and Social Services. The Chief Executives of the Local Health Boards and NHS Trusts report to the Chief Executive of NHS Wales, who is also the Director General of the Welsh Government's Department of Health and Social Services. There are regular performance reviews and progress will be overseen through monitoring the specified levels of performance by 2017 for each of the NHS assurance measures in Annex 3.

**Local Health Boards** are expected to have a local Respiratory Planning and Delivery Group to plan services effectively for their populations. Local Health Boards must build and lead coalitions with NHS Trusts, GPs, Pharmacists, Local Government and the third sector voluntary bodies to develop services as part of an integrated respiratory health service.

**Public Health Wales**, provides Local Health Boards with information and advice to inform service planning, and is responsible for promotional activity and interventions aimed at preventing smoking uptake, encouraging smoking cessation and reducing obesity.

The Welsh Ambulance Service NHS Trust plays a vital role in responding to the large number of acute respiratory emergencies.

**Local Government** also has a vital role to play to prevent lung disease. To promote a co-ordinated approach, they need to work with Local Health Boards through Local Service Boards. This includes analysis of the evidence base and development of Single Integrated Plans showing how they can contribute to improving health outcomes, in areas such as tobacco control, obesity, and exercise.

An All-Wales Respiratory Services Implementation Group will be established to provide strong and joined-up leadership and oversight and to co-ordinate action in a strategic way. The Group will be able to:

- Work in a co-ordinated way, at an all-Wales level, to support Local Health Boards to deliver the outcomes asked of them in a consistent way across Wales
- Agree how best to measure success
- Facilitate the sharing and implementation of best practice
- Identify constraints and solutions to common issues where a strategic approach is needed
- Review and assess Delivery Plan actions in light of progress and new developments

The **third sector** has an important role to play, both in providing services and acting as the voice of individuals.

**People** do not choose to develop a respiratory disease. However, we can all choose to minimise the risk of acquiring, or exposing others to the risk of acquiring, some conditions such as COPD, lung cancer, asthma and sleep-disordered breathing.

#### 8. MEASURING SUCCESS

The Quality Delivery Plan places requirements on NHS organisation to monitor a set of nationally specified performance measures and report them to the public, the Welsh Government, and their Boards at regular intervals. This Respiratory Health Delivery Plan now places a requirement on each organisation to publish an annual report on the various respiratory diseases for the benefit of the public of Wales to demonstrate progress.

Annex 3 sets out an initial set of national outcome indicators and NHS assurance measures which will encompass all respiratory diseases. These indicators will be refined in discussion with the NHS and its partners.

#### 9. LOCAL PLANS - LOCAL ACTION

Local Health Boards need to achieve full compliance with this Respiratory Health Delivery Plan. Local Health Boards should establish local Respiratory Planning and Delivery Groups (RPDG) to review, update and publish detailed local respiratory delivery plans. The Local Health Boards will support and enable the RPDGs to deliver the Respiratory Plan, report progress and publish updates on their websites every six months.

Whilst this plan sets out our expectations of the NHS, the delivery process which will follow is intended to be dynamic and flexible and able to demonstrate real improvement along the way. The Strategic Key Actions identified throughout this document are set out in Annex 2.

#### Annex 1. The respiratory health care experience

This describes the characteristics of the services expected by 2017

# Experience 1 - People are aware of and are supported in minimising their risk of lung disease through healthy lifestyle choices and medication where appropriate

- More people are informed and aware of the risks to their respiratory health from smoking
- More people are aware of the benefits of not taking up smoking and of the availability of smoking cessation services for those who wish to give up
- Smoking cessation services, including pharmacological means, are easier to access and are more co-ordinated and systematic
- More people pursue a healthy diet and achieve a healthy weight

# Experience 2 – Lung disease is detected promptly and early on in its development

- Easier and wider access to effective primary care spirometry
- More accessible information and support services for respiratory health provided through local delivery channels
- People at risk of developing respiratory disease have access to information and services to prevent or minimize disease progression
- Greater awareness by primary care, schools and the general public of the symptoms of lung disease

# Experience 3 - People with lung disease receive prompt effective treatment and care so they have the best possible chance of living a long and healthy life

- Prompt and appropriate access to clinically and cost-effective treatment in primary and secondary care, including smoking cessation services
- People experience well co-ordinated services which are compliant with national standards and guidelines and available as locally as possible
- Seamless, integrated care with all healthcare sectors primary, secondary, intermediate and voluntary, being potentially involved in patient management and at an appropriate time
- Equity of care outcomes in people with respiratory disease
- Respiratory health care is delivered by a motivated, highly educated and accredited healthcare professional workforce
- Timely access to appropriate, specialist, multidisciplinary teams with care tailored to individual patient's needs

# Experience 4 - People are placed at the heart of respiratory care with their individual needs identified and met so they feel well supported, informed and able to manage the effects of their lung disease

- Services are available as locally as possible
- The psychological, social and clinical needs of people with respiratory disease are assessed, agreed and recorded in a shared management plan with services designed around meeting those needs
- People are empowered through access to education and information to understand their respiratory condition, what care to expect, what to look out for, what to do and which service to access if problems arise
- People with chronic respiratory conditions have an agreed, personalised selfmanagement-plan, which is co-produced with all relevant healthcare professionals
- Access to, and care and support from, co-ordinated and seamless primary, secondary and community services
- More accessible educational and support services for smoking cessation provided through local pharmacies
- Access to support in maintaining a healthy lifestyle from healthcare professionals with training in behavioural change techniques

Annex 2. Strategic Key Actions

Key Action	By Whom	By When
Establish the all Wales Respiratory Implementation Group to provide strategic leadership and work at an all Wales level to support Local Health Boards' service improvements	Welsh Government	June 2014
Consider options, and review priority, for a possible All Wales Integrated Respiratory patient management system to enable improved, efficient and effective healthcare provision which would include collection of information at Local Health Board and all Wales level for the outcome indicators and performance measures	Velindre NHS Trust through the National Wales Informatics Service	Timescale for options review to be agreed by September 2014
Review progress in implementing these delivery plans and services against the expectations set out for 2017 and use the outcome to inform an updated local delivery plan to reflect activity under each of the		September 2014
Review and update delivery plans and milestones  Report progress against local delivery plan milestones on their website  Report formal progress against the delivery plans and NHS Performance Measures to Boards and Welsh Government	Local Health Boards working in partnership through their Respiratory Planning and Delivery Groups with other LHBs, Local Government and Third sector.	At least annually from September 2015  Biannually, first report April 2015 then every April and September  Annually from September 2015
Publish annual All-Wales report on effectiveness of NHS Respiratory services in Wales, based on Local Health Board reports against Performance Measures	Welsh Government	Annually from November 2015

#### **Annex 3. Population Outcome Indicators and NHS Assurance Measures**

#### Our population outcomes are:

- 1. People, through smoking prevention measures and smoking-cessation have minimal or no risk of developing smoking-related lung disease
- 2. People have a minimised risk of developing other respiratory disease and where it occurs an improved chance of living a long and healthy life

We will use the following outcome indicators to measure and track how well we are doing over time.

As we want to reduce inequalities in health, we will also examine how well we are reducing the gap between the most and least deprived parts of Wales and between age groups.

# OUTCOME INDICATOR: Reduce the prevalence of adult smoking to 20% by 2016 and 16% by 2020

#### **Population Group**

Adults resident in Wales (aged 16+)

#### Rationale

These represent various age groups of people with, or at risk of developing, respiratory disease and it is closely associated with previous and current smoking. It is an indicator of effective health promotion, prevention, patient empowerment and smoking cessation service effectiveness.

#### **OUTCOME INDICATOR: Incidence of COPD per 100,000 population**

#### **Population Group**

People 35 years or older resident in Wales

#### Rationale

This is the largest group of people with respiratory disease and it is closely associated with previous and current smoking. It is an indicator of effective health promotion, prevention, patient empowerment and service effectiveness.

# OUTCOME INDICATOR: Unscheduled hospital admissions for both asthma and COPD per 100,000 population

#### **Population Group**

People of all ages resident in Wales, including child age groups for asthma

#### Rationale

This is the population marker for the long-term successful management of these conditions in primary, secondary and community care. It is a marker of effective multidisciplinary pathways, patient empowerment and service effectiveness.

Admission rates across deprivation quintiles are used here to describe any variation in outcome for people with these conditions. Admission rates for asthma need to include variation of outcomes for childhood age groups.

# OUTCOME INDICATOR: Disease and age group specific mortality rates under age 75 per 100,000 population

#### **Population Group**

People resident in Wales

#### Rationale

This is a marker of effective health promotion, prevention, patient empowerment and service effectiveness.

Excess deaths are experienced in COPD particularly, but also in asthma, interstitial lung disease and OSAHS. To reflect the effectiveness of the service in delivering effective care, all these groups are required to be assessed. The other important group, those with lung cancer, is addressed in the Cancer National Plan.

Mortality rates across deprivation quintiles are used here to describe any variation in outcome for people with these conditions.

#### 2. NHS Assurance Measures

The following NHS Assurance Measures have been identified to measure how people receiving NHS respiratory care are better off as a result improved services. Where not currently available, these will be developed and form the basis of Local Health Boards' annual reports on respiratory care.

Some NHS services aim to reduce risk factors associated with respiratory disease such as the number of people who smoke or who are obese. NHS Assurance Measures for those services are not included here as they are set out in *Programme for Government* and in the Welsh Government's Performance Level Agreement with Public Health Wales NHS Trust.

These assurance measures are also linked to the high level respiratory health care experiences that are expected of the service, as set out in **Annex 1**.

# ASSURANCE MEASURE: 5% of smokers make a quit attempt via smoking cessation services, with at least a 40% CO validated quit rate at 4 weeks

#### What experience does this relate to?

Experience 1 – People are aware of and are supported in minimizing their risk of lung disease through healthy lifestyle choices and medication where appropriate.

Experience 2 – Lung disease is detected promptly and early on in its development.

#### **Patient Group**

Smokers of all ages.

#### Rationale

We need to identify people at-risk for smoking-related lung conditions and detect any early disease in primary care through means of assessment and spirometry. We need to identify those people with smoking-related diseases in secondary care in order to provide smoking-cessation advice and support. Smoking cessation in such patients is highly cost-effective.

This is a marker of effective self-care through patient education and empowerment, and effective NHS monitoring of people who smoke for complications and early disease.

ASSURANCE MEASURE: % of people with a chronic respiratory condition receiving a written self-management plan within 3 months of diagnosis

#### What experience does this relate to?

Experience 4 - People are placed at the heart of respiratory care with their individual needs identified and met so they feel well supported and informed, able to manage the effects of their lung disease.

#### **Patient Group**

People newly diagnosed with a chronic respiratory condition.

#### Rationale

People of all ages newly diagnosed with lung disease who receive structured education about their lung condition are more likely to be empowered and able to manage the effects of it and to stay healthy and out of hospital.

ASSURANCE MEASURE: % of patients with significant breathlessness (MRC 3 or greater) who have been referred for a pulmonary rehabilitation programme close to where they live, and the % of referrals who have successfully completed the programme.

#### What experience does this relate to?

Experience 3 - People receive fast, effective treatment and care so they have the best possible chance of living a long and healthy life.

Experience 4 - People are placed at the heart of respiratory health care with their individual needs identified and met so they feel well supported and informed, able to manage the effects of respiratory disease.

#### **Patient Group**

People of all ages diagnosed with the relevant conditions namely, COPD, bronchiectasis, ILD, in whom such programmes are known to be of benefit.

#### Rationale

This is a marker of prompt effective care through patient education and empowerment leading to a better quality of life from locally-based treatment and support.

# ASSURANCE MEASURE: % of people with diagnosed lung disease supported in the community by appropriate healthcare professionals addressing their action plan

#### What experience does this relate to?

Experience 3 - People receive fast, effective treatment and care so they have the best possible chance of living a long and healthy life.

Experience 4 - People are placed at the heart of respiratory health care with their individual needs identified and met so they feel well supported and informed, able to manage the effects of lung disease.

#### **Patient Group**

People of all ages diagnosed with respiratory disease.

#### Rationale

This is a marker of effective community-based and self-care through patient education and empowerment, and effective NHS monitoring of people with respiratory disease for complications, progression or exacerbations.

# ASSURANCE MEASURE: % of people with difficult and complex respiratory conditions being managed through an appropriate MDT framework.

#### What experience does this relate to?

Experience 3 - People receive fast, effective treatment and care so they have the best possible chance of living a long and healthy life.

Experience 4 - People are placed at the heart of respiratory health care with their individual needs identified and met so they feel well supported and informed, able to manage the effects of lung disease.

#### **Patient Group**

People of all ages diagnosed with severe bronchiectasis, ILD, difficult asthma, complex sleep-disordered breathing conditions.

#### **Rationale**

This is a marker of effective MDT networks working to national guidelines and effective NHS monitoring of people with complex and difficult lung conditions at risk of complications.

ASSURANCE MEASURE: People with asthma and COPD: number of unscheduled attendances and re-attendances to hospital and average length of stay (ALOS).

#### What experience does this relate to?

Experience 3 - People receive fast, effective treatment and care so they have the best possible chance of living a long and healthy life.

Experience 4 - People are placed at the heart of respiratory health care with their individual needs identified and met so they feel well supported and informed, able to manage the effects of lung disease.

#### **Patient Group**

People of all ages with a diagnosis of asthma and >35 years old with a diagnosis of COPD.

#### Rationale

We want to keep people with asthma and COPD well-controlled, healthy and out of hospital. This depends on the provision of personal care plans (PCPs) and the establishing of enhanced follow-up schemes post-discharge and pulmonary rehabilitation. The number of hospital admissions, re-admissions and ALOS are markers for these.

ASSURANCE MEASURE: % of patients with advanced and optimally treated respiratory disease receiving appropriate palliative and end-of-life care.

#### What experience does this relate to?

Experience 3 - People receive fast, effective treatment and care so they have the best possible chance of living a long and healthy life.

Experience 4 - People are placed at the heart of respiratory care with their individual needs identified and met so they feel well supported and informed, able to manage the effects of lung disease.

#### **Patient Group**

People of all ages with advanced and terminal lung disease.

#### Rationale

This is a marker of the effective and timely access to appropriate and specialist MDTs with care tailored to the individual and that care being locally delivered.

### Associated policy and guidance

Designed to Improve Health and the Management of Chronic Conditions in Wales: An Integrated Model and Framework

Setting the Direction: Primary & Community Services Strategic Delivery Programme

Tobacco Control Action Plan for Wales

Together for Health - Delivering End of Life Care Plan

Together for Health - Neurological Conditions Delivery Plan

Together for Health - Critical Care Delivery Plan

Together for Health – Diabetes Delivery Plan

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