



Llywodraeth Cymru  
Welsh Government

# Respiratory Health Delivery Plan 2018-2020

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Reducing inappropriate variation  
and sharing best practice



Respiratory Health  
Implementation  
Group



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# 1 ● Introduction



## Fiona Jenkins Chair, Respiratory Health Implementation Group

I am really pleased that the Respiratory health delivery plan for Wales has been extended to 2020. We have achieved so much since the inaugural plan was written in 2014, and this extended plan stretches our ambition even further. There is so much more we can do to improve respiratory health in Wales and this plan sets out a number of work streams that cover a wide range of elements that collectively will improve the health of the nation following the principles of prudent healthcare.

This support is an essential element of the delivery plan. I'm really proud of the respiratory clinicians across Wales who have volunteered to lead on different work streams, sharing their expertise so everyone in Wales can benefit. I would like to recognise and thank the valuable work undertaken by the third sector in supporting and caring for people with respiratory conditions and their families.

We will be monitoring the implementation of the plan via the national Respiratory Health Implementation Group (RHIG), which is made up from clinicians and managers from all health boards, as well as our third sector partners.

A handwritten signature in dark ink, reading 'F. C. Jenkins', with a horizontal line underneath.



## ● Introduction



### Simon Barry

#### Clinical lead, Respiratory Health Implementation Group

**Respiratory health remains a real burden to the NHS in Wales, with one in twelve people having a respiratory illness. Wales also has the highest prevalence of asthma in Europe. Respiratory disease consumes £400 million per annum and is ranked fifth in terms of spend of all disease categories. There is considerable work to be done on improving the diagnosis of asthma and COPD. For example, a national audit has shown that more than 25% of patients on COPD registers may not have the condition. As a result, considerable effort has been invested in providing quality assured spirometry training and standard equipment across Wales. Tobacco smoking remains the single biggest preventable cause of death. Smoking rates in Wales have been inexorably declining with the prevalence being 19% in 2016 – better than the target of 20% set by Welsh Government.**

This document follows the standard themes of other deliver plans, but it differs significantly because the focus has been on reducing variation and sharing best practice. To achieve this a number of different workstreams have been developed, each with interested clinicians working across primary and secondary care, across different Health Boards and

encompassing doctors, nurses, other Healthcare Professionals and third party representatives. Their role is to set key agendas, outline metrics to be measured and compare performance across Wales. By engaging a large proportion of the respiratory community in this process we believe that there will be ownership of the problems and a desire to change and improve. This will not always be a comfortable process but we are confident that this will result in value based care with a rebalancing of the healthcare funding to where it is most needed helping to fund community COPD and asthma nurses in order to reduce admissions for example.

We want to create educational resources and guidelines for patient pathways across the spectrum of respiratory medicine, and crucially we want to enthuse primary care physicians and practice nurses to engage and influence the Respiratory Delivery Plan.

A handwritten signature in black ink, consisting of a stylized 'S' followed by a horizontal line and a diagonal stroke.



## 2 ● Vision for Wales

### Simon Barry

#### **Clinical lead, Respiratory Health Implementation Group**

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As lead for the Respiratory Health Implementation Group I believe that there is a major opportunity for Wales to become world leaders in the delivery of care to respiratory patients. Whilst that might sound like an unattainable goal to sceptics, there are many factors that prepare the ground for service improvement. First, Wales has a relatively small population of 3.1 million. Second, the seven Health Boards each fund both primary and secondary care, potentially fostering a climate of cooperation between them and paving the way for a systems approach to healthcare delivery. Third, most members of the respiratory community, at least in secondary care work closely together and are well known to each other. Fourth, there is a high burden of respiratory disease in Wales, with one in seven patients dying from respiratory illness. Fifth, Wales is now implementing a fully integrated IT system which allows access to patient level information across Wales and will act as the framework for national disease databases, host national guidelines and educational tools and allow data sharing with patients through the patient portal.

It has been apparent to me for many years that despite a very motivated workforce, that there is significant variation in the delivery of care across Wales. For example, early audits of prescribing at a practice level in Cardiff and elsewhere demonstrated huge variations for COPD and asthma despite similar disease prevalence. This data led Cardiff, and other Health Boards to develop local prescribing guidelines and these have been successful in reducing prescribing variation, and cost. The logical conclusion of this work is to reduce variation further by developing national guidelines and that is exactly what we are doing.

If the RHIG has a single axiom underpinning it, it is this: 'reducing inappropriate variation and sharing best practice'. This goal is firmly embedded within the principles of prudent healthcare. There is a crucial role for robust and granular data to be able to drill down to specific issues, for example referral to treatment times for sleep and oxygen spends per COPD patient by Health Board. It is this process that will enable us to tease apart the components of best

care and enable them to be shared. There is no one Health Board that out-performs the others, and there is room to improve in many areas across all Health Boards. We hope that others see this document as a catalyst for change and improvement.

Through the development of shared pathways, prescribing guidelines and national databases our vision is that Wales becomes an attractive proposition for research both at a population level and through testing new treatments and with this in mind the development of the Respiratory Innovation Centre is very exciting. We hope to raise the profile of respiratory medicine across Wales in primary and secondary care and truly cooperate to achieve the best outcomes for our patients by maximising engagement in our specialty.





## 3 ● About us

### **The Respiratory Health Implementation Group**

RHIG was established in 2014 to support the development and strategic direction for primary, community and secondary care respiratory services in Wales. The group comprises of expert clinicians from primary and secondary care, exec leads, public health, informatics, as well as patient representatives and third sector.

### **So what is our challenge?**

In 2016/17, 8% of the Welsh population reported having a respiratory condition, and respiratory diseases caused just over 15% of deaths in 2016<sup>1</sup>. Nearly a quarter of a million people are being treated for asthma and over 70 thousand for Chronic Obstructive Pulmonary Disease (COPD). A higher percentage of patients in Wales are being treated for asthma (6.9%) than in other parts of the UK. Asthma UK estimates there are around 59,000 children with asthma in Wales, which is 9.5%<sup>2</sup> of all children.

People living in areas of high deprivation are more likely to be receiving treatment for respiratory conditions than elsewhere in Wales. The National Survey for Wales (2016/17), which includes information on lifestyle, reveals a smoking prevalence in Wales of 19% 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. If done well it is an opportunity to improve the lives of patients and their families.

People who have a respiratory condition need access to care and support whenever it is needed. These services need to be well coordinated across primary, community, social and hospital care and between statutory and third sector organisations. The right support can transform the respiratory pathway for everyone – the patient, family, carers and friends.



## 4 ● Work streams and metrics

The 2015 annual report used a template including a series of metrics around the key RHIG targets. Many of this data collected was not obviously helpful in shaping and improving service delivery, for example numbers of patients with a specific disease (such as COPD), crude mortality rates of patients with respiratory disease by Health Board, or numbers of respiratory referrals from primary care. As a result, a suggestion for changing the metrics was presented by the RHIG clinical lead at the Welsh Thoracic Society (WTS) group meeting in March 2016, receiving unanimous support.

A proposal was also presented to the WTS that the RHIG would be most efficient if working groups of interested parties were setup to oversee priority areas within the RHIG umbrella. These would be managed and overseen by the RHIG clinical lead and coordinator, but they would not directly influence the work stream developments. This scheme for developing RHIG activity was supported by the WTS.

The RHIG has been reorganised into work streams dedicated to improving quality across a range of key respiratory areas, such as, smoking, asthma, pulmonary rehabilitation, palliative care and out-patient performance, to name a few.

A lead for each work stream has been nominated together with stakeholders from across Wales, including primary care representation. Key performance metrics have been agreed, thus simplifying and focusing the annual reports into outcome goals which can be compared across the Health Boards.



## 5 ● Value based Healthcare



### Rebecca Richards

**Value based Healthcare  
work stream lead**

#### Background

Respiratory care is the fifth highest level programme of expenditure within NHS Wales and accounts for £0.4bn of annual spend (graph 1).

As such, it is a condition which warrants close scrutiny of how effectively resource is deployed.

Value Based Healthcare is an approach that aids the identification of opportunities to improve services to patients by looking simultaneously at both outcomes that matter to patients and the cost of delivering those outcomes. Increased value can be generated through an improvement in outcomes for the same or lower cost, or through a reduction in cost for the same or better outcomes.

Collecting outcomes data is still in its infancy within Respiratory care but we can look at published evidence on services that improve outcomes as a proxy whilst we move towards systematically patient outcome collection in NHS Wales.

The London Respiratory Team has previously published their Value Pyramid for COPD which pulls together several studies of interventions for COPD patients and their relative QALY impact (figure 1).

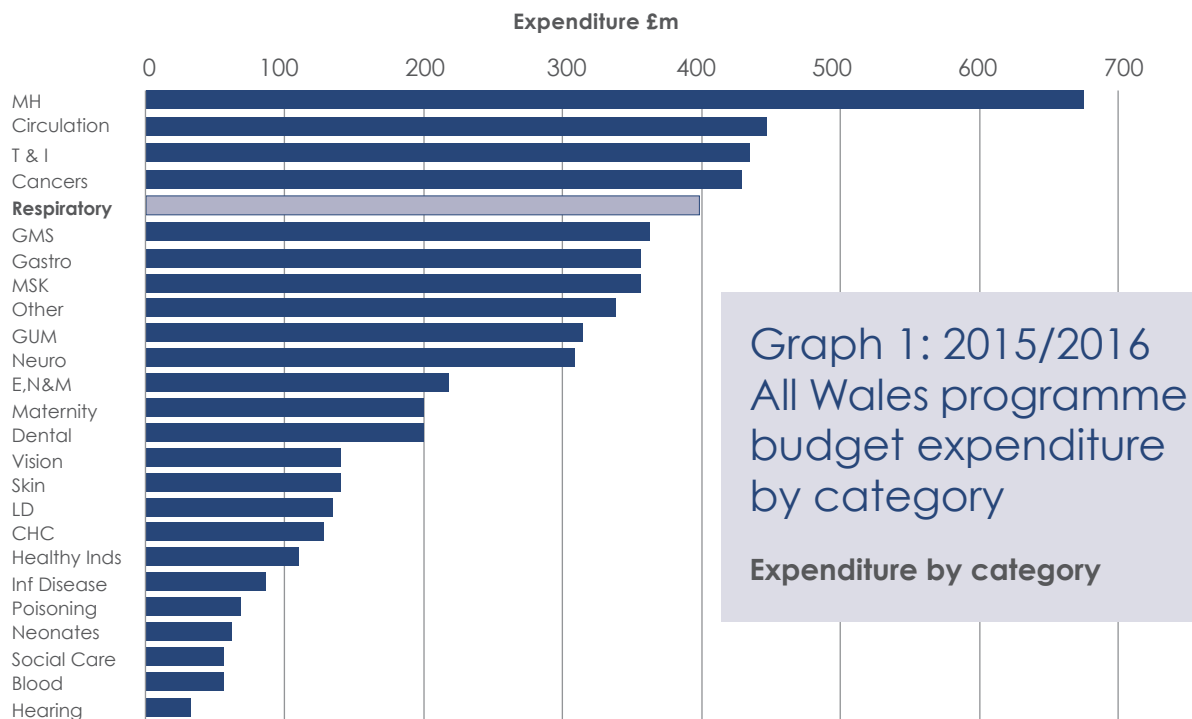




Figure 1: Evidence based assessment of the effective interventions for COPD

The diagram on the right describes the relative effectiveness on the impact on patients for each intervention and in using it as a guide, directs organisations to drive an increased uptake of higher value interventions (those at the lower end of the pyramid) thereby limiting or reducing the uptake of lower value interventions (those at the top of the pyramid).

Based on the National COPD audit data from 2014, the QALY pyramid was modelled for actual resource utilised across primary care in Wales. This is illustrated below (Figure 2).

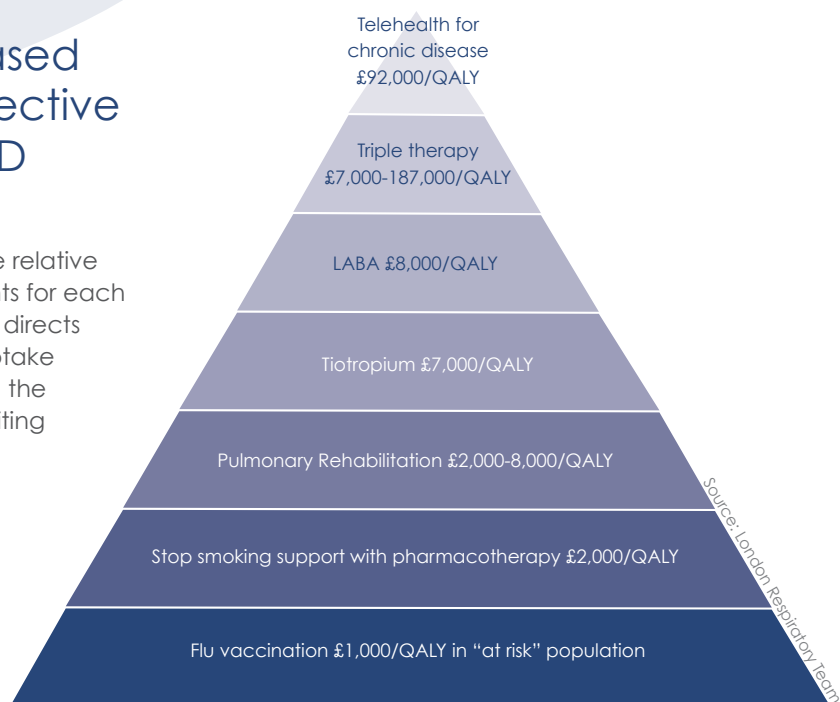
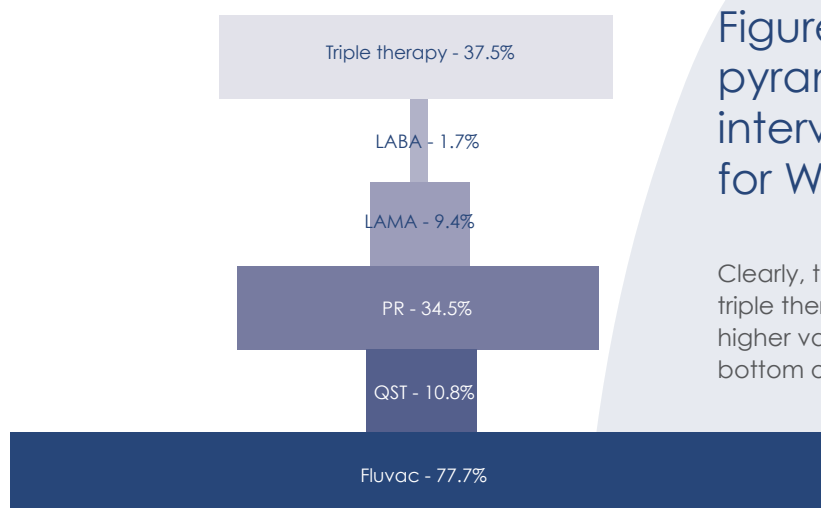


Figure 2: The value pyramid for COPD interventions for Wales

Clearly, there is a disproportional spend on triple therapy, rather than utilisation of higher value interventions towards the bottom of the pyramid.







## Value based care

### Aims

Using this evidence as a guide, we can map how we in Wales currently deploy resources across the Value Pyramid with a view to spotting opportunities to increase higher value. The overall ambition would be to reallocate the way in which resource is deployed to the extent that improved value is generated to the COPD population – this is allocative value.

Further, by taking a closer look at each intervention listed within the pyramid, we can identify opportunities for improving the way in which each intervention is deployed given the resource used – this is technical value.

Finally, when we look at how effective we are in deploying services to each individual within the COPD population, the extent to which they access the entirety of services on offer and the outcomes they experience, we can spot opportunities for improvement in value to the individual – this is personalised value.

Ultimately, the ambition is to explore where there are opportunities for increasing Value in respiratory services within NHS Wales using these methodologies.

### Results

Programme budgeting in Wales has been developed over many years and is a useful reference for comparing overall spend across organisations and between conditions. There is already significant variation in overall cost per head of population across Wales on respiratory care.

However, this analysis is not in enough detail to be able to identify whether organisations with higher spend are geared towards generating improved outcomes or whether this might be an indicator of poor deployment of resource. To make this assessment, we need to go deeper into how resource is deployed in accordance with the evidence base.

The NHS Wales Finance Academy, working with the national RHIG have commenced an exercise to identify how services are deployed to the

COPD population across Wales with a view to identifying opportunities for improvement. This approach looks across the entirety of the COPD pathway – beyond that identified within the Value Pyramid above and aims to spot where opportunities exist for allocative improvement. In other words, where there are gaps in service offerings, such as low level flu uptake and low level service offer of Pulmonary Rehabilitation to patients who need it.

This exercise has also enabled an emerging view of benchmarked spend to identify technical value opportunities, for example; high cost of prescribing or oxygen therapy in one board compared to another. The work has also begun to identify opportunities through modelling the impact of one service intervention on another, e.g. the rate at which Pulmonary Rehabilitation uptake affects admissions costs and length of stay.

### ● ● ● Actions

Following on from this initial work, there are several strands which should now be pursued through the leadership of the RHIG and supported by the NHS Wales Finance Academy. These include the following actions;

#### ***The Finance Directors Academy in conjunction with RHIG will:***

1. Finalise data collection of costs and activities across all HB's.
2. Continue with further data modeling for impact and opportunities from both a technical and allocative perspective to inform both local and National RHIG's in planning for the future.
3. Trial Time-Driven Activity-Based Costing (TDABC) in Pulmonary Rehabilitation – a costing methodology within Value Based Healthcare for identifying technical value opportunities.
4. Complete a proof of concept exercise to connect patient data on a pseudonymised basis across 5 practices to explore how personalised value might be captured, measured and evaluated.



## 6 Preventing respiratory disease



**Marion Lyons**

**Vaccination  
work stream lead**

### Background

Most people who get the flu will have mild illness, will not need medical care or antiviral drugs, and will recover in less than two weeks. Some people, however, are more likely to get complications that can result in hospitalization and sometimes death. Pneumonia, bronchitis, sinus infections and ear infections are examples of flu-related complications.

People with Chronic Obstructive Pulmonary Disease (COPD) and other chronic respiratory diseases are at increased risk of serious influenza-related complications. Surveillance undertaken by the Centers for Disease Control and Prevention (CDC) on hospital admissions with confirmed influenza during 2016/17 influenza season showed that 50% of adults and 37.5% of children had underlying chronic respiratory disease.

In Wales there are approximately 200,000 individuals aged between six months and 64 years with chronic respiratory disease who are at increased risk of influenza each season. Those with chronic respiratory disease account for 38% of all those with underlying medical conditions aged between six months and 64 years for whom seasonal influenza vaccine is

recommended (graph 2). In addition to the impact seasonal influenza has on these at risk individuals it also impacts significantly on our health service, on workforce absences and on productivity. In the mild influenza season of 2016/17 Wales had 49 influenza outbreaks, 26 of these in hospital settings. As a consequence there were ward closures, increase in staff absences and cancelled operations.

### Aims

Vaccination remains the best documented and most effective preventive measure against influenza. Each season the NHS in Wales embarks on an ambitious programme to vaccinate those over the age of 65, those in clinical at risk groups aged between six months and 64 years, young children not in risk group and pregnant women.

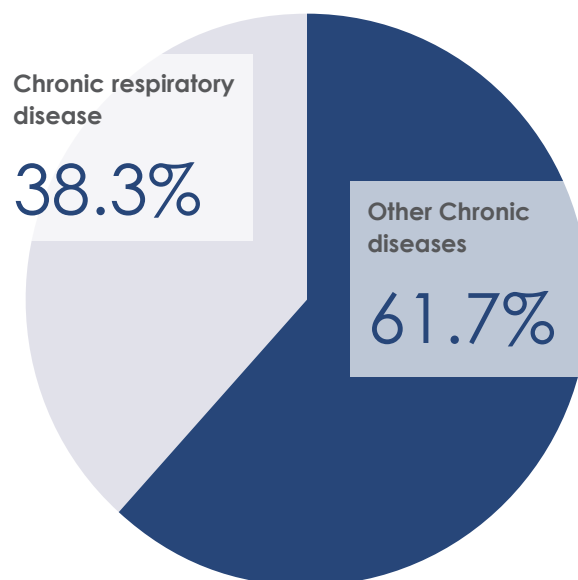
### Results

Uptake of influenza vaccine in those aged six months to 64 years in any clinical risk group was only 46.9% in the 2016/17 flu season in Wales against a target of 75%. For those with chronic respiratory disease the uptake of influenza vaccine was 46.5% (graph 3). Uptake in those in the clinical at risk groups has remained static for the last five years.

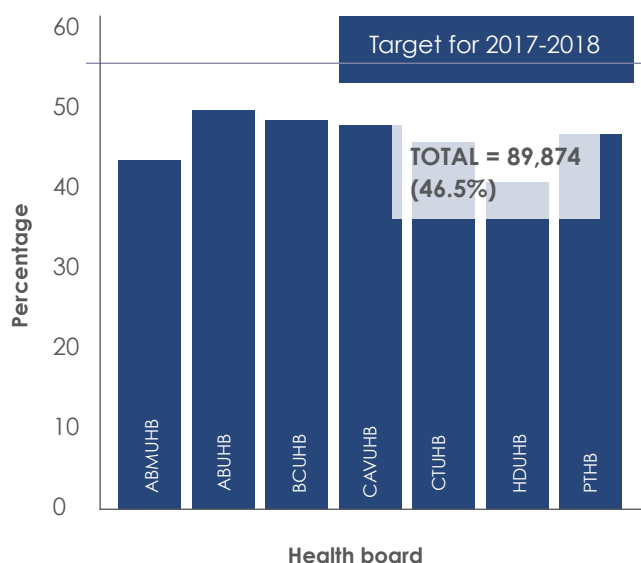


● Preventing respiratory disease

**Graph 2: Uptake of influenza immunisation in those aged six months to 64 years with one or more clinical risk (by risk category) in Wales 2016/17**



**Graph 3: Uptake of influenza immunisation in those with chronic respiratory disease aged six months to 64 in Wales 2016/17 by health board of residence**



In 2017 the Chief Medical Officer for Wales outlined his expectations for the National Influenza Immunisation Programme.

The target set for clinical at risk groups aged between 6 months and 64 years for this season is 55%.

Last season 55% was achieved in some at risk groups but uptake needs to improve across all groups to protect those who are at the highest risk of severe disease and mortality.

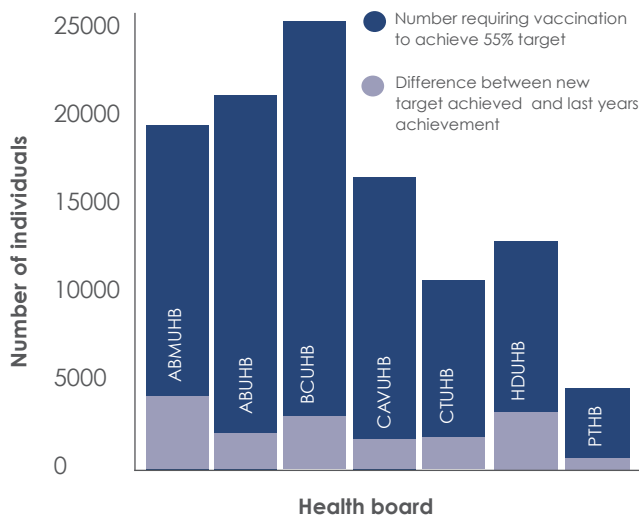
The longer term aim remains to achieve 75% uptake across all risk groups but as this is currently some way off services have been requested to focus attention on making steady progress year on year to increase the number of at risk people having the flu vaccine.





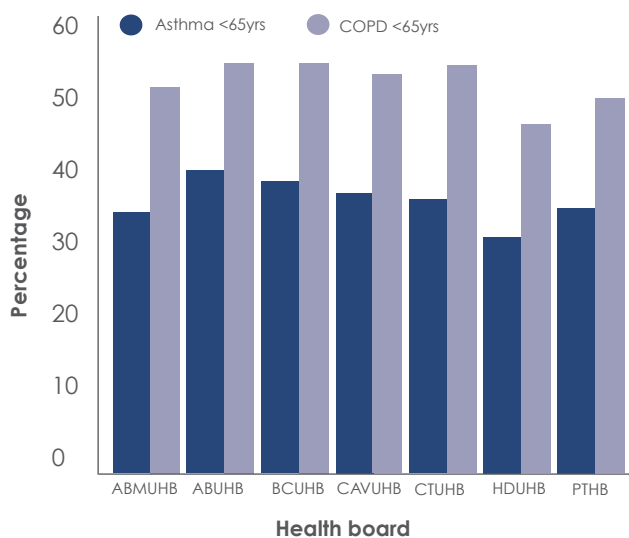
## Preventing respiratory disease

**Graph 4: Number of individuals with chronic respiratory disease aged six months to 64 that will require vaccination in 2017/18 to achieve the 55% target, by health board of residence**



To achieve the target of 55% in those with chronic respiratory disease aged between six months and 64 years this season the NHS will need to immunise approximately 16,000 more individuals than were vaccinated in the 2016/17 season (graph 4).

**Graph 5: Uptake of influenza immunisation in under 65 years age group who have asthma and COPD, per Health Board (2017)**



### Actions

#### **Health Boards to work together to:**

1. Appoint an Immunisation Champion in each Health Board.
2. Ensure that Every Contact Counts and that the risk to individuals health from flu is explained and patients are protected by vaccine.
3. Lead by example and ensuring that front line healthcare workers caring for those with respiratory disease are immunised against influenza.

#### **RHIG will engage with Health Boards to:**

4. Develop resources, in conjunction with PHW, such as the impact of influenza on health is easily understood by various groups at risk (asthmatics, those with COPD, Cystic Fibrosis etc).
5. Include a module on vaccination to the National Respiratory Education Programme (NREP) for professionals and support organisations who engage with those respiratory disease so that risk of influenza can be meaningfully explained.
6. In conjunction with PHW, engage with Health Board Planners and Infection Control Teams to minimise impact of influenza on health care settings during the flu season.



## 7 Preventing respiratory disease



### Keir Lewis Smoking work stream lead

#### Background

Smoking causes over 80% of COPD and lung cancer and causes or worsens all other respiratory conditions. Around half of all smokers are killed by their addiction and it is estimated to cause over 5400 deaths – that is, over one in five of all deaths – per year in Wales.

**Total economic cost of between £791 million – £1.04 billion<sup>1</sup>**

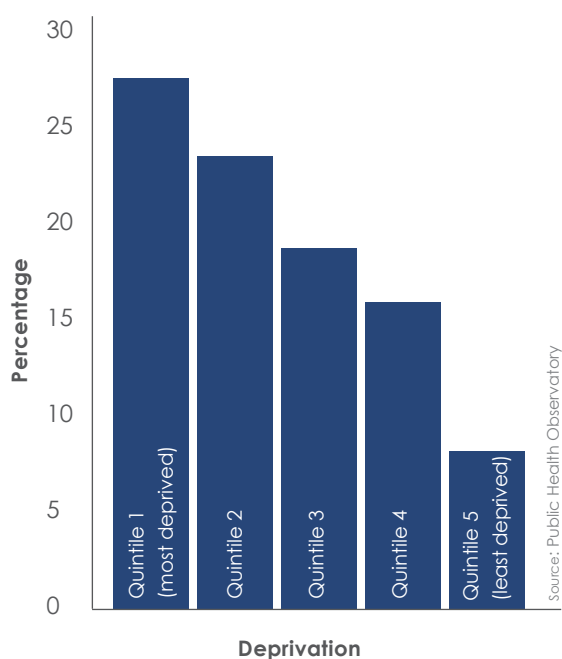
Smoking is a major cause of health inequality with smoking rates in the most deprived areas up to three-fold more common than in the least deprived areas (graph 6) and contributes significantly to the observed differences in age of death between those in the highest and lowest income brackets.

RHIG prioritised smoking because of its profound effects on causing and worsening all respiratory health, its preventable nature and the major inequalities in smoking cessation service provision especially in hospitals, in Wales.

The Welsh Government target for smoking prevalence in Wales was 20% in 2016 and will be 16% in 2020.

Despite good evidence on the effectiveness and cost-effectiveness of hospital-based smoking cessation programmes, the provision of smoking cessation within hospitals in Wales was patchy with only 4 from 17 hospitals offering an in-house service in 2013.

**Graph 6: Percentage of current smokers by deprivation (2016/17)**







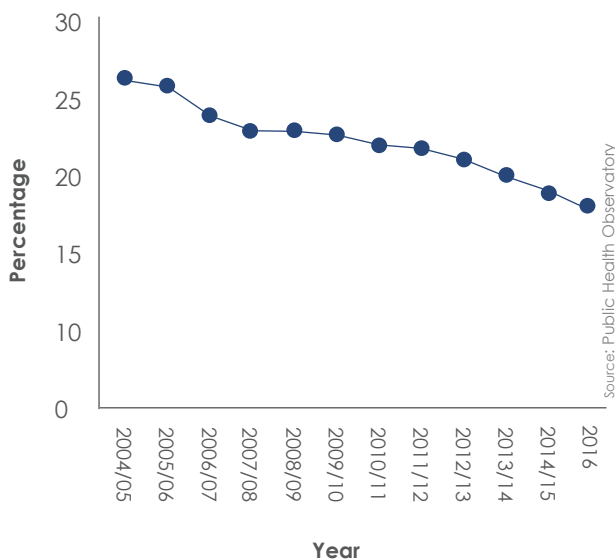
## Preventing respiratory disease

### Aims

1. To increase the provision of smoking cessation within Welsh hospitals (secondary care).
2. To support the creation and identity of a group of secondary care smoking cessation specialists.
3. To develop, implement and test the first national database for all secondary care smoking cessation specialists in the world.
4. To develop strategies to help each Health Board reach their smoking performance targets of treating 5% of all smokers annually.
5. To represent RHIG on Welsh Government and Public Health tobacco working groups.

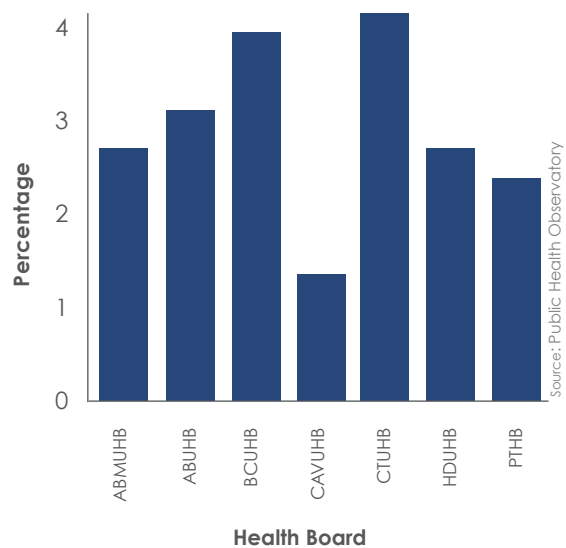
### Results

**Graph 7: Trend for smoking prevalence in Wales from 2004-2016**



The 2016 adult smoking prevalence target was met with around 19% still estimated to be smoking (National Survey 2016/7) and this continued reduction (graph 7) fits with recent trends and represents a wide range of public health, legislative and medical successes. Cardiff and Vale University Health Board (CAVUHB) now has the lowest prevalence of adult smokers at 15%. However, all Health Boards in Wales in 2016-17 have still failed to reach a major performance target

**Graph 8: Percentage of treated smokers by Health Board, Wales 2016-17**



on smoking cessation; namely that 5% of all smokers (especially those attending hospital) are treated by a specialist service (Graph 8).

Secondary care smoking cessation services are established in Hywel Dda University Health Board (HDUHB) and CAVUHB.

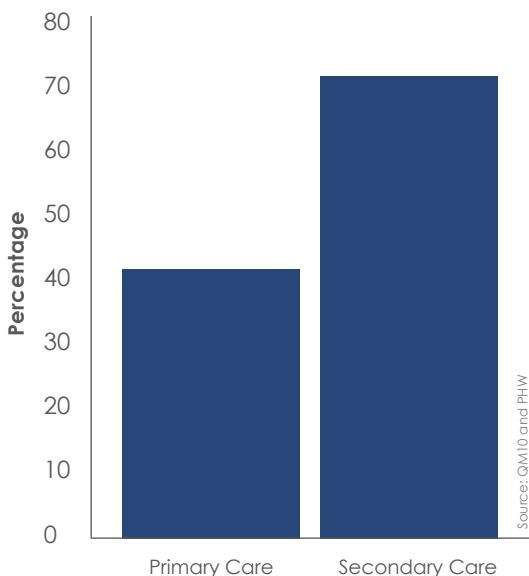
They offer one-to-one support or group work with smoking patients; they also address harm reduction in those smokers unwilling or unable





## Preventing respiratory disease

**Graph 9: Validated 4 week quit rates in Wales 2016-17 for primary and secondary care smoking cessation services**



to quit outright and this is an important service not offered elsewhere. Secondary care 4 week- quit-rates are validated with exhaled carbon monoxide (CO) and at 73% these are higher than the 40% recommended performance targets set by Welsh Government – suggesting that once patients are referred and attend these teams, their service is excellent. The 4-week quit rates from the community service (partially CO validated and partially self-reported) are 42% also within target (graph 9).

Secondary care services also expected to publish their quit rates over 1-year according to national guidelines and this is now being done at scale through their one single database. 1-year data is not routinely collected by community services but estimated from those attending at 4 weeks.

Currently, two different databases exist with all of secondary care now adopting QM10 (Solutions4Health) and Public Health Wales/Help Me Quit using Quit Manager (North 51). Through the Welsh Government's

Tobacco Action Plan, we want to create a single national database for all smokers in Wales.

RHIG strongly supports this agenda recognising the benefits this gives to smokers who can be helped by different services simultaneously and the ability to answer big questions quickly. RHIG would like to continue supporting the smoking cessation agenda and assist in implementing national integrated smoking services.

### ● ● ● Actions

#### ***Health Boards to work together to:***

1. Continue longer-term funding for secondary care smoking cessation practitioners.
2. Improve referral rates from all clinical boards to smoking cessation services.
3. Ensure that CO monitoring and referral becomes routine for all outpatients who are willing to engage with smoking services.

#### ***RHIG will engage with Health Boards to:***

4. Strengthen the secondary-care smoking cessation network identity and facilitate networking.
5. Support an All-Wales minimum service specification; in particular to work with Public Health Wales and HBs to reduce variation and help all meet their Performance targets and the second BTS national audit data collection.
6. To refine and develop the QM10 database and use it to inform service provision and standardise hospital services; to develop electronic referrals, electronic feedback mechanisms, text reminders and testing of artificial intelligence (bot) support.
7. To work with the Smoking Cessation Sub-Group of the All-Wales Tobacco Taskforce and Public Health Wales, to create unified database and minimum data set to unite community, primary and secondary care smoking cessation services across Wales by end 2018.
8. To support research and collaborations with other internationally recognised smoking cessation centres.



## 8 ● Children and young persons



### Iolo Doull

#### **Paediatrics work stream Lead**

#### **Background**

Bronchiolitis is the most common cause for lower respiratory tract infection during the first year of life, and accounts for majority of hospital admissions during this period. Between 2% to 3% of all infants are hospitalized in their first 12 months of life with bronchiolitis – in Wales this equates to nearly 1000 causing significant burden on the health care system. Although many viruses may cause the constellation of symptoms and signs that characterize bronchiolitis, 60-85% of cases are caused by respiratory syncytial virus (RSV). Supportive care is the mainstay of treatment, concentrating on fluid replacement, gentle suctioning of nasal secretions, prone position (if in hospital), oxygen therapy and respiratory support if necessary.

NICE have published guidance on bronchiolitis which highlights a number of investigations that are often performed (such as blood tests and chest X-rays) and treatments offered (such as bronchodilators or steroids) despite evidence of lack of benefit.<sup>1</sup> A recent audit across Wales has highlighted marked variation in care and length of stay for infants admitted with bronchiolitis across Wales. A more recent





## Children and young persons

study has suggested that many infants with bronchiolitis can be discharged home safely earlier than previously thought, without increased morbidity and social implications, all of which can be relieved by Continuous Positive Airway Pressure (CPAP) therapy.

### Aims

A group of lead respiratory paediatricians and stakeholders met to agree the core standards for assessment and management, and developed a simple audit tool incorporating important outcome measures based on the previous audits of bronchiolitis care in Wales. Through an iterative process consensus has been achieved. The pathway and audit tool will be implemented this winter (bronchiolitis season).

### Results

The development of a simple and standardised assessment and management tool for infants admitted with bronchiolitis offers numerous opportunities. Standardised management will decrease the variation in care across Wales, decrease the number of in-appropriate investigations performed and decrease the number of in-appropriate treatments offered. Furthermore there is the opportunity to decrease the number of infants hospitalised, and decrease the length of stay. This would offer optimal prudent healthcare, offering improved care to infants while decreasing the huge seasonal pressures on paediatric services over the bronchiolitis season.

By combining the assessment and management tool with a simple audit tool, there is the potential for continued improvement in care through outcome reviews and peer review to promote quality improvement and national standards. Standardised care across a whole country also offers a unique opportunity for future research, both observational and interventional.

### ● ● ● Actions

#### **Health Boards to work together to:**

1. Have a lead for care of infants admitted with bronchiolitis, who contributes to both the pathway development and the annual audit.
2. Offer patients and parents Asthma Action Plans.

#### **RHIG will engage with Health Boards to:**

3. Develop an All-Wales pathway for the care of infants with bronchiolitis. The pathway should conform to the NICE guidance.
4. Develop All-Wales paediatric asthma guidelines.



## 9 ● Early diagnosis. Fast, effective care



**Ramsey Sabit**  
COPD work stream lead

### Background

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. Breathe Easy support groups and activities such as singing for lung health can improve quality of life for patients living with COPD and reduce unplanned admissions. Adherence to evidence-based guidelines, regular review in primary care, self-management initiatives, long-term oxygen therapy and Pulmonary Rehabilitation programmes can all improve quality of life and reduce hospital admission.

Individuals with COPD 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 help the individual cope with distressing symptoms such as breathlessness, as well as ensuring that exacerbations are treated earlier to prevent worsening damage to the lungs. Professionals involved in supporting individuals with COPD should be trained to diagnose and monitor the disease with

precision and promote techniques which build self-sufficiency in their clients, in particular addressing health related behaviours such as smoking, obesity and physical deconditioning through a lack of exercise.

### Aims

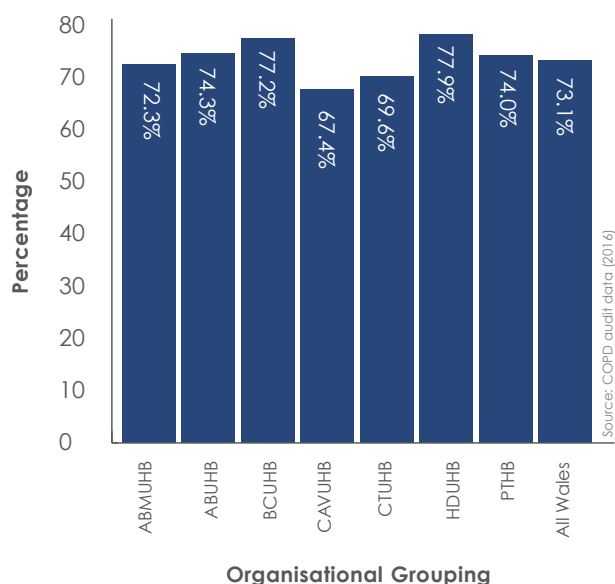
1. To improve the accuracy and speed of diagnosis across primary and secondary care.
2. To enhance early supported discharge for patients with COPD admitted to hospital.
3. Develop an All-Wales COPD care and prescribing pathway
4. To ensure access to Pulmonary Rehabilitation Programmes.
5. Reduce unplanned admissions across Wales by supporting community-led COPD teams.



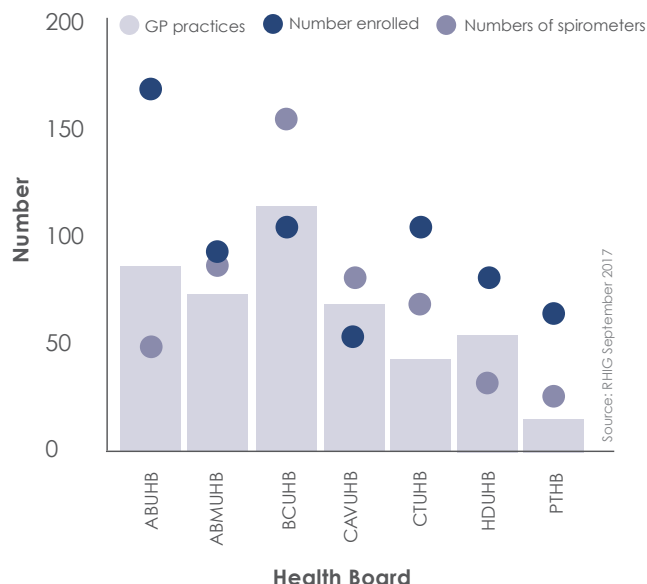


Early diagnosis.  
Fast, effective care

**Graph 10: The percentage of people with COPD who have ever had a FEV<sub>1</sub>/FVC ratio was between 0.2 and 0.7 consistent with airways obstruction (2014/15)**



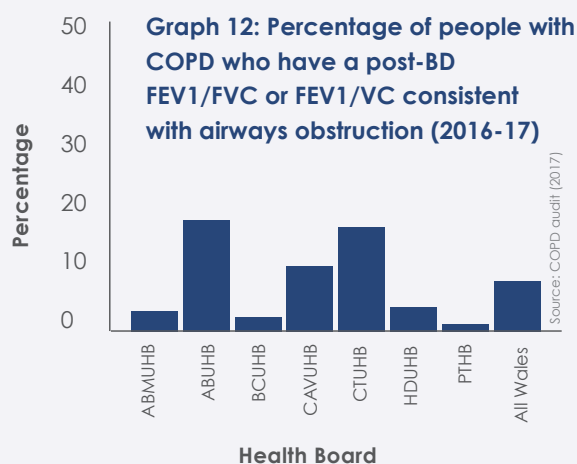
**Graph 11: Number of candidates enrolled ARTP spirometry, number of GP practices and number of spirometers distributed per Health Board (2017)**



## Results

Improving early diagnosis is an integral component of COPD management, an area which we have repeatedly failed to do with precision. From the National COPD audit 2014, where people on the COPD register did have a record of having had this test, 26.9% had a value that was not consistent with COPD (graph 10).

This is being addressed by a National competency-based education programme to increase standards in spirometry assessment and interpretation. To date there are over 600 practitioners enrolled on to ARTP spirometry programme (graph 11). More recently the two day course has been condensed into a one day course supplemented by e-learning, which has improved uptake and completion.



**Graph 12: Percentage of people with COPD who have a post-BD FEV<sub>1</sub>/FVC or FEV<sub>1</sub>/VC consistent with airways obstruction (2016-17)**

Coding for spirometry in primary care remains a problem. The recent COPD audit 2017 emphasises this, where only 8.1% of COPD patients have a post-bronchodilator FEV<sub>1</sub>/FVC ever recorded (graph 12).

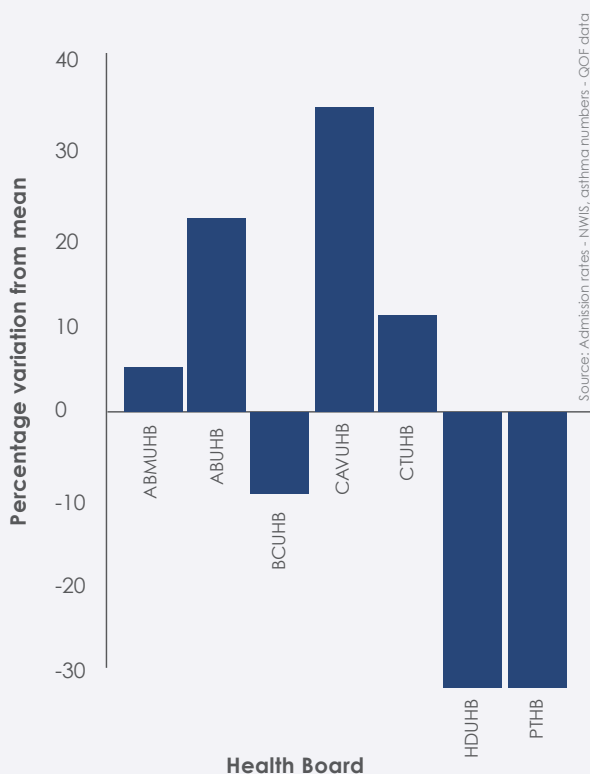
This is largely down to variation and incorrect coding. Around 44% of people with COPD had a record of another spirometry Read code (i.e. excluding 339m) and a ratio consistent with COPD. This suggests, allowing for a discrepancy in choice of Read code, that only 52.1% of patients may have quality assured diagnosis.





## Early diagnosis. Fast, effective care

**Graph 13: COPD admission rate per COPD population by Health Board (2016/17)**



HDUHB and PTHB admit less patients with COPD per population compared to any other HB.

It is clear that the early detection of COPD needs to occur in primary care. The group will explore the possibility of an IT red flag system suggesting a COPD assessment and spirometry for patients over the age of 40 years who present with repeated chest infections.

The group will explore the possibility of other health care professionals such as community pharmacists or smoking cessation counsellors being able to perform spirometry in patients at risk of COPD. The COPD work-stream does not support the use of formal screening programmes as there is no evidence at present that they alter outcome.

The British Lung Foundation (BLF) in conjunction with Public Health Wales runs regular National Campaigns ("Missing Millions") to highlight COPD and raise awareness about smoking cessation services. There has been a more recent 12 month online campaign aimed to introduce exercise for patients with breathlessness. 260,000 patients have taken part to date with around 45% referred to their GP for further tests.<sup>1</sup>

The BLF also delivers geographically based campaigns to raise awareness of COPD ("Love your Lungs" campaign) with 150 of 600 people screened being sent to their GP for further tests.

### ● ● ● Actions

#### **Health Boards to work together to:**

1. Ensure exacerbations are treated promptly including supported discharge following admittance to hospital. This centres on being able to access primary care and in some cases using a rescue pack in suitable patients.
2. Improve referral rates and access to Pulmonary Rehabilitation Programmes including quick access post-exacerbation.
3. Participate in National audits.

#### **RHIG will engage with Health Boards to:**

4. Educate the workforce around diagnosis, management and coding of COPD in conjunction with the NREP.
5. Develop an All-Wales COPD care pathway, which includes prescribing guidelines. This will ensure an evidence-based approach in managing COPD patients across Wales.
6. Improved self-management for patients using various media.
7. Development of an All-Wales COPD discharge bundle.



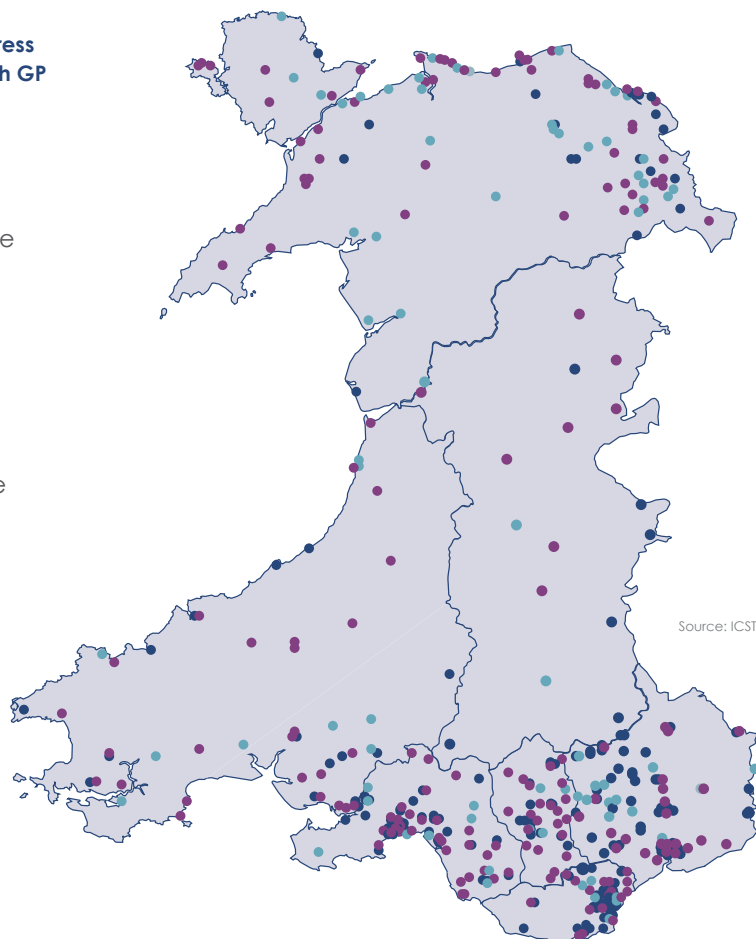
## Early diagnosis. Fast, effective care

**Figure 3: All-Wales map showing the progress of ARTP spirometry practitioners in all Welsh GP surgeries and hospitals**

The bespoke Welsh dashboard gives visibility of who is progressing through the education programme and where they are based. This shows national, regional and service level activity.

The data is collected from those that have been registered onto the education programme. The progress of each individual is fed into the dashboard, which enables you to see the progressive rise in skill levels within your healthcare region and to correlate this to clinical practice and patient outcomes.

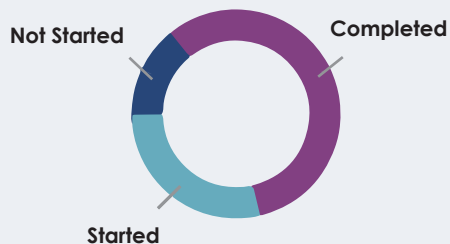
To illustrate this, the map of Wales below shows the progress of ARTP spirometry practitioners in all Welsh GP surgeries and hospitals. This is shown in a simple info-graphic for all Health Boards.



### The Health Care Region

ARTP Spirometry  
More Information

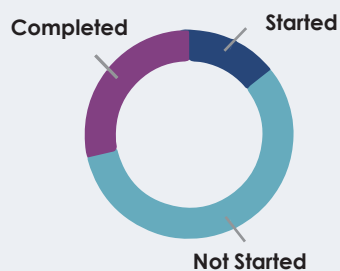
Not Started: 37  
Started: 56  
Completed: 118



### Specific practice

#### Powys Teaching Health Board

Bronllys Hospital, Bronllys, Powys  
Total Nurses: 7 | Not Started :1  
Started: 4 | Completed: 2





# 10 ● Case study



## Gaynor Lloyd

### A patient's story

#### I live with COPD.

I stopped smoking in 2013 following a chest infection where I was admitted to hospital. I didn't undergo pulmonary rehabilitation or any other formal exercise programme, but I have continued to remain active by tending to my allotment with my husband.

I work on the allotment several times a week and I've not been admitted to hospital since. I strongly believe that staying active is very important for managing my condition.





# 11 ● Early diagnosis. Fast, effective care



**Katie Pink**  
Asthma work stream lead

## Background

Asthma is a common inflammatory disorder of the airways and the prevalence in Wales is amongst the highest in the world. Most people with asthma have mild to moderate disease; their symptoms can be controlled with moderate doses of medication and are successfully managed in primary care. However, confidential enquiries such as the National Review into Asthma Deaths (NRAD) have highlighted major deficiencies in asthma care and have come to the striking conclusion that around half of these deaths are potentially avoidable<sup>1</sup>.

Living with severe or poorly controlled asthma has a significant impact on both the individual and also on the wider health service.

Symptoms can be disabling; interfering with daily activities, impacting on quality of life and with the risk of life-threatening asthma attacks. Asthma also places a significant economic burden on the NHS; in excess of £1.1 billion per year.

The diagnosis of asthma can be challenging; there is currently

no gold standard diagnostic test and diagnosis is largely based on history together with evidence of variable airflow obstruction (peak flow diary or spirometry). Studies suggest up to 30% of adults with a diagnosis of asthma have no clear evidence of the condition<sup>4</sup>.

Conversely, other studies suggest that asthma may be under diagnosed<sup>5</sup>.

About 5-10% of all asthma patients have severe or difficult to control asthma with symptoms that persist despite currently available therapy. This group requires specialist investigation and management. In Wales, a collaborative, networked approach has been established to discuss the more difficult of these cases through the Welsh Difficult Asthma Group (WeDAG). The vision is that the necessary diagnostic tests are performed at a local or regional level, the network provides an MDT to assimilate the information and make treatment recommendations, and care is devolved back to local hospitals to be delivered to the patient close to home. This approach is especially important given the rapidly expanding array of costly biological agents now available to treat severe asthma. There is no designated tertiary asthma service within Wales and significant work is still required to ensure all patients with difficult asthma have access to appropriate expertise.

**In Wales the cost is estimated at more than £211 million, with over £40 million spent on prescribing costs alone.<sup>3</sup>**

## Aims

1. To increase the provision of specialist asthma services across Wales.
2. To support the development of the Welsh Difficult Asthma MDT.
3. To improve the accuracy of asthma diagnosis in primary care.
4. To support primary care with the ongoing implementation of the recommendations from the NRAD report.
5. To support the development and implementation of a National Airways Database.

**3,400**  
emergency  
asthma admissions  
... with **71** deaths  
across Wales  
(2015/16)<sup>2</sup>





## Early diagnosis. Fast, effective care

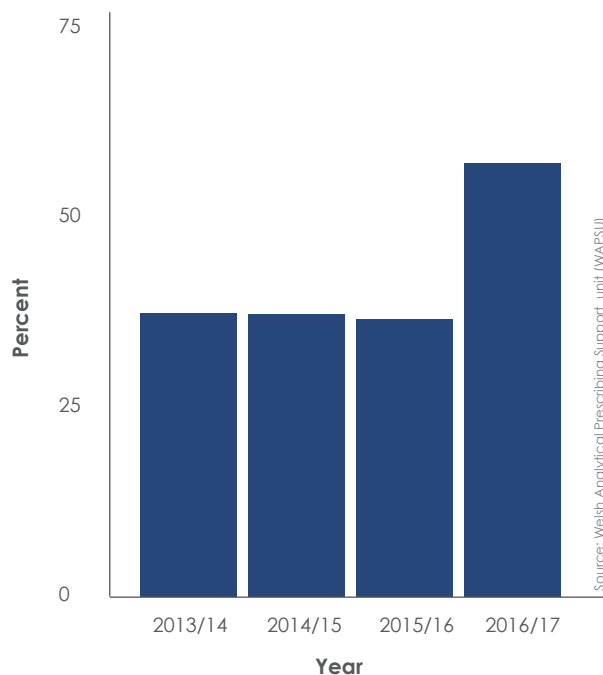
### Results

Accurate diagnosis is a key priority. There has been significant progress with spirometry training within primary care (to ARTP standards). The NICE guidelines for the diagnosis and management of asthma have recently been published<sup>6</sup> and these will require collaborative working between primary and secondary care to implement. The British Thoracic Society also produces evidence-based guidelines on the management of asthma. Anti-inflammatory medication with inhaled corticosteroids is the main therapy.

All patients with asthma should have an annual review including a measure of asthma control (e.g. asthma control test, RCP 3 questions), inhaler technique, review of concordance with medication and education including a jointly agreed asthma action plan to support their self-management. Objective measures of concordance should be checked (e.g. prescription refill rates). Ensuring all patients receive a comprehensive asthma review, as highlighted by the NRAD report, is both a challenge and a priority for Wales.

It is important that patients with asthma are managed according to their disease severity – this includes ensuring therapy is stepped down in those with well-controlled disease. Over the past few years there has been a concerted effort to reduce inhaled corticosteroid (ICS) strength (graph 14). At the other end of the severity spectrum it is essential to ensure timely access to novel, high cost therapies (e.g.

**Graph 14: Low strength ICS prescribing as a percentage of all ICS prescribing**



biological agents, thermoplasty) in those with the most severe disease.

It is essential that patients with uncontrolled asthma are able to receive a timely review within a designated secondary care clinic. Each hospital/ Health Board within Wales now has a consultant with a specialist interest in asthma who is part of the WeDAG. Referral to treatment times (RTT's) times should be maintained. There is a clear consensus from published guidelines that patients with severe, difficult to control asthma should be systematically evaluated by a dedicated multi-disciplinary service utilising a team experienced in the assessment and management of difficult asthma. Whilst the WeDAG acts as a 'tertiary opinion' there is a need to ensure local diagnostic support and systems to deliver care including access to specialist nurses, respiratory physiotherapy, psychology and specialist speech and language therapy. There is currently inconsistent access to these key components of care. Access to specialist nurses is a particular concern that needs urgently addressing. Only ABUHB has a dedicated specialist asthma nurse (table 1).

**Table 1: Dedicate asthma consultant and nurse per Health Board**

Health Board	Dedicated asthma consultant lead	WTE asthma nurse
ABMUHB	Yes	0
ABUHB	Yes	0.7
BCUHB	Yes	0
CAVUHB	Yes	0
CTUHB	Yes	0
HDUHB	Yes	0
PTHB	No	0





## Early diagnosis. Fast, effective care

The specialist asthma nurse for ABUHB has a coded weekly list of asthma admissions that are seen in her asthma clinic. All patients are provided with an asthma action plan, general asthma advice and have their inhaler technique checked. Their allergy and immunity status is also reviewed. The specialist asthma nurse also undertakes an antenatal clinic for all pregnant women with asthma under consultant-led care.

The WeDAG MDT meets monthly to discuss patients with complex disease and to support investigation and management decisions. A number of new high-cost biological agents have recently become available for treating severe eosinophilic asthma – the MDT is able

to provide an opinion on the suitability of these agents in individual cases. The MDT has an important role in developing and sharing protocols and disseminating best practice between Health Boards, improving equity in care throughout Wales. There is a need for a coordinator to support these monthly meetings and to collect robust data with regard to the recommended interventions and their effectiveness. The RHIG have been supportive of the bid for this coordinator and the post is soon to be advertised.

### ● ● ● Actions

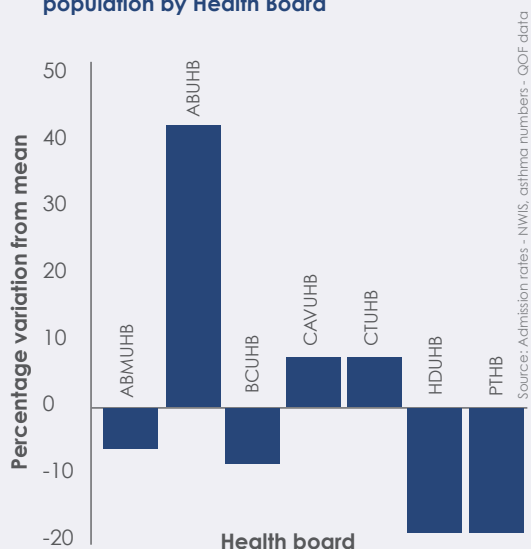
#### **Health Boards to work together to:**

1. Nominate a lead physician for asthma with a dedicated secondary care asthma clinic, supported by an asthma specialist nurse.
2. Employ an asthma clinical lead within primary care responsible for implementing the recommendations from NRAD.
3. Support the development and implementation of an up-to-date All-Wales prescribing pathway on the management of asthma, to ensure cost-effective, evidence-based prescribing.
4. Integrate asthma diagnostic guidelines into clinical practice. This will require different ways of working such as the establishment of diagnostic hubs within primary care with support from secondary care.
5. Ensure their asthma service is sufficiently resourced to ensure patients with severe asthma are able to access new therapies within 3 months of publication of relevant NICE guidance.

#### **RHIG will engage with Health Boards to:**

6. Support the development of an All-Wales Prescribing Pathway.
7. Support the development of the WeDAG MDT including coordinator support and database development to allow accurate record of patients discussed, recommendations and outcomes.
8. Develop an All-Wales airways database.

**Graph 15: Asthma admission rate per asthma population by Health Board**



Graph 15 highlights the variation in admission rates between Health Boards and, interestingly, ABUHB has significantly more asthma admissions than each of the other Health Boards. The reasons for this are currently unclear. One role of RHIG is to highlight such differences and to work with individual Health Boards to investigate further and to develop strategies to improve care and reduce variation.



# 12 ● Early diagnosis. Fast, effective care



## Martha Scott

### Cough work stream Lead

#### Background

Chronic cough is defined as one lasting more than eight weeks. It is reported in 10-20% of adults and is more common in females and obese patients. Chronic cough accounts for more than 10% of referrals to secondary care and patients typically present with a dry or minimally productive cough. There is wide variation in primary care in terms of interventions tried before referral onwards to secondary care, often treatment trials are too short or sub-therapeutic dosages are used.

#### Aims

The primary aim of this group is to help practitioners to diagnose cough due to airways inflammation – asthma and asthma type syndromes and start appropriate treatment to prevent airways remodelling and chronic changes in lungs. The group will:

1. Develop all Wales guidelines on the management of chronic cough by primary care in order to:
  - Empower primary care to successfully treat patients with chronic cough.
  - Reduce the amount of time patients suffered with a chronic cough.
  - Reduce referrals of patients with a chronic cough who could be successfully treated by primary care.

2. To develop all Wales guidelines to enable secondary care to manage and treat patients with chronic cough who had failed to respond to the primary care guidelines interventions in order to ensure:

- Patients received the best available care irrespective of where they lived.
- Ensure interventions were effective and followed value based principles.

#### Results

There is no readily available data on the reason for referrals to respiratory medicine. However an audit of 300 consecutive referrals between 20/06/2016 and 02/08/2016 in ABUHB found that 15.5% of referrals were primarily for chronic cough. A similar audit in CAVUHB found that 25% of 98 primary care referrals in 2013 were for cough.

#### ● ● ● Actions

##### **Health Boards to work together to:**

1. Implement All-Wales cough guidelines for primary and secondary care via App interface.

##### **RHIG will engage with Health Boards to:**

2. Work with NWIS to measure cough referrals per Health board.
3. Work with NWIS to correlate reasons for referral.
4. Develop primary and secondary care pathways.





# 13 ● Early diagnosis. Fast, effective care



**Ben Hope-Gill**  
Interstitial lung diseases  
work stream lead

## Background

The Interstitial Lung Diseases (ILD) are a diverse group of conditions which include Idiopathic Pulmonary Fibrosis (IPF), sarcoidosis, hypersensitivity pneumonitis and connective tissue disease-associated lung disease. Together they comprise ~10% of secondary care respiratory workload. These are serious conditions that may be progressive and ultimately fatal. Therefore, timely access to specialist care, diagnostics and appropriate support during the course of the illness is crucial.

Central to the diagnostic pathway for patients with suspected ILD is the interpretation of clinical, radiological and pathological data within multidisciplinary teams (MDT). However, due to frequent overlapping features between conditions misdiagnosis is common.

## Aims

Both published and emerging data from specialist UK ILD Centres shows significant differences in diagnoses reached between low case-volume local hospital teams and higher-volume expert centres. In addition, NICE guidance for the diagnosis and

management of IPF (CG163) and technical appraisals for the prescribing of high-cost anti-fibrotic medication stipulate that patients are evaluated at specialist ILD MDTs to improve diagnostic accuracy, consistency of care and prudent use of resources.<sup>1</sup>

## Results

The Respiratory Health Implementation Group supported the development of a weekly specialist ILD MDT based in CAVUHB to enable timely access to expert opinion for the following groups of patients from South Wales from April 2016:

- Patients with diagnostic uncertainty
- Patients who may require diagnostic lung biopsy
- Patients who may be eligible for high-cost therapy.

During the period April 2016 to March 2017, 267 patients with ILD were discussed at the South Wales ILD MDT; this is a tele-linked meeting to enable referring clinicians to participate and to facilitate communication and education within the region. The mean time from referral to the South Wales MDT for discussion has reduced from 19 weeks prior to April 2016 to



## ● Early diagnosis. Fast, effective care

1.2 weeks currently. The service has been commissioned by WHSSC from April 2017.

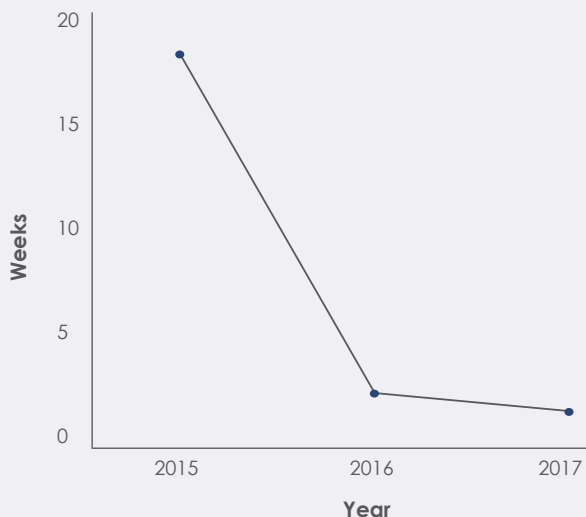
For patients in North Wales there have been established clinical and geographical links with the Specialist ILD Service at Aintree Hospital in Liverpool. Therefore, a different model has been developed and supported by WHSSC to serve the needs of patients in North Wales. A monthly MDT meeting is hosted at Wrexham Maelor Hospital which is tele-linked to the other North Wales acute hospitals. This MDT is attended by two ILD physicians and two ILD radiologists from Aintree Hospital.

A proportion of patients (13% ILD MDT referrals) would benefit from a lung biopsy to aid diagnosis. A significant constraint in South Wales is timely access to surgical lung biopsy meaning that patients often face unacceptable diagnostic delay.

A more recent technical advance using lung cryobiopsies holds promise as a highly cost-effective technique to improve both access and diagnostic quality and which also has the potential to reduce capacity constraints on thoracic surgical services in South Wales.

The diagnostic process and initiation of drug therapy is a small part of the care required by patients with ILD. It is preferable that the majority of care is provided locally to the patient. Consequently, the ILD service framework for Wales uses a hub and spoke model. It is fully recognised that patients should have access to local ILD teams including relevant diagnostic support, a lead ILD clinician, ILD clinical nurse specialists, pulmonary rehabilitation, oxygen assessment and palliative care. However, there is currently inconsistent access to these key components of care for patients with ILD in Wales.

**Graph 16: Mean time from referral to South Wales MDT**



## ● ● ● Actions

Priorities relating to care of patients with ILD in Wales are focused on ensuring equitable and timely access to essential components of care throughout the patient pathway, irrespective of where patients live. The following development goals reflect this:

### **Health Boards to work together to:**

1. Have a nominated lead clinician for ILD with an established specialist ILD clinic to support patient pathway development and to facilitate patient care.
2. Ensure all patients with ILD to have ready access to ILD Clinical Nurse Specialist support.
3. Ensure all patients with ILD who would potentially benefit to have rapid access to pulmonary rehabilitation.
4. Ensure all patients with progressive ILD to have access to specialist palliative care services.
5. Ensure all patients with ILD to have access to patient support groups.
6. Facilitate timely access to lung biopsies for patients with indeterminate radiology; either cryobiopsy or surgical lung biopsy.

### **RHIG will engage with Health Boards to:**

7. Develop an All-Wales ILD database.



# 14 ● Early diagnosis. Fast, effective care



## Simon Barry

### Tuberculosis work stream lead

#### Background

Despite Wales having a relatively low prevalence of tuberculosis (TB) compared to other parts of the United Kingdom, such as London and Birmingham, the management of TB cases, contact tracing and controlling outbreaks can place a significant demand on local services. Cardiff is an initial processing centre for asylum seekers, whilst Newport, Swansea and Wrexham are asylum seeker dispersal centres. It is therefore necessary that appropriately skilled staff with time dedicated to TB management are available in each Health Board, both to manage cases and their contact and to screen at risk groups such as asylum seekers.

TB cohort review was introduced into Wales in 2012 following an assessment of the North London cohort review process. It is a quality assurance process with the following aims:

1. Improve TB case management and identification of contacts.
2. Improve treatment completion and contact investigation outcomes.
3. Increase staff accountability for outcomes.
4. To motivate staff.
5. To reveal programme strengths and weaknesses.

6. To indicate staff training and education needs.

Significant improvements have been demonstrated across Wales through the adoption of cohort review.

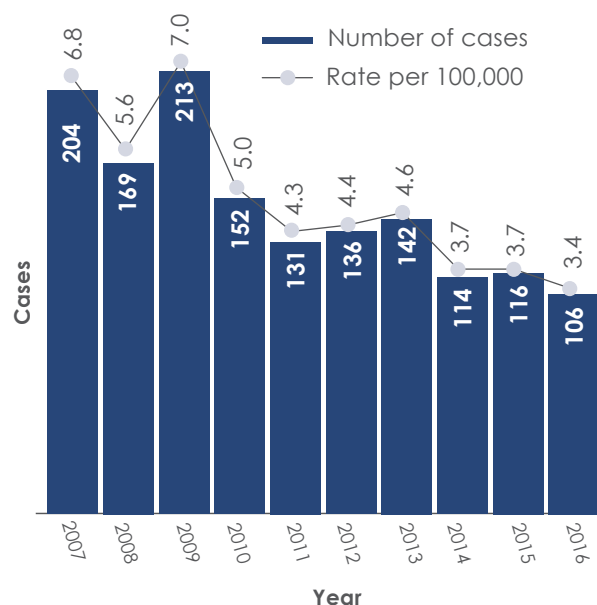
#### Aims

1. Ensure the presentation of all TB cases in Wales at TB cohort review.
2. Ensure compliance with cohort targets.
3. Ensure an equitable workforce with appropriate training to deal with TB cases and outbreaks in each Health Board.
4. To deliver excellent care for patients with TB in Wales.

#### Results

The number of TB cases in Wales is low compared to most other UK regions.

**Graph 17: Number of Cases and Rate of TB per 100,000 population, Wales (2007-2016)**



The incidence of TB in Wales has been decreasing since 2009 when there were 7.0 cases notified per 100,000 population (213 cases). TB rates vary by local authority with most cases in urban centres, Newport and Cardiff.

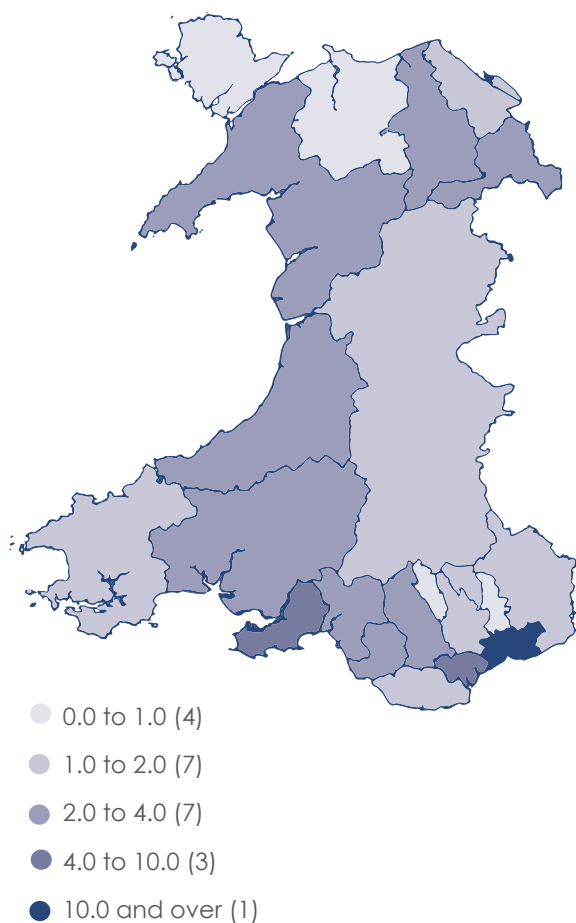


## ● Early diagnosis. Fast, effective care

Of the 106 cases notified in 2016 42% were reported in the White ethnic group, 55% were in the non-White population and 4% were of an unknown ethnic group. In 2016, 50% of tuberculosis cases were in the non-UK born population and South East Asia and Sub-Saharan Africa were the most common region of birth for non-UK born cases.

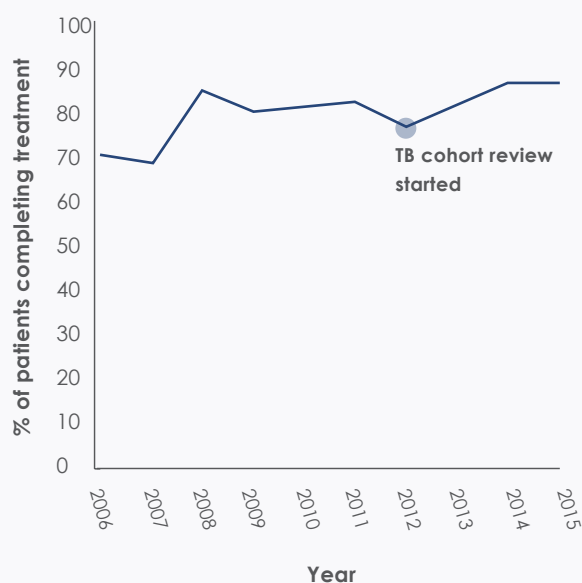
Approximately, one half (27/53) of non-UK born cases were diagnosed more than five years after UK entry. The rate of tuberculosis in those who reside in the most deprived areas of Wales was 7.0 per 100,000 population compared to 1.1 per 100,000 population in the least deprived areas.

**Figure 4: Rate of TB per 100,000 population by Local Authority, Wales; (2016)**



**Graph 18. Percentage of drug sensitive Tuberculosis patients who had completed treatment when outcome was last recorded, Wales; 2006-2015<sup>12</sup> (Tuberculosis in Wales Annual Report, November 2017)**

<sup>1</sup>Excludes initial and amplified rifampicin resistant TB and MDR-TB treated



The proportion of TB cases notified in Wales being presented at the TB cohort review increased from 67% in 2012 to 93% in 2015.

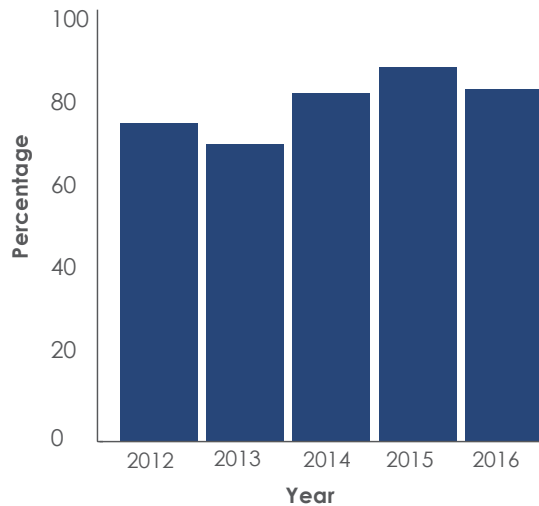
As at October 2017, 88% of cases notified in 2016 had been presented at the cohort review with all outstanding cases due to be presented in November.

The proportion of cases presented was over 95% in all Health Boards. Complete presentation of cases at TB cohort review facilitates discussion and improvements to practice. Where cases are not presented, outcome data is not captured and thus lessons cannot be learned by the Health board or the TB clinicians across Wales. Since the introduction of TB cohort review, there has been a steady improvement in TB completion rates.



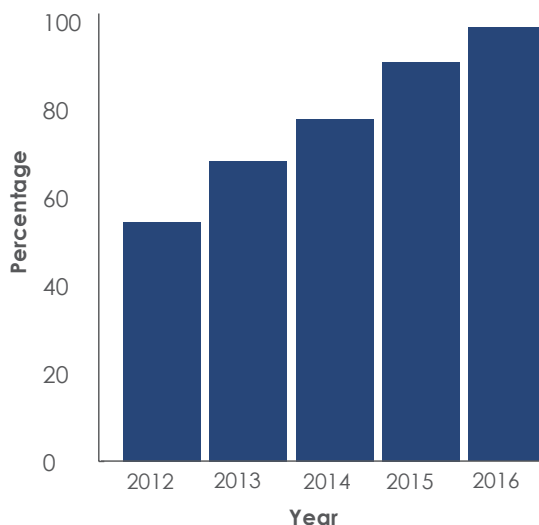
## ● Early diagnosis. Fast, effective care

**Graph 19: Proportion of pulmonary cases confirmed by culture (%), by health board of residence, Wales (2012-2016)**



The European Centre for Disease Prevention and Control (ECDC) sets the target at 80% for the proportion of pulmonary TB cases that should be confirmed by culture. Obtaining TB culture results is an important marker of good practice since it allows identification of drug resistant strains and tailoring of appropriate therapy. Across Wales, the 80% target was exceeded again in 2016 with 83.6% (61/73) of cases being culture confirmed.

**Graph 20: Proportion of cases offered HIV testing, excluding those where HIV status is already known and those diagnosed post mortem, Wales (2012-2016)**



Identification of co-infection with both TB and HIV is a public health priority. For people living with HIV, the risk of developing (TB) is estimated to be between 26 and 31 times greater.

The London Cohort Review Guidance originally recommended a target of 90% for the proportion of TB cases being offered a HIV test and this target was reached in 2015. For cases notified in 2016 this target was increased to 100%. In 2016 95.8% were offered HIV testing, those who were not offered an HIV test were either young children or elderly.

**Table 2: Description of TB services including workforce strengths by Health Board (2016)**

Health board	Dedicated TB consultant lead	WTE TB nurse	Screening of university students
CAVUHB	Yes	2.0	Yes
ABUHB	Yes	0.75	No
HDUHB	Yes	No	No
CTUHB	Yes	0.3	Yes
BCUHB	No	No	No
ABMUHB	Yes	0.6	Yes
PTHB	No	No	No

There is a significant variation in the nursing workforce dedicated to TB across different HB. Whilst the number of active TB cases remains small, much of the work of TB nurses involves important public health measures such as contact tracing, screening and vaccinating at risk populations.

In addition TB nurses are frequently involved in screening patients from rheumatology, gastroenterology and dermatology who are due to start biologic therapy.

Importantly, in an era of high population mobility and increasing student numbers the risks of TB





## ● Early diagnosis. Fast, effective care

outbreaks is significant. Data from the screening of students from high prevalence countries in Cardiff, it is estimated that screening approximately 200 at risk students will identify one active case. Therefore, there needs to be a national strategy to screen at risk populations, including those in prison and this will require resource allocation.

Many active TB cases are from disadvantaged backgrounds, without stable family support and require enhanced case management and frequently directly observed therapy (DOT). This results in significant time investment for respiratory nurses which is particularly difficult to achieve when they have to fulfil a number of simultaneous roles within respiratory medicine.

### ● ● ● **Actions**

#### ***Health Boards to work together to:***

1. Ensure that there is a lead clinician with a responsibility for managing TB cases.
2. Ensure that there is sufficient dedicated specialist nurse time allocated to TB management including contact tracing and outbreak management in each Health Board.
3. Ensure attendance of clinicians at TB cohort review.
4. Support the implementation of an All-Wales senior nurse role for TB to provide clinical leadership required.

#### ***RHIG will engage with Health Boards to:***

5. Develop All-Wales management guidelines for MDR and XDR TB.
6. Develop a business plan for screening universities and prisons across Wales and to present to Welsh Government.
7. Create a business plan and institute video observed therapy (VOT) as an alternative to DOT.



# 15 ● Early diagnosis. Fast, effective care



**Jamie Duckers**  
**Chronic lung sepsis**  
**work stream lead**

## Background

Bronchiectasis (BE) is a disease characterised by irreversible dilation of one or more bronchi. Current estimates suggest 30-60,000 patients suffer from BE in the UK. It is a debilitating illness with patients typically suffering a persistent cough, chronic daily sputum expectoration, recurrent chest infections and a poor health-related quality of life (Smith 2011). BE has been shown to be associated with significant mortality that displays a year on year increase of up to 3% per annum (Roberts 2011).<sup>2</sup>

Morbidity is also high and is associated with significant healthcare costs and UK hospital admission data found that BE was the primary diagnosis in 1 in 1800 admissions.

## Aims

1. Facilitate closer working between primary and secondary care.
2. Develop appropriate All-Wales guidance for the management of patients with BE.
3. Ensure a consistent and high standard of care across all of Wales.

## Results

Until the British Thoracic Society Guidelines 2010 were published there were no guidelines for the management of BE. The evidence base for many of the treatments recommended in the current guidelines relies primarily on expert consensus or on evidence translated from other conditions (BTS, 2010). The guidelines indicate that management should be focused on improving or maintaining lung function, reducing exacerbations, promoting good airways clearance taught by a specialist respiratory physiotherapist, improving quality of life and promoting the development of expert patients and effective self management.

There have been 3 annual Non CF bronchiectasis BTS audits and a BTS Quality Standards for clinically significant bronchiectasis in adults (July 2012) which have begun to guide what constitutes a good quality bronchiectasis service.

## ● ● ● Actions

### **Health Boards to work together to:**

1. Increase utilisation of self-management plans.
2. Increased Chief Investigator activity and portfolio listed trials and grant capture.
3. Increased participation in commercial trials.
4. Ensure people with bronchiectasis who meet the criteria for continuing secondary care to be managed by a multidisciplinary team led by a Respiratory physician.

5. Participate in British Thoracic Society Bronchiectasis Audit.

### **RHIG will engage with Health Boards to:**

6. Develop and share All-Wales protocols, guidelines and good practice.
7. Support education events with Primary, secondary and tertiary care.



## 16 ● Case study



### Mary Rowell

#### A patient's story

**I was born in October 1932, a fit and healthy baby. At the age of 3 years I caught whooping cough and from then on I had a constant cough and breathing difficulties. I was diagnosed with Bronchiectasis from a very young age.**

At the age of 17, I had to leave school to have a lobectomy in the Brompton Hospital, London. My surgeon was Sir Clement Price Thomas who later performed a similar operation on King George VIth, who was a heavy smoker. I have never smoked but my parents and many friends did in those days. After my operation I was advised to get out in the fresh air as much as possible, so I started sailing at home in Tenby. For me being out in the fresh air is much more enjoyable and beneficial than a gymnasium or health club. I find the fresh air, exercise and company beneficial to my health. I have made so many friends over the years through golf and people still play into their eighties and even their nineties.

I am convinced that fresh air and lots of outdoor exercise is the best tonic for anyone with breathing problems. I hope to play golf for many years to come.





# 17 ● Early diagnosis. Fast, effective care



## Alina Ionescu

### Pleural disease work stream lead

#### Background

Pleural disease is a common condition; according to the British Thoracic Society pleural disease guideline of 2010 it affects 3000 people per million of population every year. There are a few characteristics of this respiratory condition.<sup>1</sup>

- It is often associated with malignancy of the lung or other organs.
- It crosses speciality boundaries since often pleural effusions are found in other conditions such as heart, liver or kidney failure.
- It often involves the need for emergency management (such as pneumothorax or significant volume pleural effusions).
- It involves procedures for the diagnosis and management of the pleural disease, procedures which are performed by Respiratory Physicians and their trainees (occasionally by trained advanced nurse practitioners).
- Some pleural conditions are managed with chest drains which involve care by nurse specialists, ward nurses and occasionally district nurses (for chest drains managed in the community). Therefore the management

of pleural disease often crosses the boundary between secondary and primary care as well as has a direct interface with the acute front door services and in more complex cases, with thoracic surgery.

Recently the National patient's safety standards for invasive procedures (NatSSIproc) document has identified pleural procedures as the one group of medical procedures, which need to come under the guidance of this National standards (most specialities that come under the NatSSIproc guidance are surgical procedures).<sup>2</sup> Moreover, the National Patient Safety Investigation into serious complications of chest drain insertions (2008) has lead to increased awareness and governance issues (training, national auditing) of pleural interventions and chest drain insertion in particular. Patients with pleural disease often need diagnostic tests, which involve invasive procedures from simple aspiration of the pleural fluid or pneumothorax to diagnostic and therapeutic thoracoscopy.

#### Aims

1. The Pleural stream has come together to ensure high quality care is provided in each Health Board.
2. To deliver fast and effective care for patients with pleural conditions.
3. To provide a forum for discussion of challenging pleural cases.





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### Results

The Wales Pleural Interest Group (WPIG) has agreed that data collection is important for quality assessment and collaborative work. Data collection takes place in various forms in several Health Boards and it is one of the objectives of the Welsh Pleural Interest Group to work together and agree on a more structured and unified way of collecting relevant data for the purpose of audit, quality improvement and collaborative research.

Pleural disease has various causes, often malignancy or infection but it crosses speciality boundaries since it is frequently encountered in heart, kidney and liver disease or some rheumatological conditions, therefore one of the characteristics of this speciality is that referrals come towards the pleural specialist from numerous specialities.

Infection of the pleural space is a serious condition therefore early treatment is of paramount importance. Patients with suspected empyema are referred to the speciality from Primary Care or Acute Services as well as other specialities. The management of empyema involves close discussion with Thoracic Surgeons and in some cases early referral for surgery.

Pneumothorax – if primary spontaneous, usually affects young adults and if non-resolving also involves referral to surgical centres for definitive treatment. Therefore in such conditions, as well as occasionally in cases of suspected pleural malignancy, collaboration with surgical centres is of paramount importance. Prompt management of the pleural disease often prevents complications, reduces hospital stays and re-admission rates and the pleural services being able to manage aspects of the pleural disease via ambulatory care pathways.

Pleural disease can occasionally be managed through ambulatory pathways and with support of specialist nurses trained in the management of pleural disease, forms of pneumothorax and occasionally recurrent

malignant pleural effusions are examples of effective management in the community where the patients are supported by trained nurses.

Patients who are managed in hospital chest drains are best looked after on specialist wards where attention is given to the training of nursing staff who deals with chest drains and maintenance of skills of both nursing staff and doctors who work on such units is ensured. WPIG has as objective to encourage support for such pleural units in all Health Boards to deliver safe care to patients who need chest drains or other pleural intervention, prevent complications related to such procedures, ensure effective care of the chest drain and support for the patients as well as their families in cases of chest drains dealt with in an ambulatory fashion the community.

### ●●● Actions

#### **Health Boards to work together to:**

1. Implement All-Wales standards for pleural procedures.
2. Ensuring that there is a dedicated pleural procedure room for all larger hospitals.

#### **RHIG will engage with Health Boards to:**

3. Develop training, competencies and maintenance of skills for all professionals involved in the management of patients.
4. Develop standard operating procedures for pleural interventions performed by Advanced Nurse Practitioners.
5. Develop All-Wales standard operating procedures and other guidance, as well as assessment tools for nursing staff involved in pleural intervention (as well as for other professionals such as junior doctors and consultants, who deal with pleural patients, manage chest drains and other pleural devices).
6. Develop a unified and structured All-Wales database for pleural procedure information (basic procedures and advanced procedures).



# 18 ● Early diagnosis. Fast, effective care



## Ian Williamson Lung cancer work stream lead

### Background

Lung cancer is one of the most common cancers in Wales. There are around 2,400 new cases in Wales every year. It kills more men and women than any other form of cancer. When lung cancer is picked up earlier, treatment is more likely to be successful. Lung cancer can affect people of all ages; however, it starts to get more common after the age of 50.

Despite it being more common in smokers, around one in eight people with lung cancer never smoked.

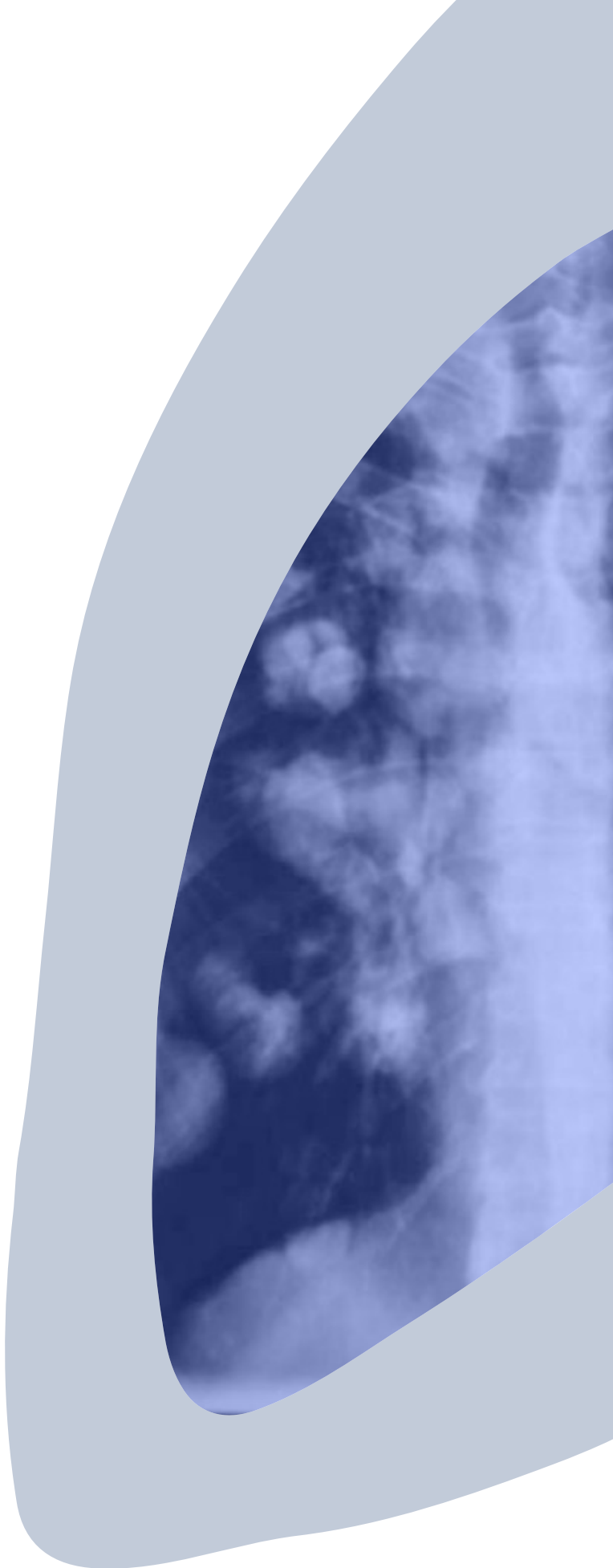
### Aims

To present data for patients diagnosed with Lung Cancer in 2015 by Health Board relating to:

1. Stage at presentation.
2. Compliance with key clinical indicators.

### Results

Data is collected annually by all Health Boards with a Lung Cancer MDT and submitted to the National Lung Cancer Audit (NLCA)



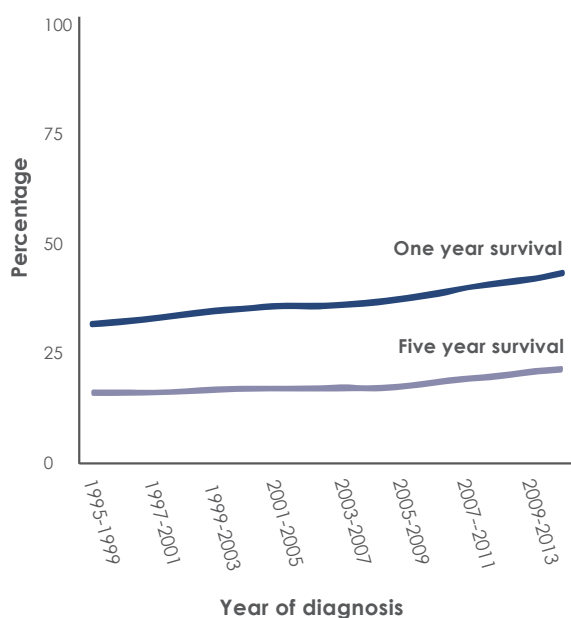




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for analysis.<sup>1</sup> This produces an annual report benchmarking the performance of Health Boards against agreed standards. The lung cancer advisory group to the Welsh cancer network has been reorganised and is developing a series of workstreams to support improvements in performance and outcomes.

**Graph 21: One year and five year age standardised net survival for lung cancer in Wales, 2010-2014**



## ● ● ● Actions

### ***Health Boards to work together to:***

1. Continue to submit data annually to the NLCA to review performance.
2. Undertake analysis of areas of non-compliance with key clinical indicators with particular focus on treatment rates and survival. Detailed case note review should be undertaken where there are low active anticancer treatment and low radical treatment rates to determine why patients with good performance status did not receive the most effective treatment option.



# 19 ● Early diagnosis. Fast, effective care



**Simon Barry**

**Outpatients  
work stream lead**

## Background

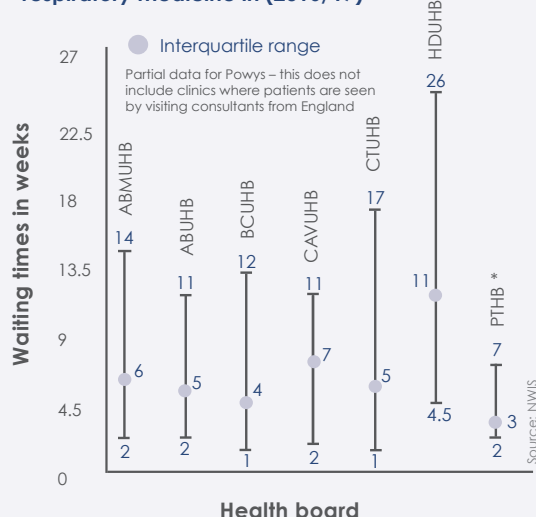
Current data collected by Health Boards on patients waiting for out-patient review is generally those waiting greater than 6 months.

However, this does not reflect the performance of different respiratory teams in reviewing new patients. We therefore sought to collect more specific data on out-patient reviews. We asked NWIS to provide this data which includes urgent suspected cancer (USC) referrals.

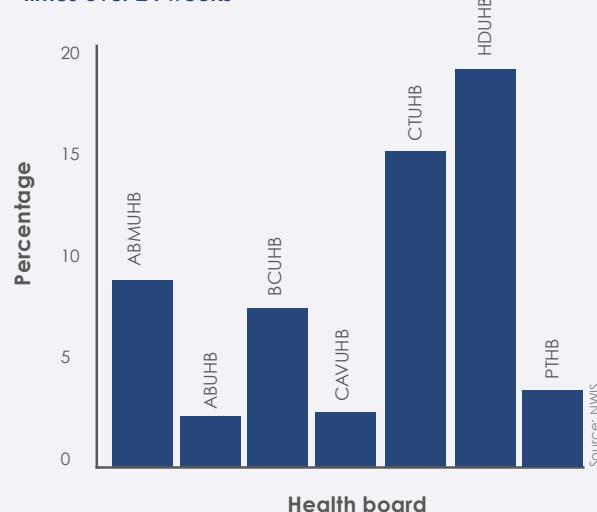
## Aims

1. Present new respiratory out-patient waiting times in weeks by median and IQR by Health Board.
2. Present the percentage of all new patients waiting longer than 24 weeks by Health Board.
3. Present the new patient did not attend (DNA) rate by Health Board.

**Graph 22: Outpatient appointments for respiratory medicine in (2016/17)**



**Graph 23: Outpatient appointment wait times over 24 weeks**



## Results

Data for all Health Board was provided by NWIS except for that from HDUHB and PTBH, which was provided from their local informatics team. Across Wales, the median waits for new respiratory outpatient ranged from 4 weeks in BCUHB, to 11 weeks in HDUHB (graph 21).

There was a significant variation in patients waiting longer than 24 weeks from less than 3% of all new referrals in Aneurin Bevan Health Board (ABUHB) and CAVUHB, to 15% in CTUHB and 19% in HDUHB (graph 23). Nevertheless, overall the vast majority of new respiratory patients in Wales were seen within a reasonable time frame, with moderate variability between Health Boards.



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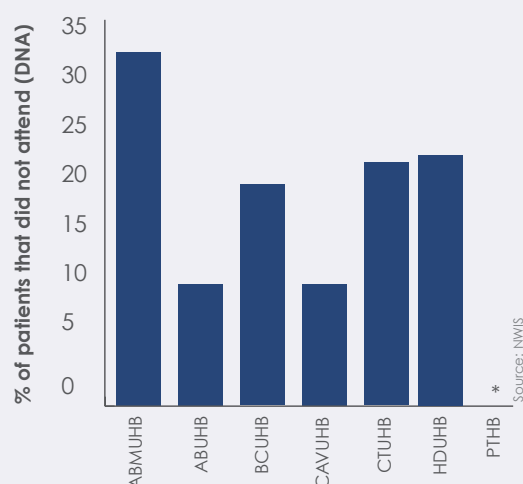
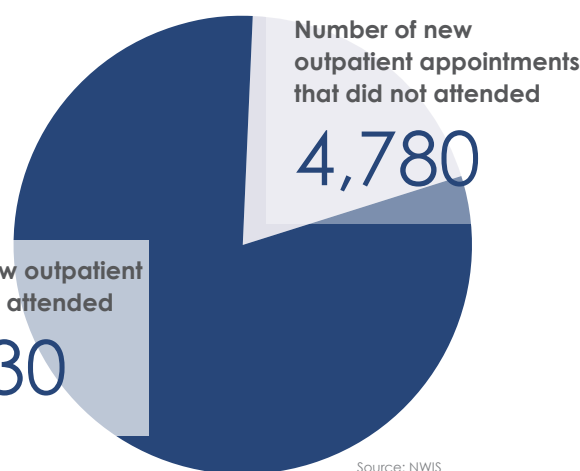
## Graph 24: All Wales referral summary

Total number of new referrals to respiratory medicine in Wales

**24,610**

Number of new outpatient appointments attended

**19,830**



## Graph 25: Referral by Health Board

There was a large variation in the new patient DNA rate by Health Board. This ranged from 11% in ABUHB and CAVUHB to greater than 30% in ABMUHB. This high DNA rate is of significant concern and adversely affects service provision and efficiency of the service.

\* No data available for Powys Teaching Health board

### ● ● ● Actions

#### **Health Boards to work together to:**

1. Report outpatient waiting times.
2. Provide outpatient data to NWIS systems for central data extraction.

#### **RHIG will engage with Health Boards to:**

3. Work with NWIS should to distinguish USC referrals from sleep referrals and other general respiratory referrals and explore breaking down referrals by category (e.g. breathlessness, cough etc) to further develop useful management algorithms.
4. Liaise with the Welsh Government outpatient transformation workshop to improve outpatient performance to improve the DNA rate. Solutions include automatic text reminders to patients prior to their appointment.
5. To continue to monitor and track performance by Health Board and feedback the results to local management teams.



## 20 ● Early diagnosis. Fast, effective care



### Nicola Perry-Gower Pulmonary rehabilitation and exercise work stream

#### Background

This work stream is focussed on expanding self-management and exercise to people affected by lung conditions. Its primary function is to improve access to (PR) with the aspiration that anyone with an MRC of 3 and above should be able to access gold standard PR in the community. Key findings

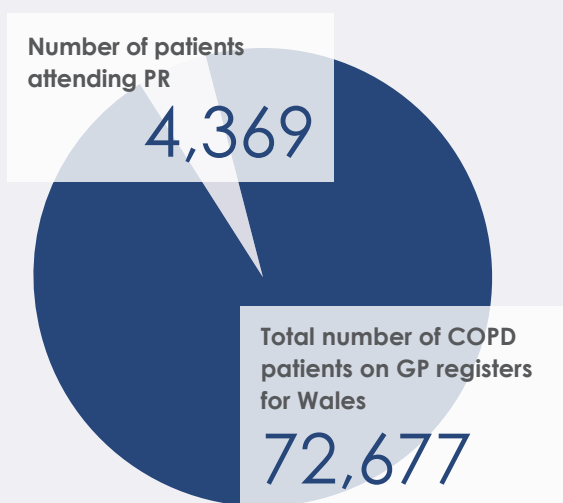
from the National Pulmonary Rehabilitation Audit (February 2016) revealed that (PR) delivers significant health benefits but too many patients are missing out.<sup>1</sup>

There is a significant gulf between the number of patients requiring PR and those attending and the pattern suggests that capacity is outweighed by the likely demand (graph 26).

Patients that do complete PR, on average, show substantial improvements in quality of life and ability to exercise but around 40% of patients who attend PR do not complete the treatment. Furthermore, over a third of patients in England and Wales are waiting longer than the three months.

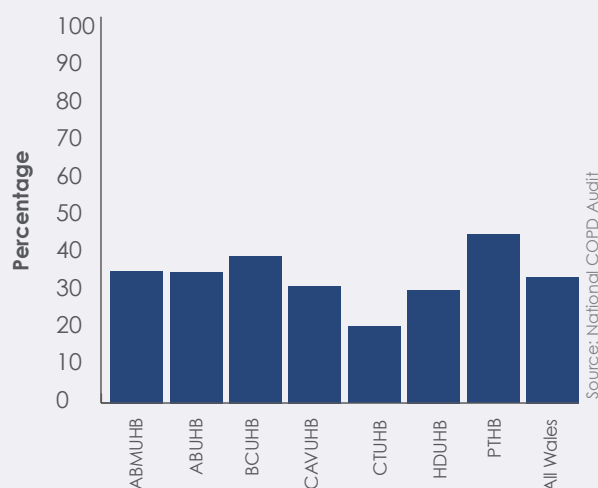
It also stated that there is under referral of eligible people for PR - 65.5% of people with a MRC breathlessness grade 28, 29 and 30 had never been referred for PR. Higher referral rates for this high-value intervention are critical to improving care in this cohort of patients as well as reducing waiting times. It is important to note, however, that the recent GOLD guidelines (2017) highlight that pulmonary rehabilitation is beneficial to all COPD patients of all severity.<sup>2</sup>

**Graph 26: Number of patients attending PR between 2015 and 2017 as a percentage of all COPD patients**



Source: Stats Wales (2016/17)

**Graph 27: People with COPD whose latest MRC breathlessness score is 3,4 or 5 and have ever had a referral to pulmonary Rehabilitation**



Source: National COPD Audit



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### Aims

The primary aim of this group is to oversee and support developments in pulmonary rehabilitation and exercise for people with respiratory conditions in Wales and report to RHIG. The group will:

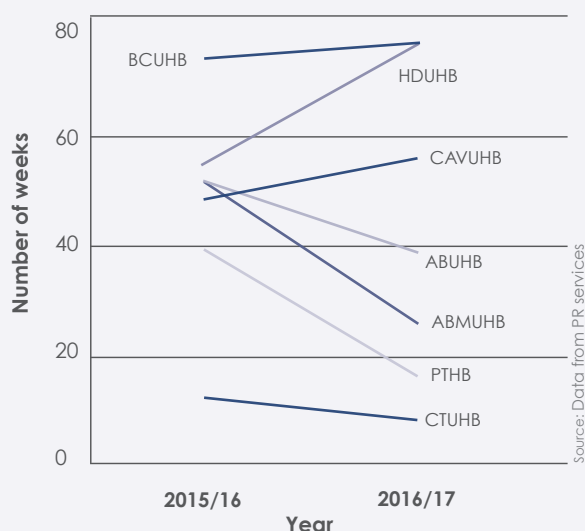
1. Develop appropriate guidance to be used Wales-wide.
2. Consider data and metrics for measuring outcome and impact of PR and exercise services in Wales.
3. Comment on the metrics reported by each Health Board bi-annually and make recommendations to RHIG as appropriate.

### Results

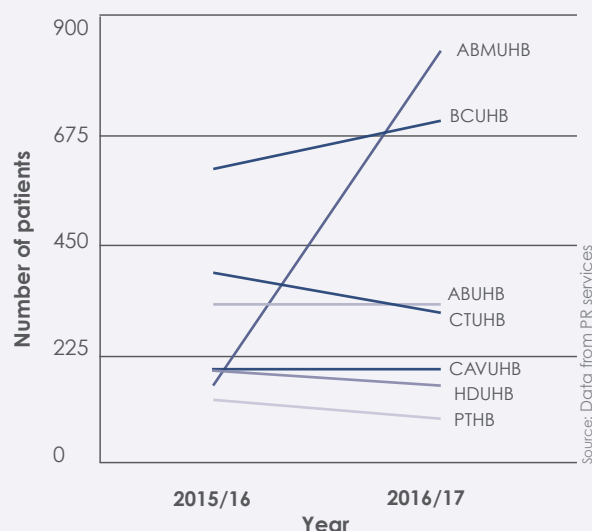
Data collection is undertaken by pulmonary rehabilitation and National Exercise Referral Scheme (NERS) professionals. There is a wide range of measures that different pulmonary rehabilitation teams use to measure the education and fitness of participants, whilst NERS use the same measures across Wales. During the next three years the work stream will develop standardised measures to make it easier to track outcomes in pulmonary rehabilitation, NERS and other self-management programmes.

PR programmes are under resourced in most parts of Wales and are a long way from the BTS Gold Standard. There has been a significant difference in waiting times between 2015/16 and 2016/17 in most Health Boards (graph 28).<sup>1</sup>

**Graph 28: Waiting time in weeks per Health Board between 2015/16 and 2016/17 per Health Board**



**Graph 29: Number of patients seen between 2015/16 and 2016/17 per Health Board**



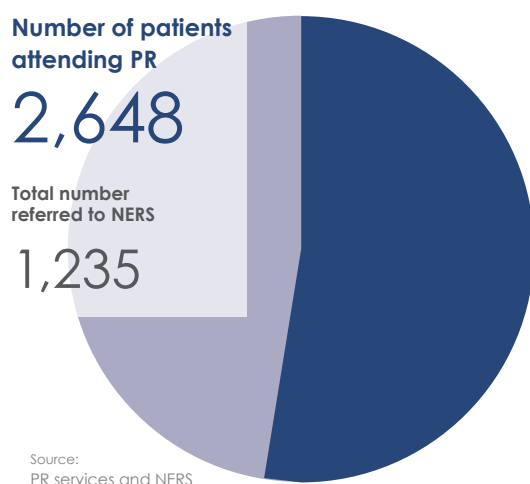
PTHB has seen a decrease in waiting times between 2015/16 and 2016/17, with a small decrease in numbers of patients attending between the two periods. ABMUHB however has seen a similar improvement trend in referral time, but with a remarkable increase in number of patients between 2015/16 and 2016/17. In 2016/17 ABMUHB expanded their PR service using Welsh Government primary care funding to develop a community-based service for each GP cluster at a cost of approximately £1.5m a year. In HDUHB there has been a significant increase in waiting times despite the number of patients attending decline slightly.



## ● Early diagnosis. Fast, effective care

A key part of any PR service is the partnership with NERS. In every programme across Wales, participants should be discharged into NERS to continue exercising or take part in other forms of activity such as singing and tai chi, for example. However, the total numbers of referrals to NERS are not consistent with the number of patients attending PR. Despite showing the greatest drop in waiting times for PR, ABMUHB and PTHB also have the lowest number of respiratory patients referred to NERS.

**Graph 30: Number of patients referred to NERS as a percentage of all patients attending PR (2016)**

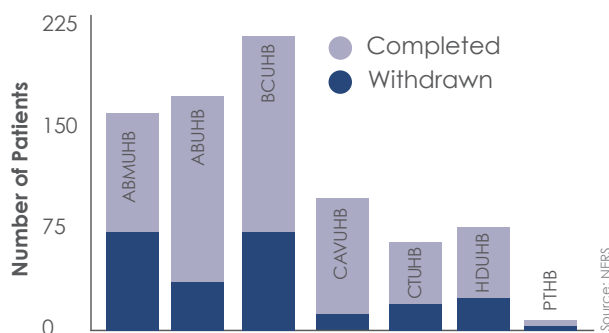


There is quite significant variation in the number of respiratory patients referred to NERS who complete the course between Health Boards. CAVUHB have a very high completion rate whereas ABMUHB has the worst completion rate (Graph 31).

NERS is an evidenced-based health intervention incorporated physical activity and behavioural change techniques to support patients to make healthy lifestyle changes to improve their health and well-being.

If NERS did not exist in its current form the lifestyle change begun by pulmonary rehabilitation would not continue and patients would become deconditioned. Without the service patients would need re-referring to PR sooner at a greater cost.

**Graph 31: NERS consultations and outcomes for Pulmonary Pathway per Health Board**



## ● ● ● Actions

### **Health Boards to work together to:**

1. Ensure people with COPD and self-reported exercise limitation (MRC breathlessness 3-5) are referred to PR and develop self-management and exercise programmes for people with an MRC score of 1-2.
2. Ensure that PR programmes can support patients with bronchiectasis or pulmonary fibrosis.
3. Improve referral rates to, and uptake of, PR programmes.
4. Ensure community and hospital-based PR providers have an adequate, long-term funding framework that will allow programmes to recruit and retain staff with an appropriate skill mix.
5. In conjunction with Public Health Wales, support the ongoing provision of the NERS programme.

### **RHIG will engage with Health Boards to:**

6. Ensure All-Wales referral pathways are developed so that all patients are offered referral to PR or other activity-based intervention.
7. Develop consistent Wales-wide outcome measures and a mechanism to collect these for use in PR, NERS, self-management and local exercise programmes.
8. Ensure PR services across Wales address variation providing access to a multidisciplinary team approach involving a range of key rehabilitation professionals such as occupational therapists, physiotherapists and exercise professionals. Teams must also ensure access to dietetic and psychological support.
9. Develop strategic use of telehealth to assist delivery of PR in rural communities.



## 21 ● Early diagnosis. Fast, effective care



### Claire Hurlin

#### Oxygen work stream lead

##### Background

Long Term Oxygen Therapy (LTOT) is a widely used treatment that improves survival in patients with (COPD) and severe hypoxaemia. Once started this therapy is likely to be lifelong. The British Thoracic Society (BTS) (2015) recommends that LTOT and any oxygen therapy prescribed for use outside of the hospital setting should only be prescribed

after appropriate assessment by a specialist oxygen service. Home Oxygen Service (HOS) Teams provides this service across Wales working in partnership with primary care, secondary care and patients themselves. Initial requests for home oxygen can be completed by any health professional on a Home Oxygen Order Form (HOOF A), but all further support specialist oxygen assessment and follow up care which must be based on the clinical standards set out by the BTS.<sup>1</sup>

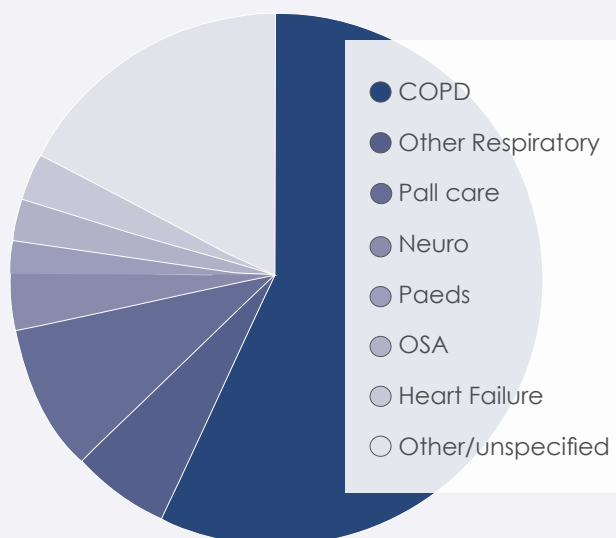
Patients across Wales should have access to standardised clinical assessment, appropriate and safely prescribed oxygen therapy and formal arrangements for follow-up care thus ensuring that the prescribed LTOT adequately corrects hypoxaemia, that there is good compliance with LTOT and other forms of oxygen therapy, to detect clinical deterioration and to ensure continuing requirement for domiciliary oxygen.

More than 50% of Home Oxygen is prescribed to patients with COPD (graph 32). Interstitial lung disease, pulmonary hypertension, cluster headaches and palliative care are other common reasons for Home Oxygen. A high proportion of patients on Home Oxygen are unspecified (18%), meaning we have no understanding what it is they have been prescribed Home Oxygen for in the first place.

Graph 32: Expenditure  
on Oxygen by  
disease category  
Wales (2016-17)

Total oxygen  
expenditure in Wales

**£4,092,000**



Source: Baywater





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### Aims

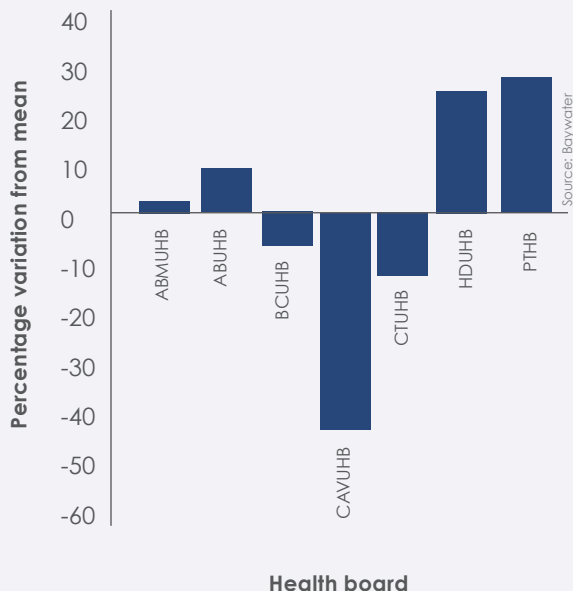
1. Providing a systematic and integrated service within each Health Board.
2. To reduce variation and poor quality of care, and strengthen affordability and value, through targeting those who benefit from home oxygen.
3. Ensure a high standard of clinical treatment and rapid diagnosis.
4. Ensure that service users have a positive experience of care.
5. Standardise training and assessment across Wales.

### Results

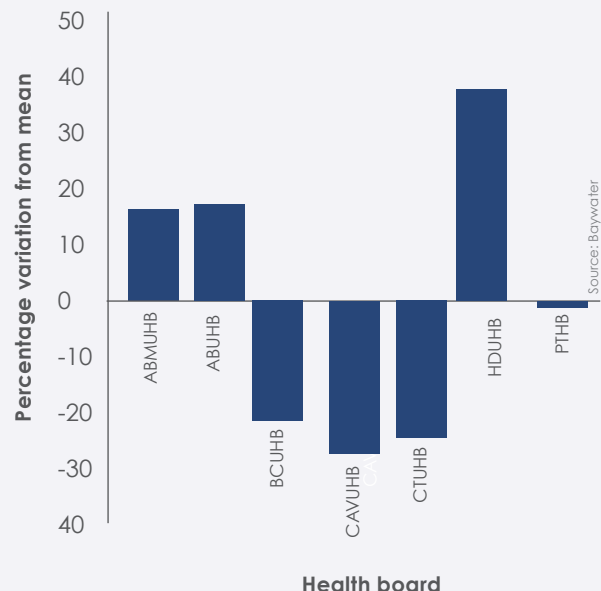
All Health Boards in Wales have HOS Teams either based in secondary or community care. These teams support people requiring home oxygen therapy on a long term basis but each service operates independently and there is wide variance between health boards in terms of spend per head of population on oxygen alone (graph 33).

There are many factors which may influence this variance, but ultimately it is getting the balance right between the risk of under prescribing and truly cost efficient practice. Understanding the causes of this variance is a crucial role of this work stream group. In doing so we can share best practice to raise standards, reduce waste and save money.

**Graph 33: Percentage variation from the mean for oxygen spend on COPD by Health Boards 2016-17**



**Graph 34: Percentage variation from the mean for oxygen spend per capita by Health Board, Wales 2017**







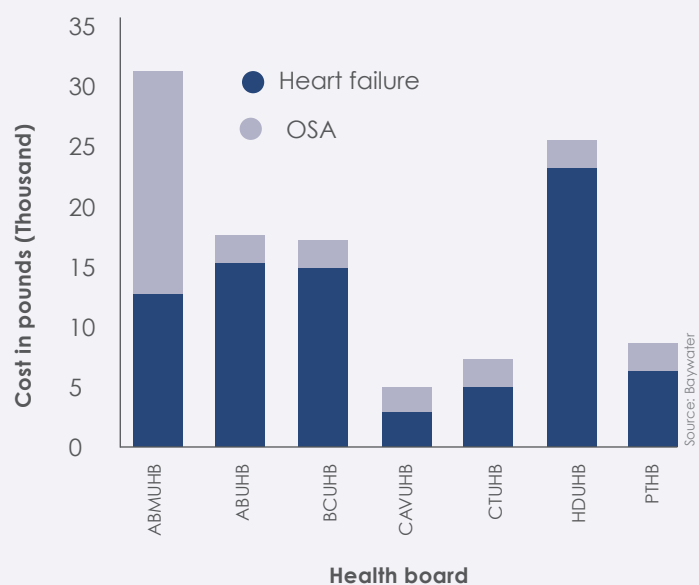
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Although the majority of spend on oxygen is for patients with COPD (graph 32), there are a number of other disease groups where oxygen is not normally considered to be a treatment unless hypoxaemia is also present, for example heart failure and OSA.

Graph 34 demonstrates significant differences in spend for these conditions across Wales. A further area of concern is the number of 'not known' and 'other' categories. More effective screening and assessment of patients is required.

### Graph 35: Oxygen spend per Health Board on Heart failure and OSA 2016-17

By utilising the BTS quality standards and examining clinical performance this will ensure a high standard of care in relation to the assessment and management of patients on home oxygen and meet the aims of the HOS network.



## ● ● ● Actions

### **Health Boards to work together to:**

1. Ensure that all oxygen prescribing is done through HOS teams across Wales.
2. Review patient outcome data collection to meet BTS Quality Standards.
3. Address inappropriate variation and support the implementation of specialist oxygen nurses

### **RHIG will engage with Health Boards to:**

4. Reduce unnecessary variation in oxygen prescribing by sharing best practice.
5. Develop All-Wales competency-based training for earlobe capillary blood gas sampling.
6. Implement an All-Wales Risk Assessment Form.
7. Develop an All-Wales Guidance of Removal of Home oxygen Policy.
8. Develop an All-Wales Patient Information Leaflet.
9. Implement an All-Wales PREM for oxygen.



## 22 ● Early diagnosis. Fast, effective care



### Aneurin Buttriss

#### Sleep services work stream lead

##### Background

Sleep disordered breathing is a common condition with the vast majority of cases due to obstructive problems, and only a minority due to intrinsic sleep problems such as narcolepsy. However, there are indeed over 70 separate sleep disorders other than sleep apnoea, such as parasomnias, restless-leg syndrome and insomnia, for example.

Sleep, even in healthy individuals, is accompanied by loss of stability of the upper airway; a phenomenon manifested most commonly by snoring which represents vibration of this unstable airway. In approximately 20-30 % of loud snorers, the pharynx may occlude periodically during sleep, resulting in recurrent pauses in breathing. These brief episodes are accompanied by increases in heart rate and blood pressure and reduction in blood oxygenation. These 'events' are terminated by transient arousals from sleep. The consequent fragmentation of sleep results in the characteristic daytime symptoms - typically those of chronic sleep deprivation.

Estimates of prevalence conducted 10-15 years ago suggest that the condition affects 2-4% of middle aged males and about one third to one half as many adult females. Recent estimates suggest that only 20-30% of affected individuals have currently been diagnosed in the UK. Untreated obstructive sleep apnoea is associated with a 5-7 fold increased risk in road traffic accidents and is independently associated with many chronic disease, so will cause or exacerbate problems such as hypertension, insulin resistance, diabetes, atrial fibrillation, risk of cardiovascular death and stroke.

Due to historical inequity of sleep provision across Wales, a strategy document was developed in 2010, outlining the recommendations for the development of a framework for sleep provision encompassing level 1, 2 and 3 services. Diagnosis and management of non-respiratory sleep disorders often requires an advanced sleep laboratory capable of performing full polysomnology (PSG) and other advanced diagnostic tests, such as the Multiple Sleep Latency Test (MSLT). However, there remains a wide variation in sleep services across Wales. Currently, data collection by Health Boards for those patients referred with possible sleep disorders is limited and incomplete and there is not an agreed national standard measure of waiting times. This has led to a variation in practice between Health Boards with some opting for time from referral to first outpatient attendance, time from referral to first



## ● Early diagnosis. Fast, effective care

test performed, or time from referral to treatment being adopted. With this varied data collection departmental performance cannot be robustly correlated across Wales.

Ultimately, the prevalence of OSA is increasing as the frequency and severity of obesity is increasing. Untreated OSA has significant morbidity and social implications, all of which can be relieved by Continuous Positive Airway Pressure (CPAP) therapy.

### Aims

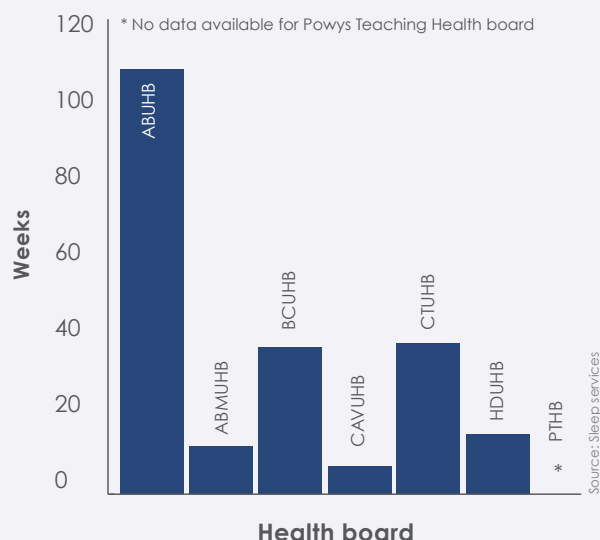
1. To reduce variation in sleep services across Wales by collecting data with a standard measure of waiting times.
2. Ensure adequate and equitable provision of workforce to deliver sleep services in every Health Board.
3. To improve provision of specialist sleep services.
4. Improve the efficiency of the patient pathway from referral to treatment.

### Results

There is currently no data available from PTHB. There are no services for the management of patients with sleep disordered breathing in PTHB, with patients being referred to centres in HDUHB, BCUHB and England. Data for all other HB was provided by contacting local sleep departments. At the time of data collection only maximum waiting time from referral to CPAP setup were collected. Across Wales, the waits ranged from 6 weeks in CAVUHB to 108 weeks in ABUHB.

This significant difference in waiting times reflects a different service model, with most patients in ABUHB being seen by a consultant. All other HB offer variations on an MDT approach, where most patients progress through a sleep algorithm with only a minority of patients requiring OP consultant review. (graph 36).

**Graph 36: Waiting time in weeks from referral to treatment per Health board**



With the exception of ABUHB all patients requiring CPAP setup for OSA were treated before 40 weeks with ABMUHB, HDUHB and CAVUHB patients being treated within 16 weeks.

### ● ● ● Actions

#### **Health Boards to work together to:**

1. Ensure data is provided for referral to treatment times.
2. Support sleep services as laid out by the Welsh Sleep Strategy document.

#### **RHIG will engage with Health Boards to:**

3. Develop an All Wales MDT approach to sleep patients with a standard proforma. Those areas employing an MDT approach to the assessment of sleep patients had significantly lower waiting times than those adopting a tradition model of assessment.
4. Identify staff numbers dedicated to sleep per local capita.
5. Continue to monitor and track performance by Health Board and feedback to local clinical and management teams.
6. Develop a National database for sleep.
7. Work with NWIS and Welsh Government to pilot the inclusion of diagnostic tests within the diagnostic and therapies return.



## 23 ● Early diagnosis. Fast, effective care



### Sara Fairbairn Non-invasive ventilation work stream lead

#### Background

Non Invasive Ventilation (NIV) has significant evidence for use in the acute setting and in the domiciliary setting in appropriately selected respiratory patients. The All Wales NIV group has previously developed guidelines for acute NIV, which have been adopted across all acute hospitals in Wales. Guidelines for chronic NIV have also been written for those with COPD, neuromuscular disease, obesity and chest wall disease.

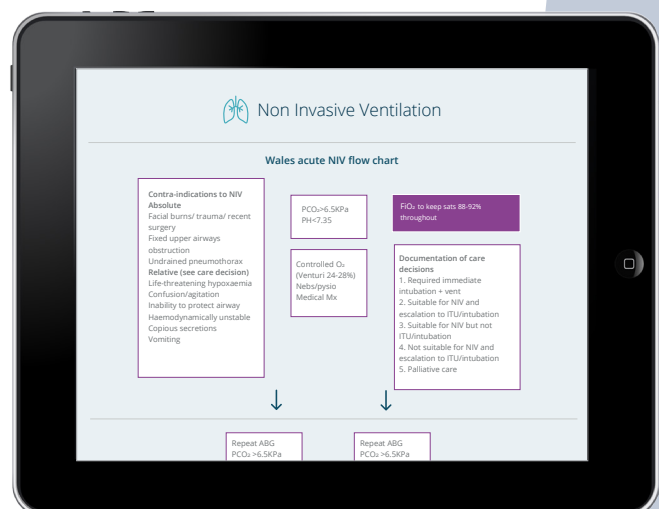
In the acute setting evidence supports the use of NIV in a selected proportion of those admitted with Acute Hypercapnic Respiratory Failure (AHRF). In relation to provision of the acute NIV service, the NCEPOD (National Confidential Enquiry into Patient Outcomes and Deaths) have recently published a report highlighting the inconsistencies in service provision and patient outcomes and suggested areas of development that need to be addressed.<sup>1</sup> The provision of ward based NIV in Wales is poor with only one appropriately staffed unit currently in operation in Newport.

The numbers of patients on long term NIV are increasing as the evidence supports the use of this treatment modality. This includes those with

severe COPD, with recent research highlighting the survival benefit that treatment can offer. Patients with neuromuscular disease such as those with muscular dystrophies and motor neurone disease require complex multi-disciplinary care and coordination to achieve good outcomes. There is wide variation in the availability of specialist respiratory nurses or physiotherapists to support patients with domiciliary NIV. This is a crucial issue as these specialist teams can often manage patients in the community and avoid lengthy admissions to hospital. Achieving an equitable and suitably trained workforce to safely deliver NIV in the acute and chronic settings are key aims of this work stream.

#### Aims

1. Support the development of ward based NIV units in larger hospitals in Wales to comply with NCEPOD guidance.
2. Disseminate the acute and chronic NIV guidelines.
3. Develop a national NIV database to capture the acute and chronic NIV demand and inform workforce development.
4. Standardise NIV equipment (interfaces and machines) and go through national procurement process.



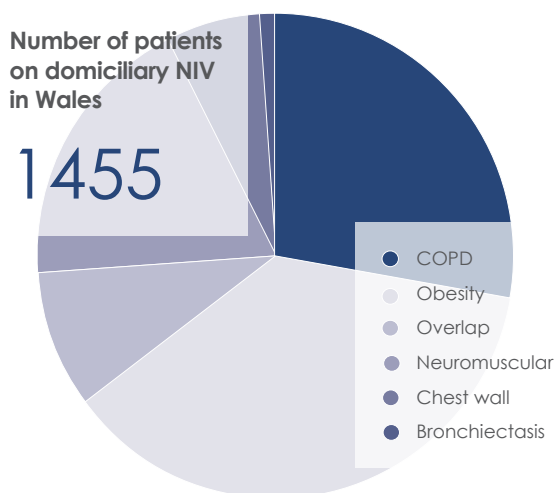




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## Results

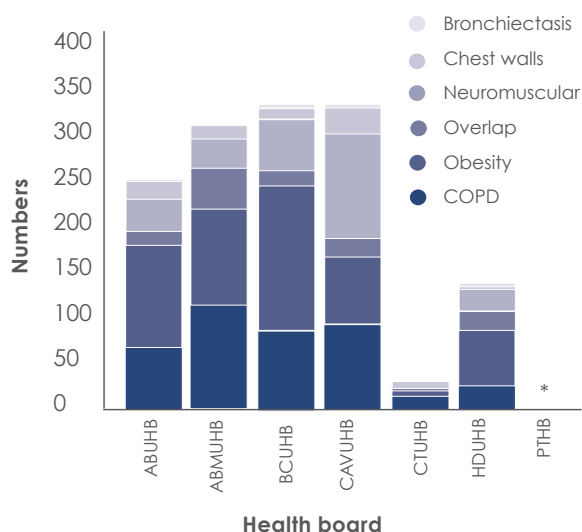
**Graph 37: Numbers of patients on long term NIV by disease category, all Wales (2017)**



There has been a significant increase in the provision of domiciliary NIV across Wales, with 1,455 patients having this treatment. Obesity and overlap syndrome (obesity and COPD) together account for 46% of all patients.

**Graph 38: Numbers of long term NIV patients by disease category and Health Board (2017)**

\* No data available for Powys Teaching Health board



There is a significant variation in the proportions of patients being managed on NIV by disease category in different Health Boards.

For example, 52% of patients in BCUHB had obesity or overlap syndrome as a cause for NIV in BCUHB, more than any other Health Board. In CAVUHB there are a high proportion of neuromuscular patients on NIV but 39% of these are from other Health Board.

CTUHB have small numbers of patients on long term NIV for their population size despite high rates of smoking, and deprivation. It is likely that there are multiple factors to account for these variations beyond that of differences in disease prevalence between the Health Board.



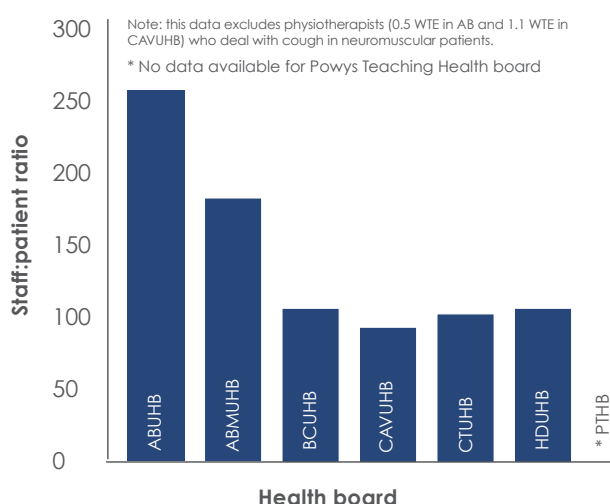


## Early diagnosis. Fast, effective care

**Table 3. Whole time equivalent (WTE) nurse, physiotherapy and physiologist support for domiciliary NIV by Health Board, Wales (2017)**

Health board	WTE respiratory nurses	WTE physiotherapists	WTE Physiologists	Ratio staff: patient
ABUHB	0.5	0.5	0.5	260
ABMUHB	1.7	0	0	185
BCUHB	3.2	0	0	107
CAVUHB	3.6	1.1	0	95
CTUHB	0.3	0	0	103
HDUHB	1.1	0	0.2	108
PTHB	0	0	0	N/A

**Graph 39. Staff: patient ratios for long term ventilated patients by Health Board, Wales, (2017)**



There is a wide variation in dedicated nurse or other HCP support for domiciliary NIV across different HB. CAV is the best supported with a staff: patient ratio of 95, including 1.1 WTE dedicated physiotherapy support for neuromuscular patients. ABUHB had the highest staff:patient ratio of 260. Having adequate specialist support enables home setup on NIV and rapid review of patients in the community to prevent hospital admissions. The variation in workforce needs to be addressed to help develop home ventilation equitably across Wales and support the wider range of problems associated with complex NIV patients such as those with neuromuscular disease.

## ●●● Actions

### **Health Boards to work together to:**

1. Ensure major hospital NIV units comply with NCEPOD standards.

### **RHIG will engage with Health Boards to:**

2. Develop an All-Wales business case to support the implementation of the NIV NCEOPD recommendations for acute NIV.
3. Standardise training provision and competency based assessment for NIV.
4. Standardise equipment and allow national procurement with an All-Wales model.
5. Develop a 'Domiciliary NIV' Service model to support service development in line with predicted expansion in community service provision.
6. Develop a All-Wales database for patients on acute and domiciliary NIV.



## 24 ● Early diagnosis. Fast, effective care



### Mel Jefferson Palliative care work stream lead

#### Background

Palliative care has been defined by the World Health Organization as 'an approach that improves the quality of life of patients and their families facing the problems associated with life limiting illness, through the prevention of, and relief of, suffering, by means of early identification and impeccable assessment and treatment of pain and other problems, physical and spiritual.'

Palliative care differs in philosophy from curative strategies in focusing primarily on the consequences of a disease rather than its cause or specific cure. Approaches are therefore necessarily holistic, pragmatic and multidisciplinary. The approach therefore complements other treatments; it does not substitute for or replace them.

Palliative care is not synonymous with end of life care and patients may benefit from support from palliative care at different stages of their illness. Many however may be referred in the latter stages of their illness and the End of Life Care delivery plan highlights some of the priorities of care that are important at such a time.

Whilst some patients may require the support of specialist palliative care teams, many may continue to receive palliative care from their existing respiratory team with advice if required.

#### Aims

1. To enable patients to make informed decisions and choices of end of life care.
2. To Improve staff communication skills to enable discussions about end of life.
3. To ensure those with advanced COPD, and those close to them are identified and offered palliative care at an appropriate time.<sup>1</sup>

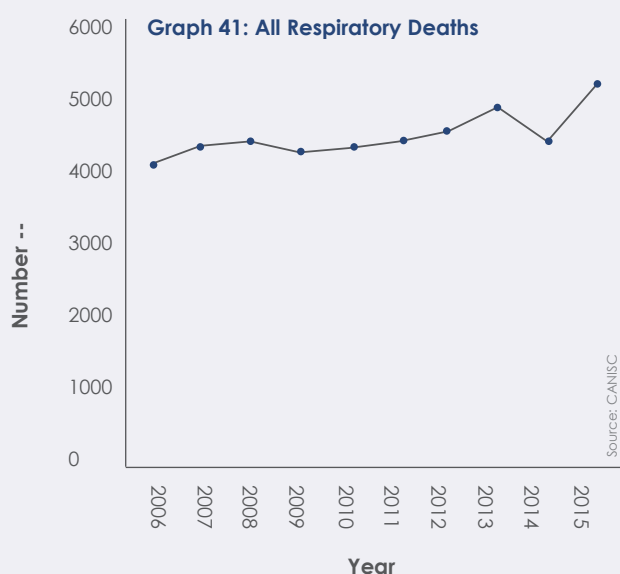
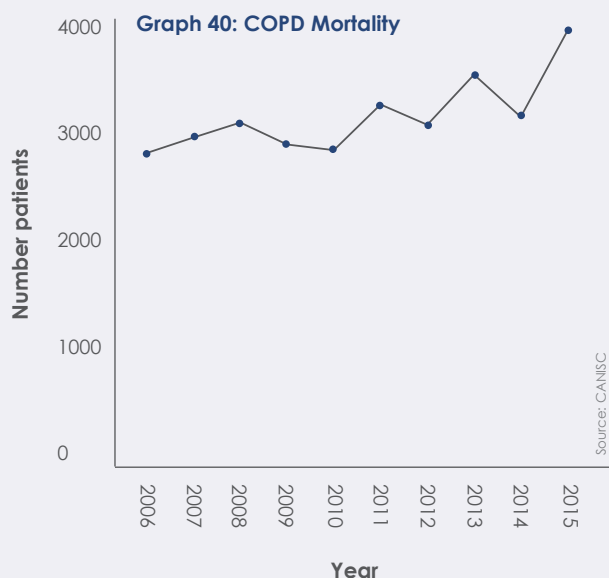




## Early diagnosis. Fast, effective care

### Results

It is estimated that 0.75% (23,000) of the overall population in Wales have palliative care needs at any one time and the number of people dying each year continues to increase. This means that we will see more people living with multi-morbidity and frailty, not necessarily following a typical or predictable trajectory towards death.



In Wales, approximately 33,000 people currently die each year, and it is estimated that 75% of these will require either end of life or palliative care at some level. While the Welsh population overall is due to increase by less than 6%, the number of people aged 65 and over is projected to increase by 37.2% by 2039. This means that in 2039, the number of deaths each year is predicted to increase by about 15%. As people live longer, they tend to develop multiple, complex health conditions.

Patients are far more likely to receive specialist palliative care if they have a cancer diagnosis than if they are terminally ill with a non-cancer diagnosis. In 2015-16, 51.9% of people who died from cancer received specialist palliative care compared with 16.7% of those who died from another illness. However this demonstrates some changes from 2014-15 when just over 15% of patients with a non-cancer diagnosis received specialist palliative care. However not all people towards the end of their lives will require specialist palliative care. Even taking this into account, the number of all expected non-cancer deaths accessing specialist care is low (16.7%) and continuing efforts are needed to ensure that specialist palliative care is accessed fairly and appropriately by non-cancer patients.

### ● ● ● Actions

#### **Health Boards to work together to:**

1. Continue to promote discussions concerning advanced care planning for respiratory patients who may be entering a more palliative phase of their illness.
2. Increase the use of advance care plans that are easily available for all health professionals in different health settings to find.
3. Ensure that respiratory teams alert primary care to those patients with advancing COPD to ensure they are included on the GP palliative care register and receive appropriate support.



## Simon Barry

**Clinical lead,  
Respiratory Health  
Implementation Group**

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A key aspect of the respiratory plan is information sharing and pathway standardisation. Once we have developed All Wales pathways and guidelines for cough, NIV, COPD and asthma prescribing amongst others, these need to be hosted on a single site, linked to the Welsh Clinical Portal. They will be accessible in an App format from any desktop computer, tablet or smartphone. The guidelines will be supplemented by a range of educational videos explaining, for example, how to use different inhalers, how to insert a chest drain or how to take ear lobe blood gases.

Working with the Institute of Clinical Science and Technology, the RHIG has successfully adapted spirometry training into a flexible, accessible programme for the ARTP and this is going to be the model adopted in England. We intend using a similar process to standardise training and competencies for a range of other interventions such as performing ear lobe blood gases, setting up non-invasive ventilation, performing talc pleurodesis and many more. All of this will be hosted through the same platform, linked to the RHIG.

We recognise the need to develop disease-specific databases for a number of conditions. Foremost amongst these will be asthma, COPD, ILD and NIV. These will be designed and constructed by close collaboration with NWIS, ensuring that the data generated is primarily to inform clinical decision making and drive best practice. Lastly, we aspire for respiratory medicine to be at the forefront of developing patient facing interfaces, allowing patients access to important information about their disease and helpful resources but also having the ability to input data themselves relevant to particular databases.



## 26 ● Case study



### Derek Cummings A patient's story

**The vast majority of patients will use technology, and find the use of technology very convenient, and educational. The hope is that we can educate the patient, and help him or her to lead a better more fulfilling life, and that by education it will enable the patient to stay out of hospital, and become more active. Age is not a barrier for most. I find the use of technology an exciting challenge and one that has the opportunity to offer many advantages.**

Indeed the use of technology is paramount in advancing patient knowledge, and understanding of their condition. Technology in health is already finding many avenues that both help the patient, and the clinician. I use an app on my phone to record my blood pressure for instance. Plus have managed to do a short ecg using an app on my smart phone that was correct in showing my persistent AF.





## 27 ● Targeting respiratory research



### Keir Lewis

#### **Professor in Respiratory Medicine Health and Care Research Wales specialty lead for respiratory medicine**

This has been the best year so far regarding respiratory research activity in Wales. Our population of over 3 million remains largely untapped for research and we are remarkably stable genetically allowing unique opportunities for new genomics work.

Importantly Wales offers a single point of contact for R&D approvals and there is no purchaser-provider split, meaning a single R&D contract covers Primary and Secondary Care in the same region. This has proved attractive to several large pharmaceutical and industrial companies, including large investment from Pfizer, Siemens and Fujitsu.

Our Welsh Respiratory Research Group has evolved since starting in 2005 with 2017 having the highest respiratory research grants capture and most Chief Investigators and Principal Investigators. We now have access to specialist facilities supporting commercial and portfolio recruitment in Wales including:

- First-in-human and drug development e.g. see [www.simbecorion.com](http://www.simbecorion.com), the JCRF in Swansea
- University and Cardiff University Trials Unit.
- Genomic/metabolomic/proteomic/lipidomic profiling in lung disease e.g. [www.aber.ac.uk/en/ibers/](http://www.aber.ac.uk/en/ibers/) (Aberystwyth University).





## Targeting respiratory research

- Advanced lung physiology (Bangor and Cardiff Metropolitan Universities).
- Access to the SAIL databank providing linkable, anonymized datasets on billions of person based records now covering 75% of General Practices, through a unique Gateway platform, complete with analysis tools (Swansea University) see [www.saildatabank.com](http://www.saildatabank.com)
- Farr Institute @CIPHER (Centre for Improvement in Population Health through E-records – Research) (Swansea University)
- Innovation Campus (Cardiff University) see [www.cardiff.ac.uk/innovation/campus-investment](http://www.cardiff.ac.uk/innovation/campus-investment)
- An industry facing centre /meeting Place: Life Sciences Hub Wales [www.lifescienceshubwales.com/contact](http://www.lifescienceshubwales.com/contact)

There are currently 28 respiratory commercial trials recruiting over 550 NHS patients with state-of-the-art respiratory drugs in Wales (Summer 2017), particularly in COPD, asthma and lung cancer. Trial performance data are available

through Health Care Research Wales and each Health Board's R&D department.

Cardiff is the regional centre for adult cystic fibrosis, however, we have large untapped bronchiectasis, COPD and idiopathic pulmonary fibrosis populations across Wales and we are starting work as networks with industry to expand our portfolio in these other respiratory disease areas.

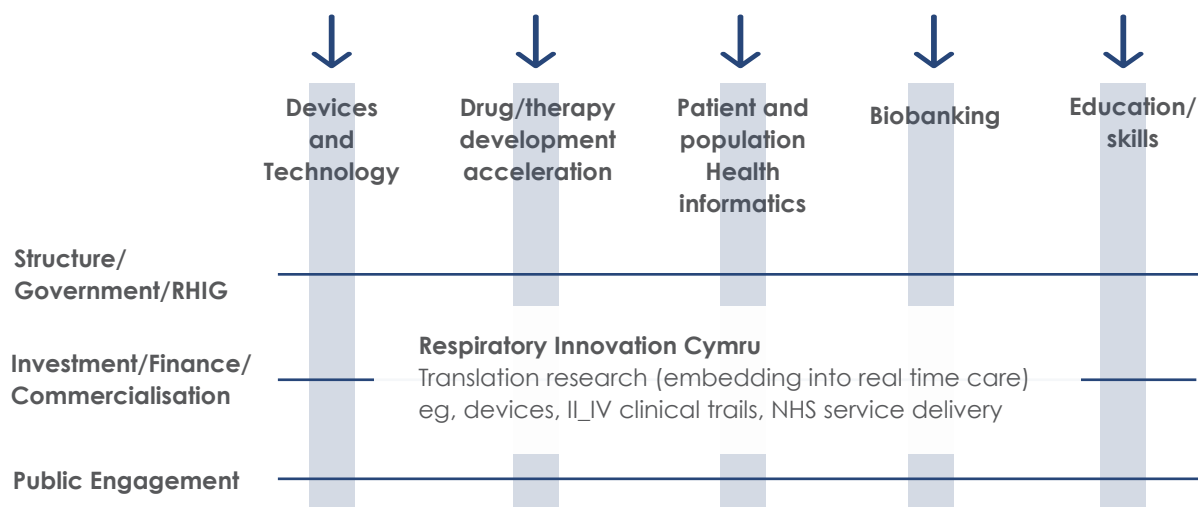
Most excitingly, we submitted a 5-year business plan in October 2017 for a £5m Respiratory Innovation Centre to be run by an independent (not for profit) Ltd company with specialist teams for Medical Tech /Devices, Therapeutics (drugs and specialist treatments), Population Health Informatics and Biobanking.

This initiative has been strongly supported especially by RHIG but also by all Welsh Universities, the NHS, Industry and Welsh Thoracic Society. So far encouraged by Welsh Government, we hope to hear a response by early 2018.



### Discovery research (university and specialist centres)

E.g. first human molecule discovery, hypothesis generation. Using collective strength to win grant income and address gaps.





## 28 ● Delivery plan implementation



### Rhys Jefferies

#### Plan monitoring lead

You will have seen from this plan that a lead for each work stream has been nominated together with stakeholders from across Wales, including primary care and third sector representation. The work stream list is not exhaustive and further groups will inevitably develop where variation in practice exists, such as pneumonia management and antibiotic prescribing, for example. Work streams have been developed as a body of experts to develop metric criteria, all of which are listed in the appendices, but also to analyse the data and provide recommendations and feedback. Performance metrics should simplify the reporting process and focus the annual reports into key outcome goals that can be compared across the different Health Boards. Conceptually, this has been illustrated throughout this document.

The data and recommendations will be presented as the interim report in the summer, and an annual performance report in the winter. We will also deliver key messages through short videos, patient stories and case studies of good practice, as well as further additions to the RHIG documentary series, workshops across Wales and the National Respiratory Education Programme, which will all help improve the skills and knowledge necessary to make safe and effective changes to service delivery.

Without positive engagement from the wider workforce, we simply cannot accomplish the RHIG vision. Nor can we make the real cost-savings and reinvestment that we have set out to achieve. This reporting structure and communication strategy should empower clinicians and managers at all levels across Wales to help make informed changes to service provision, offer a conduit to highlight good news stories and provide mechanisms to share best practice with the rest of Wales.



## Simon Barry

**Clinical lead,  
Respiratory Health  
Implementation Group**

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**The RHIG offers an exciting opportunity to fully engage the respiratory community in Wales in a shared agenda for improving respiratory care for our patients. The work stream papers demonstrate the breadth and depth of this engagement, although we recognise we need to do more to bring primary care physicians on board and that is something that we will focus on going into the future.**

We want to utilise a systems based approach to deliver these improvements focussing on treatments that produce the greatest value and on reducing inappropriate variation. It is likely that this will result in a rebalancing of resources towards supporting specialist nurses working in the community to deliver respiratory care and reduce hospital admissions and unnecessary cost. Highlighting variation is the crucial lever to gain support for such changes.

We are aware of the need to create a document that has clear aims, presents relevant data and reflects the agenda of the respiratory community. We hope that has been achieved. However, a document like this is only part of the strategy for communication. Accompanying it will be a documentary linking strategy with patient stories and this will be available on a dedicated RHIG internet-based tv channel. We will build guidelines, educational resources and databases within the same IT platform. This will be a powerful tool to educate and create competencies for all in the respiratory community as well as laying the foundations for real world research at a national level, primarily driven by the desire to find what treatments or interventions work best for our patients.



# 30 ● Appendices

## Vaccination Work stream

### Members

**Dr. Marion Lyons** (National Public Health Service Wales)

**Dr. Simon Cottrell** (PHW)

### Metric data

1. Influenza uptake for high risk patients (6 months to 64 years) and proportion to respiratory.
2. Influenza uptake for NHS staff and proportion on respiratory wards.
3. Influenza uptake for COPD and asthma as a percentage.

## Smoking Work stream

### Members

**Prof. Keir Lewis** (H DUHB)

**Dr. Simon Barry** (CAVUHB)

**Dr. Anna Lewis** (CTUHB)

**Dr. Katie Pink** (CAVUHB)

**Helen Poole** (CAVUHB)

**Cath Einon** (H DUHB)

**Dawn Davies** (H DUHB)

**Rebecca Evans** (PHW)

**Margaret Munkley** (PHW)

**Trina Nealon** (PHW)

**Delyth Jones** (BCUHB)

### Metric data

1. Performance target on smoking cessation.
2. Number and percentage of smokers referred for a quit attempt as a percentage of all smokers.
3. Use of CO monitors for secondary care smoking cessation services.
4. CO validated quit rates at 4 weeks for all smoking cessation providers.
5. CO validated quit rates at 52 weeks for all smoking cessation providers.
6. Number of prescriptions of combined NRT (+/- Verenciline) for patients admitted to hospital who smoke.

## Paediatrics Work Stream

### Members

**Dr. Iolo Doull**

### Metrics Data

1. Bronchiolitis admissions per Health Board
2. Paediatric asthma admissions per Health Board

## COPD Work Stream

### Members

**Dr Ramsey Sabit** (CAVUHB)

**Dr Paul Neill** (CTUHB)

**Dr Aneurin Buttfress** (CAVUHB)

**Louise Walby** (CTUHB)

**Jackie Reynolds** (ABUHB)

**Clare Hurlin** (H DUHB)

**Dr Jerome Donagh** (ABMUHB)

**Dr Ruth Williams** (ABUHB)

**Joseph Carter** (BLF)

**Dr. Anna Lewis** (CTUHB)

### Metric data

1. Percentage of COPD patients with obstructive spirometry.
2. Number of primary care and secondary care services with ARTP spirometry qualified practitioners.
3. Presence of early supported discharge and number of those supported discharges per health board.
4. Median length of stay for COPD patients per health board.
5. Prevalence of hospital admission ratio per practice or cluster.
6. Presence of accelerated pulmonary rehab programme for patients recently admitted to hospital with exacerbation.
7. Availability of secondary care based advice or telephone advice service for the benefit of primary care.

## Asthma Work Stream

### Members

**Dr. Katie Pink** (CAVUHB)

**Dr. Richard Robinson** (H DUHB)

**Dr. Livingstone Chishimba** (CAVUHB)

**Dr. Daniel Menzies** (BCUHB)

**Dr. Gwyneth Davies**

**Dr. Alison Whittaker** (ABUHB)

**Dr. Shehnoor Tarique** (CTUHB)

**Dr. Michael Pynn** (ABUHB)

**Dr. Jacqueline Wooley** (ABMUHB)

**Dr Sinan Eccles** (CTUHB)

**Daisy Ellis** (Asthma UK)

**Jackie Reynolds** (ABMUHB)

**Claire Williams** (ABUHB)

### Metric data

1. Asthma mortality rate.
2. Asthma hospital admission rate.
3. Percent of patients receiving annual asthma review.
4. Percent of patients with an asthma action plan.



## Appendices

5. Number of patients receiving more than 12 reliever inhalers per year without asthma review.
6. Number of patients on asthma register with >80% adherence with ICS.
7. Participation in national audit (and results of audit).
8. Percent of patients on asthma register receiving high dose ICS versus low dose ICS.
9. Access to dedicated asthma specialist nurse in secondary care.
10. Number of primary care healthcare professionals carrying out asthma reviews who have had specialist training in asthma.
11. Number of patients on biological agents (omalizumab, mepolizumab, relisumab).
12. Number of patients referred to secondary care with uncontrolled asthma and referral to treatment times.
13. Number of patients discussed at All Wales MDT.
14. PROMS implementation Nationally using ACQ6/7 and mini AQLQ.

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### Cough Work Stream

#### Members

**Dr. Martha Scott** (ABUHB)  
**Dr. Claire Killduff** (BCUHB)  
**Dr. Nicola-Xan Hutchinson** (ABMUHB)  
**Helen Fowles** (ABMUHB)  
**Kirsty Hett** (CAVUHB)

#### Metric data

1. Number of referrals for chronic cough per Health Board.

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### Interstitial Lung Diseases Work Stream

#### Members

**Dr. Ben Hope-Gill** (CAVUHB)  
**Dr. Kim Harrison** (ABMUHB)  
**Dr. Mat Jones** (ABUHB)  
**Dr. Mark Steele** (BCUHB)  
**Pam Lloyd** (BCUHB)  
**Dr. Robin Goshal** (HDUHB)  
**Dr. Paul Neill** (CTUHB)  
**Julie Hocking** (CAVUHB)  
**Doria Barbonchielli** (CAVUHB)  
**Cheryl Roberts** (ABMUHB)

#### Metric Data

The following metrics aim to measure the quality of ILD service provision:

1. Referral to treatment times
2. MDT discussion rates
3. Palliative Care referral rates
4. Pulmonary Rehab referral rates
5. Access to ILD CNS support
6. Referral to lung biopsy times

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### Tuberculosis Work Stream

#### Members

**Dr Simon Barry** (CAVUHB)  
**Liz Weeks** (CAVUHB)  
**Yvonne Hester** (CAVUHB)  
**Karen Baker** (CAVUHB)  
**Pam Lloyd** (BCUHB)  
**Steve Kelly** (BCUHB)  
**Ashan Mugha** (ABUHB)  
**Linzi Johnson** (ABMUHB)  
**Natalie Murray** (ABMUHB)  
**Melissa Hack** (ABUHB)  
**Rhian Bunce** (ABUHB)  
**Carol Llewellyn Jones** (HDUHB)  
**Debbie Hartman** (HDUHB)  
**Gwen Lowe** (CCDC)  
**Sion Lingard** (PHW)  
**Nic Hathway** (PHW)  
**Ceri Harris** (PHW)  
**Gary Porter-Jones** (BCUHB)  
**Matt Backx** (CAVUHB)  
**Sue Morgan** (PHW)  
**Janis Downs** (CTUHB)  
**Helen Ryan** (CTUHB)  
**Michael Ruddy** (ABMUHB)  
**Rhian Williams** (CTUHB)  
**Ian Campbell** (CAVUHB)

#### Metric data

1. Number of cases by HB.
2. Percentages of case reported at cohort review.
3. Compliance with cohort recommendations.

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### Chronic Lung Sepsis Work Stream

#### Members

**Dr. Jamie Duckers** (CAVUHB)  
**Dr. Carol Llewellyn-Jones** (HDUHB)  
**Tom Lines** (CAVUHB)



## Appendices

**Donna Akers** (CAVUHB)  
**Rebekah Mills Bennett** (H DUHB)  
**Dr. Rishi Dhillon** (PHW)  
**Dr. Dawn Lau** (CAVUHB)

### **Metric data**

1. Benchmarking across BE services in Wales to be updated and against tertiary UK centres.
  2. Diagnosis of bronchiectasis confirmed by CT chest (using 1mm slices).
  3. Percentage of patients taught appropriate airways clearance techniques by a specialist respiratory physiotherapist.
  4. Percentage of bronchiectasis patients having sputum bacteriology culture when clinically stable recorded at least once each year.
  5. Number of referrals and attendances to PR.
  6. Percentage of bronchiectasis patients with individualised written self-management plan.
- 

## Pleural Disease Work stream

### **Members**

**Dr. Alina Ionescu** (ABUHB)  
**Dr. Daniel Menzies** (BCUHB)  
**Dr. Ali Thahseen** (BCUHB)  
**Dr. Mark Andrews** (H DUHB)  
**Dr. Shehnoor Tarique** (CTUHB)  
**Dr. Sinan Eccles** (CTUHB)  
**Dr. Sherouk El-batrawy** (CTUHB)  
**Dr. Emma Watkins** (ABMUHB)  
**Dr. Amit Benjamin** (ABMUHB)  
**Dr. Michael Pynn** (ABUHB)  
**Dr. Nicola Pring** (ABMUHB)  
**Clare Chaplin** (ABUHB)  
**Dr. Helen Davies** (CAVUHB)  
**Artemio Gonzales** (ABUHB)  
**Jane Whittingham** (CAVUHB)

### **Metric data**

1. Number of cases referred for opinion and advice to the WPIG.
2. Number of empyema cases referred to surgery.
3. Days wait to surgery for empyema cases.
4. Outcome of surgery for empyema (conservative management or intervention).
5. Number of patients with pneumothorax referred to surgery.
6. Days wait to surgery for pneumothorax cases.

7. Outcome of surgery for pneumothorax cases (conservative management or intervention).

Metric data will be obtained from individual Health Boards and from the 2 thoracic surgical centres in Wales.

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## Lung Cancer Work stream

### **Members**

**Dr. Ian Williamson** (ABUHB)  
**Dr. Diane Parry** (CAVUHB)  
**Dr. Dyfed Huws** (PHW)

### **Metric data**

1. Survival rates.
  2. Proportion undergoing surgery.
  3. Proportion undergoing radical radiotherapy/ chemotherapy.
  4. Stage at diagnosis.
  5. Proportion with histological confirmation.
- 

## Outpatients Work Stream

### **Members**

**Dr. Simon Barry** (CAVUHB)

### **Metric data**

1. Waiting times for respiratory medicine.
  2. Wait times over 24 weeks.
  3. DNA rates.
- 

## Pulmonary Rehabilitation Work Stream

### **Members**

**Nicola Perry-Gower** (ABMUHB)  
**Pip Ford** (CSP)  
**Claire Hurlin** (H DUHB)  
**Jeannie Wyatt-Williams** (NERS)  
**Lynda Rees** (ABUHB)  
**Michelle Owen** (BCUHB)  
**Rachel Knight** (H DUHB)  
**Dr. Stuart Gray** (CAVUHB)  
**Tom Lines** (CAVUHB)  
**Jane Mullins** (CAVUHB)



## Appendices

**Carol Anne Davies** (H DUHB)

**Hilary Mott** (CTUHB)

**Andrew Colwill** (PTHB)

**Joseph Carter** (BLF)

### **Metric data**

1. Pulmonary rehabilitation is offered according to British Thoracic Society guidelines.
2. Pulmonary rehabilitation is offered in a primary care/ community setting.
3. Numbers and percentage of all COPD patients referred for rehab.
4. Numbers and percentage of MRC dyspnoea level 3 to 5 patients referred for rehab that attend.
5. Numbers and percentage of MRC dyspnoea level 3 to 5 patients referred for rehab that complete.
6. Numbers of COPD patients attending PR with MRC dyspnoea scores of 5.
7. Wait for all patients attending PR.
8. Wait for patients recently admitted with exacerbations attending PR.
9. Numbers and percentages of patients with COPD referred to NERS.
10. Number and Percentage of patients who complete pulmonary rehab who are referred to NERS.
11. Numbers and percentage of COPD patients referred to NERS that attend.
12. Number and percentage of patients who are referred to NERS and complete the programme.
13. Description of available NERS services.
14. Number of ILD patients referred for rehab that attend as a percentage of all referrals that attend.
15. Number of ILD patients referred for rehab that complete as a percentage of all referrals that complete.
16. Number of bronchiectasis patients referred for rehab that attend as a percentage of all referrals that attend.
17. Number of bronchiectasis patients referred for rehab that complete as a percentage of all referrals that complete.

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## Oxygen Work Stream

### **Members**

**Claire Hurlin** (H DUHB)

**Amanda Cullen** (CAVUHB)

**Caroline Rowlands** (CAVUHB)

**Ceri Gambold** (CAVUHB)

**Cheryl Owen** (ABMUHB)

**Claire Griffiths** (CTUHB)

**Coral Wood** (ABUHB)

**Corynne Piper** (ABUHB)

**Dawn Harry** (ABMUHB)

**Hayley McAuley** (H DUHB)

**Helen Jones** (CTUHB)

**Janet Roberts** (BCUHB)

**Jenny Brooks** (BCUHB)

**Kim Ash** (BCUHB)

**Kirsty Evans** (BCUHB)

**Kylie Smith** (H DUHB)

**Lavina Stallard** (PTHB)

**Lisa Rose** (BCUHB)

**Louise Eynon** (ABUHB)

**Louise Walby** (CTUHB)

**Lynda Rees** (ABUHB)

**Melanie Nicholas** (ABUHB)

**Michelle Davies** (ABMUHB)

**Natalie Jones** (ABUHB)

**Olwen Davies** (BCUHB)

**Pat Clark** (H DUHB)

**Sam Jones** (ABUHB)

**Sam Williams** (BCUHB)

**Sharon Hughes** (BCUHB)

**Sian Margetts** (ABUHB)

**Tanya Howells** (H DUHB)

**Zoe Lee** (CTUHB)

### **Metric data**

1. Expenditure per disease category.
2. Spend per head.
3. Spend on Heart failure and OSA.
4. Number inappropriate referrals (unknown and other).

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## Sleep Service Work Stream

### **Members**

**Dr. Aneurin Buttreff** (CAVUHB)

**Dr. Jose Thomas** (ABUHB)

**Dr. Amit Benjamin** (CTUHB)

**Jeanette Richards** (ABUHB)

**Dr. Liz Brohan** (BCUHB)

**Helen Griffiths** (BCUHB)

**Prof. Keir Lewis** (H DUHB)

**Julia Roberts** (BCUHB)

**David Clough** (BCUHB)

**Lois Penhaligan** (CAVUHB)

**Hannah Hunt** (CAVUHB)



## Appendices

### **Metric Data**

1. Present waiting times from time of referral to initial consultation or sleep related test.
  2. Referral to treatment time.
  3. Present waiting times from point of initial referral to sleep service e.g. GP to patient setup with continuous positive airway pressure devices in Obstructive Sleep Apnoea patients.
  4. Present data on the number of patients referred with a potential sleep disorder.
  5. Present data on DNA rates.
  6. Present data on the sleep diagnosis prevalence.
  7. Present compliance data in OSA patients (defined as  $\geq 4$  hours for  $\geq 70\%$  nights) at 3 months and one year with subjective measurements of sleepiness.
- 

## Non-Invasive Ventilation Work stream

### **Members**

**Dr. Sara Fairbairn** (ABUHB)  
**Joe Annandale** (HCUHB)  
**Dr. Simon Barry** (CAVUHB)  
**Dr. Chris Subbe** (BCUHB)  
**Julia Roberts** (BCUHB)  
**Sam Jones** (ABUHB)  
**Dr. Anna Lewis** (CTUHB)  
**Joe Annandale** (HCUHB)  
**Pam Lloyd** (BCUHB)  
**Dr. Flavas Thaivalappil** (ABMUHB)  
**Alice Richards** (CAVUHB)  
**Gareth Dyton** (CAVUHB)  
**Chris Powell** (CAVUHB)  
**Andrew Bishop** (CAVUHB)  
**Sam Jones** (ABUHB)  
**Kate Jones** (ABMUHB)  
**Cheryl Owen** (ABMUHB)  
**Jacqueline Woolley** (ABMUHB)  
**Rebecca Heathcote** (ABMUHB)  
**Liz Brohan** (BCUHB)  
**Laura Bryant** (BCUHB)  
**Michelle Davies** (ABMUHB)  
**Linzi Johnstone** (ABMUHB)  
**Stuart Packham** (ABMUHB)

### **Metric data**

1. Numbers of patients on long-term ventilation by disease category.
2. Description of workforce dedicated to NIV.
3. Number of acute NIV admissions by health board.

## Palliative care work stream

### **Members**

**Anthony Byrne** (CAVUHB)  
**Mel Jefferson** (CAVUHB)

### **Metric data**

1. Number of CODP referrals
  2. Number ILD referrals
- 

## Plan monitoring

### **Members**

**Rhys Jefferies** (RHIG)  
**Pam Lloyd** (CTUHB)  
**Linos Thomas** (BCUHB)  
**Claire Hurlin** (HCUHB)  
**Sophie Lloyd** (PTHB)  
**Fiona Hughes** (ABMUHB)  
**Ali Gough** (ABUHB)





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