OSA: the experts' viewpoint

CONFERENCE REPORT

February 1st 2014

Blackpool Hilton Hotel

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Executive summary

Up to two per cent of middle-aged women and four per cent of middle-aged men have symptomatic obstructive sleep apnoea (OSA) – this means they have apnoeas (breathing pauses) when asleep and are also very sleepy when awake. Up to three per cent of children have OSA, with prevalence much higher in children with certain disabilities / conditions e.g. Down's syndrome. Having undiagnosed OSA increases the risk of high blood pressure, and is associated with other serious conditions such as strokes and heart attacks, type II diabetes and depression. OSA affects men, women and children.

The British Lung Foundation (BLF) has been running a project to raise awareness of OSA and campaign for improved access to services for people with OSA along the patient pathway. The BLF has worked in partnership with health care professionals and organisations throughout the project, and this work culminated in the BLF hosting a half day conference for invited guests in February 2014, which included a series of interactive presentations and discussions. The aim of the conference was to share examples from across the UK of effective clinical practice and mechanisms to support people with OSA, and to discuss priorities for ensuring that OSA remains a priority for health care provision in the future. This is believed to be the first UK conference on OSA, bringing together experts from across the UK to provide a snapshot of the issues they face, to share innovative practice, and to discuss OSA as an ongoing priority.

The patient pathway

Screening and referral – the role of GPs is changing, and in England GPs, through their local CCGs, are now commissioning sleep services as well as having a role in service provision. There is a need to raise awareness of the importance of OSA with GPs, particularly in relation to the link OSA has with associated co-morbidities and traffic collisions, and sleep healthcare professionals have a role in this. When GPs take an active role in screening and referral pathways then this is beneficial to the patient, the GP and the sleep clinic.

Assessment and diagnosis – the key components to a good service are a good quality referral, an assessment of sleepiness, a sleep study and a clinical assessment. A one-stop shop for treatment set-up can shorten the total patient pathway, especially from diagnosis to treatment, and can reduce concerns about driving.

Local specifications for assessment, diagnosis and treatment of OSA – a successful model for developing sleep services is one which demonstrates the need, looks at current service provision, identifies what services should be in place, and offers a proposed structure based on current guidelines and local need. It includes the roles of all those in the local network, including primary, secondary and tertiary care, and gives detail about resource and training requirements, key performance indicators, potential funding streams, and locally agreed fees.

Management, ongoing support – services face a growing mountain of patients on treatment. There are different ongoing support models being practiced. If the follow up service is provided directly by the sleep clinic, a team approach is needed. Some clinics outsource follow up to another provider through a partnership agreement for uncomplicated, so called "barn door" cases. Continuous positive airway pressure (CPAP) treatment only becomes cost-effective after time, and initial set-up is very important as the long term pattern of CPAP use is established in the first week. CPAP compliance has been shown to be better than compliance with medication for asthma or hypertension. Use of new technology can help in the early days, using a wireless monitoring device.

Minimum standards

England – OSA services are, from April 2013, mainly commissioned through the 211 CCGs. There are no minimum standards, and the tariff and coding system needs reviewing.

Scotland – there is a minimum standards document on referral, diagnosis and treatment, patient review, national core data set and driving issues. An electronic referral protocol is in place in some areas.

Northern Ireland – there is a service framework for respiratory health and well-being and there has been some investment recently in sleep services, with the first full PSG about to start in Belfast.

Wales – there is a Welsh strategy for sleep disordered breathing. Four key standards were identified concerning investigation, treatment, following NICE guidance on CPAP and provision of centres to investigate complex cases. A hub and spoke three tier model was introduced.

Across the UK, there has been a rise in demand for services, and there are funding and resource issues in some areas. Service provision varies across the UK. There is a need for GP awareness and an increased role of GPs in care pathways.

Ensuring OSA is a priority in the future

Key themes to emerge were: ensuring that the patient is at the centre of service planning and provision; ensuring that health care professionals in sleep work in partnership with a range of local stakeholders; ensuring that health care professionals and the BLF continue to work together; ensuring that local business cases for service provision are developed, emphasising the association between OSA and co-morbidities, and including incentives for GPs.

Introduction

The BLF has been running a project to raise awareness of obstructive sleep apnoea (OSA) and campaign for improved access to services for people with OSA along the patient pathway.
During the project, the BLF worked with a wide range of health care professionals (HCPs) who specialise in sleep medicine / OSA. Initially, the partnership working between the BLF and HCPs was geared towards engaging HCPs in the project, researching the issues that they faced in their work, and the learning about issues faced by the patients they were supporting, so as to inform the project planning.
As the project developed, HCPs began to make requests to the BLF to put them in touch with other HCPs who were doing work that they found interesting and that they could learn from, and this evolved into a stream of work that had not been planned initially but which became increasingly embedded in the project.
This work led to the BLF being involved in giving presentations at meetings and conferences, including Department of Health meetings and a national conference on respiratory health, about innovative and successful examples of OSA clinical practice. We also featured case studies of effective practice in our "Next Steps" report on OSA which was launched during our parliamentary reception at Westminster in April 2013.
The BLF culminated this partnership working by hosting a half day conference for invited guests in February 2014, which included a series of interactive presentations and discussions.
We shared examples of effective practice along the patient pathway, discussed where sleep medicine and OSA fit into the new NHS landscape in England, and in health service provision models across the UK, and debated the priorities for the provision of sleep services in the future.
This report summarises findings from the day, and will be disseminated this to key decision-makers and influencers, including parliamentarians, commissioners and providers.

OSA – the issues

Up to two per cent of middle-aged women and four per cent of middle-aged men have symptomatic obstructive sleep apnoea (OSA) – this means they have apnoeas (breathing pauses) when asleep and are also very sleepy when awake. Up to three per cent of children have OSA, with prevalence much higher in children with certain disabilities / conditions e.g. Down's syndrome.
Having undiagnosed OSA increases the risk of high blood pressure, and is associated with other serious conditions such as strokes and heart attacks, type II diabetes and depression.
OSA affects men, women and children.
You are more likely to have OSA if:
- You are a man and middle-aged
- You are a woman past your menopause and not on HRT
- You are overweight, with a neck size of 17 or over
- You have a small airway, a set back or small lower jaw, large tonsils or a large tongue
- You are a child with a particular condition / disability or are overweight

Untreated OSA poses a serious economic health care burden. OSA can seriously affect the quality of life of the patient and their immediate family. Driving when sleepy is associated with 20 per cent of road traffic accidents (RTAs), and driving with untreated OSA increases the risk of RTA by three to seven times. Studies suggest a particularly high rate of OSA in truck drivers and estimates of prevalence in the US range from 28 per cent to over 50 per cent. Up to 80 per cent of people with OSA have not been diagnosed.

Benefits of successful treatment include:
- Benefits to the patient – health and quality of life can be drastically improved
- Benefits to their loved ones – better sleeping at night for partners and a better quality of life
- Benefits to health care costs – reduced health care burden
- Benefits to society – reduction of road traffic accidents

Barriers to treatment include:
- Lack of awareness of OSA amongst the general population
- Lack of undergraduate training for medical and dentistry students
- Lack of recognition of the key symptoms by general practitioners
- Lack of widespread screening based on the key symptoms
- Possible referral bias towards middle-aged overweight men amongst general practitioners
- Lack of standardised, accredited training for sleep medicine health care professionals

• Lack of standardised, specified service provision
• People not coming forward: not thinking there is a problem; embarrassment; fear of losing driving licence; not knowing there is treatment

Overview of the conference

Aim of the conference

To share examples from across the UK of effective clinical practice and mechanisms to support people with OSA, and to discuss priorities for ensuring that OSA remains a priority for health care provision in the future

Summary

The conference opened with four presentations by health care professionals who have been identified by the BLF as providing effective and innovative services for people at risk of OSA, or with an OSA diagnosis. The presentations were delivered to provide examples of practice along the entire patient pathway, and include examples from primary care, secondary care and tertiary care:

- Screening for OSA, particularly in primary care
- Assessment and diagnosis of OSA
- Treatment of OSA
- Ongoing management of OSA, including options for clinical support and self-management

This was followed by the opportunity for participants to engage in group discussions with the HCPs who had delivered the presentations. There was then an overview from around the UK about where we are in terms of setting up minimum standards for OSA across the patient pathway – speakers from the four nations gave a brief update about the situation in their nation, and this was be followed by a group discussion with all participants.
Finally, there was a chaired group debate, involving a panel, including speakers from all the presentation sessions. The focus of this debate was to discuss how we can ensure that OSA remains a priority in the future.
All discussion sessions were scribed by members of BLF staff so that the main discussion points could be recorded.

Conference plan

The conference plan included a breakdown of the sessions that were covered. The plan, shown on page seven, was summarised in the conference programme (appendix 1).

The conference was chaired by Dr Brendan Cooper, President of the Association for Respiratory Technology and Physiology (ARTP).

Time	Session	Theme	Contents / style	Confirmed speakers 24/9/13
9.00	Registration / tea and coffee			
9.30	Welcomes and Introductions 5 mins			Steven Wibberley Brendan Cooper
9.35	1 20 minutes	Patient pathway - **screening for OSA**	**Presentation** - initiating and delivering a screening programme in partnership with the local hospital **Presentation** - recent / current recommendations in the literature about primary care screening (including professional drivers). Resources / materials available in primary care for OSA screening (ESS / STOP Bang)	Malav Bhimpuria John Stradling
9.55	2 20 minutes	Patient pathway - **assessment and diagnosis of OSA**	**Presentation** - setting up and running a one stop shop for assessment, diagnosis and treatment initiation	Maxine Hardinge
10.15	3 20 minutes	Patient Pathway - **treatment of OSA**	**Presentation** – setting up a local service specification for the assessment, diagnosis and treatment of OSA	John O'Reilly
10.35	4 20 minutes	Patient pathway - **management of OSA**	**Presentation** – why is ongoing support important / offering patient reviews / Resources available Discussion	Adrian Williams / Jayne Pateraki Beccy Mullins (ResMed) David Dawson - NHS service working with Philips Respironics
10.55	Break			
11.10	5 40 minutes	Patient Pathway	**Discussion in 4 groups** with facilitators – each group discusses the 4 stages of the pathway ; speed dating with the speakers – 10 mins each	Facilitators: speakers in sessions 1-4 BLF scribe in each session to record the discussion (Steven, Judy, Bev, Katie)
11.50	6 25 minutes	Minimum standards	**Facilitated discussion** – setting up local / national minimum standards – where are we now? Representatives from the 4 nations give overview, followed by open discussion	Martin Allen (England) Eric Livingston (Scotland) Martin Kelly (Northern Ireland) Amit Benjamin (Wales)
12.15	7 15 minutes	What next?	**Panel debate** – how do we ensure that OSA is a priority in the future?	Chairperson (Brendan) and panel of speakers
12.30	Closing remarks followed by Lunch			

Brendan Cooper opened the conference, and confirmed ARTP's support for the BLF's work in OSA.

Steven Wibberley, Director of Operations and Innovation at the BLF, summarised the OSA project's aims and objectives and highlighted some key achievements:

- Moving from a baseline of little knowledge and activity around OSA to being one of the UK's leading players
- Producing a suite of patient information, some of which is award winning. Last year we distributed 30,000 copies of our OSA leaflet, one of the most popular of any of our titles
- Producing the mapping of OSA risk and local sleep services in the UK – a ground-breaking piece of work
- Carrying out the OSA patient survey, with almost 3,000 completing this – the results will hopefully be published at a major conference this year

Steven said that although the project is coming to an end, the BLF's work on OSA is not, and we will be focussing on developing a health economics report, and a commissioning / planning toolkit for OSA services.
Finally Steven offered thanks to: conference sponsors ResMed, Philips Respironics and Fisher and Paykel; ARTP and BSS for their support of the project; and Judy Harris, who has led the BLF's OSA project.

Notes from the conference sessions

The following pages provide a summary of all the presentations and discussions. Research that was quoted in the presentations has not been referenced in full for the purposes of this report. To source research references, please contact the BLF: ***osa@blf.org.uk***

The patient pathway: sessions 1 – 5

This part of the day involved a series of presentations followed by a break out session. During this break out session, the audience split into four groups and each group had the opportunity to discuss the patient pathway presentations they had just heard, with the speakers from those sessions. These discussions were scribed by BLF staff, who also facilitated the groups. The presentations are summarised in order, and the notes from the group discussions follow directly after each presentation summary.

Session 1 – screening

The role of GPs

Dr Malav Bhimpuria, a GP in Huntingdon, was due to open the session with a presentation about a screening and referral programme that he has set up in his local area, in partnership with Papworth Hospital. Unfortunately, Dr Bhimpuria was unable to attend due to an unforeseen family crisis. His slides have been made available and are summarised here.

The service was established for his patients August 2009. Numbers were initially small (year one: 12, year two: 20).This has now developed into a full hub/spoke/satellite service, where Papworth Hospital is the "hub", five GP surgeries (one per market town) are the "spokes", and the other surgeries are "satellites".
Governance and booking systems have been set up. Patients are seen by their GP with suspected obstructive sleep apnoea syndrome, and are sent home with a pulse oximeter for an overnight study. The results, along with the results of an Epworth Sleepiness Scale and a clinical examination, are sent to Papworth. Dr Bhimpuria explains how tariffs have been unbundled and incentives created. Training is provided for the "spokes", and all five have been fully operational since August 2012.
12 months data (Oct 12 to Sept 13) on 327 patients:

- 179 (55 per cent) needed outpatient assessment
- 24 (seven per cent) were admitted directly into the service

- Three (<one per cent) underwent more community diagnostics
- 121 (37 per cent) had no further action

The outcomes are increased awareness across primary care, reduced patient journeys, care closer to home, rapid diagnosis and treatment and joint working between commissioning groups and primary and secondary care.

Dr Bhimpuria estimates savings of at least £19,092, thereby holding back the tide of rising costs and reversing it.
Future plans include extending the service further afield and extending the service to include GP follow ups and advanced health checks.
His final thoughts were: innovate; take a risk.

Emeritus Professor John Stradling gave a presentation on the role of GPs. He set the scene with some statistics about the burden of OSA and in particular, the cost of road collisions, estimated by Douglas and George in 2002 to be £1.25 million for a fatal accident. They also calculated that treating 500 patients for five years prevents one fatal accident, 75 injury accidents, and 224 property damage accidents, and that £5.3 million would be saved, with an estimated treatment cost of £0.4 million (12.3 times return on investment).
Professor Stradling went on to compare the situation of OSA management in primary care now, with that of hypertension in primary care in the past, from the 1950s when management in primary care was virtually non-existent, to the 1990s by which time the use of ambulatory blood pressure monitoring was increasing.
He then gave examples of existing models:

1. GP with a special interest does sleep studies and refers positive studies for treatment trial or equivocal studies for more complex study
2. Each surgery has simpler recording pulse oximeters, with all tracings sent to sleep centre for review (or GP interprets)
3. A few GP 'hub' surgeries provide the service for a larger number of surgeries, using more complex devices, e.g. Grey Flash/Apnea-link or equivalent. Study uploaded to server, sleep centre interprets

Outcomes from option three, used locally:

- CPAP: 43 per cent so far have been positive and needed CPAP
- Letter: 30 per cent reassured OK by letter
- Outpatients: 19 per cent needed outpatients department appointment as symptomatic and diagnosis unclear
- Failed study: eight per cent (too short or forgot to put in new batteries)

No studies have needed repeating by the hospital

Professor Stradling presented a screening tool called OSA50, which he felt may encourage greater awareness, and which assesses the following:
Overweight (by waist size)
Snoring
Apnoeas
50 years or over
He compared this with the STOP Bang which was developed for use by anaesthetists, which asks four questions and takes four measures.
He questioned whether screening at risk groups would be of benefit, e.g. those with type II diabetes, diabetic retinopathy, macular oedema, abdominal aortic aneurysm, thoracic aneurysm, ischaemic heart disease, renal disease, fatty liver, lorry/truck/bus/coach drivers.
He reported that proof is not yet available that formal screening for OSA in these situations is truly valuable.
He concluded by saying that sleep studies ARE going to move into primary care, and that the challenge is to design a cost effective system that has a low false positive/false negative rate (training is more important that the specific technology and use of arbitrary thresholds).
Finally he encouraged sleep units to engage with their CCGs and GPs before they go it alone.

Session 1 discussions – the role of GPs in screening

Raising GP awareness and GP engagement

- There is an issue about inappropriate referrals, e.g. for tiredness It is important GPs differentiate between tiredness and sleepiness. Refer when 'sleepy'
- GPs are receptive to figures e.g. costs of fatal accidents
- Can't give GPs a problem unless you give them a solution as well
- Provide a financial incentive / agree a local tariff for reporting
- There is a need for education / training
- GPs are too busy
- Create an alert / flag? But there are already too many of these – could an alert be attached to an existing one, such as BMI?

Screening and Referral

- There can be a problem with getting standard referrals from GP – even if a standard template is in place then it is not always used. Clinics need standard information from GPs and should reject the referral if it is not correct.
- Challenge using IT systems for referrals - GPs don't want to use a check list and education is not working in some areas, therefore the sleep service is bombarded with referrals
- Some GPs are keen to have templates/prompt but some feel it's just something else to bother with
- If GPs can reduce referrals coming to secondary care by more work in primary care they should get a percentage of the tariff
- Epworth Sleepiness Scale (ESS) is probably not the best tool
- We should be persuading GP colleagues to ask the right questions in 'high risk' patients with co-morbidities, and there is a need for education. There was concern over general population screening and the group thought it better to focus on case finding in symptomatic patients
- What about areas of high deprivation where the GP surgeries can be very busy? Some people feel there's a credibility issue and that GPs don't have the necessary skills
- If we try to get the UK to the levels of treatment in other countries, the current system couldn't cope. GPs need the support of local expertise. There is a need for all centres to be involved, not just centres of excellence. Also need to consider variability in predicted prevalence as highlighted in BLF maps

Local network approach

- Can use a model of outreach into the community from secondary care
- Increased role of GPs can be seen as a threat to secondary care – especially sleep technicians – this would need addressing
- We convinced the hospital we'd earn more for outsourcing sleep studies and we were right – wins for patient, GP and hospital
- Develop a pathway with referral protocol, education and training
- The GP working with Papworth is looking at diagnostic pathways and they have developed an algorithm for diagnosis and referral

Interpreting sleep studies carried out in primary care / staffing levels

- Who interprets GP info? There could be issues of accuracy of wireless transmission and of interpretation – need to identify lower costs and better outcomes
- Our technicians don't get involved in sleep studies – we concentrate all our resources on CPAP set-up
- Technology will help in the accuracy of interpretation and will support more GP involvement
- Scotland – ENT won't accept referrals for some patients who snore but don't have sleepiness

Outcomes

- Quality adjusted life years (QALY) – mild patients drive up costs so need to get the thresholds right for referral and set-up on treatment
- Quality and Outcomes Framework points (QOF) – there have been attempts to include a QOF point for OSA but to no avail

Session 2 – assessment and diagnosis

Setting up and running a one stop shop for assessment, diagnosis and treatment initiation

Dr Maxine Hardinge, consultant physician, described the service that has been set up at the Oxford University Hospitals.
She began by summarising the elements of designing a sleep service:

- Patient numbers
- Streamlined service for patients
- Staffing availability
- Multi-disciplinary team
- Available facilities – sleep labs, day case unit
- Efficiency for staff
- Optimum clinical outcomes

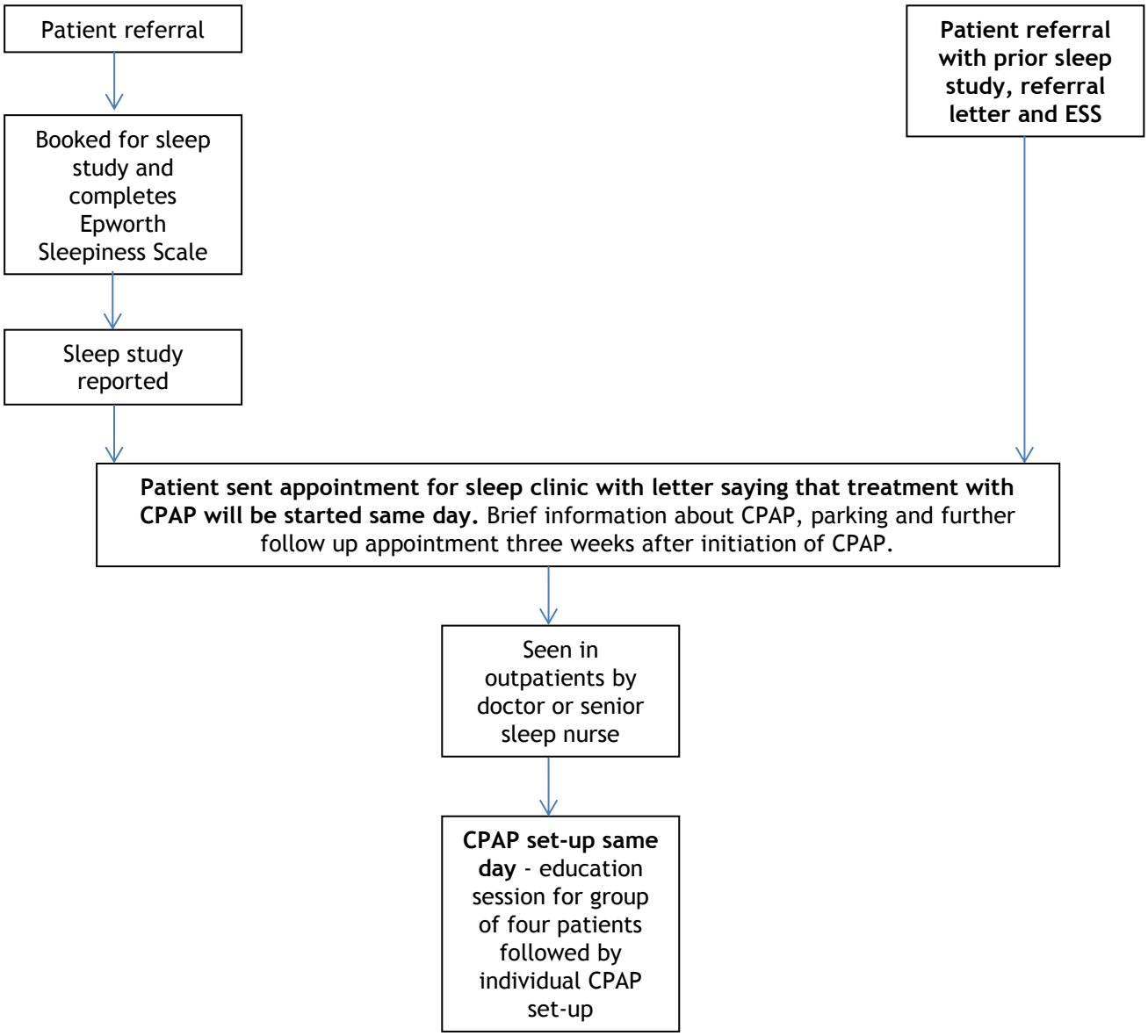
She outlined the key components of assessment and diagnosis as being a "good" referral letter or OSA questionnaire, sleepiness score, sleep study and clinical assessment. The results of these would lead to deciding if the patient has OSA syndrome likely to respond to CPAP treatment.
Dr Hardinge then went on to outline why Oxford University Hospitals decided to develop a one-stop approach to CPAP set-up:

- To shorten the total patient pathway
- To reduce waiting time from diagnosis to treatment
- To reduce concerns about driving

Research carried out and published by the team had provided evidence for establishing day case set-ups, with good outcomes and patient feedback. 75 OSA patients with an overnight CPAP titration in the sleep laboratory were compared with 75 OSA patients who were seen in outpatients and then set up on CPAP the same day. There were no differences in any of the outcome measures. Research had also established that using an algorithm derived CPAP pressure (based on neck circumference and OSA severity) provided equal outcomes to overnight autoset titration (at one week and six months), with outcomes for patients set up on a fixed pressure faring a little worse.
An original three steps approach was devised, involving an initial pilot of 40 patients. They were offered one visit for an overnight in-patient sleep study, and an out-patient visit and CPAP set up the following morning.

Patient feedback - there was too much information too quickly at one visit
Staff feedback – it was challenging to facilitate sleep reporting before the out-patient appointment for several patients.

A revised pathway was developed:



Criteria for selecting patients to attend one stop shop:

- Referral letter suggests history typical of OSA
- Raised ESS
- Sleep study confirming moderate/severe OSA
- Likely diagnosis OSAS requiring CPAP treatment
- No contra-indications to day case set-up (e.g. mobility/ language difficulties)

Session 2 discussions - Assessment and diagnosis, setting up a one stop shop

Different models

- Wrexham do oximetry first to reduce clinic appointments
- Putting straightforward patients straight on CPAP with a consultant appointment
- Offer group sessions, especially if there is a high rate of DNA
- Use health trainers (Liverpool)

What to include in education

- Weight management should be built into the pathway

Patient perspective

- A "one stop" approach can be overwhelming for patients – "two stop" might be better
- Consider offering longer appointments

Commissioning

- Do GPs want to take on OSA – needs willingness and payment
- Even some respiratory consultant colleagues aren't interested in sleep – challenge to reverse this
- Local funding issue discussed with one CCG having a contract with an acute hospital which is not local for patients when nearby tertiary centre has all the facilities. Patients are being told to flag this up and complain to their local MP which is beginning to happen
- Patient self-help groups can became a pressure group and successfully harness the patient voice using local people

Driver and Vehicle Licensing Agency (DVLA)

- The current situation with DVLA is difficult and it is hard to negotiate with for change. The best time to inform them if possible is when patients are on CPAP; hence a one-stop approach is ideal. Legally, the patient is supposed to inform DVLA on suspicion of diagnosis but how 'suspicious' should you be? Is there a disparity in interpretation?
- What is a near miss? The American Thoracic Society has the best guidelines about driving and near misses
- If a patient is put on CPAP when should they be allowed to drive? There are different thresholds used

Session 3 – treatment

Setting up a local service specification for the assessment, diagnosis and treatment of OSA

Dr John O'Reilly, a consultant physician working at Aintree Hospital, gave a presentation about his experience of setting up sleep services through the North West Regional Strategic Health Authority Task and Finish Group.
He presented a four stage model for service development that was used:

1. What is the need?
2. What services do we have now?
3. What services should we have?
4. Proposed solution

1. What is the need?

This stage focuses on:

- **highlighting the demand for the service**
- **explaining the medical condition**
- explaining the consequences, such as major cause of potentially fatal road accidents, breakdown of personal relationships, impaired quality of life, lost work productivity
- **explaining the prevalence and impact**, such as OSA affects up to four per cent of middle-aged men and two per cent of middle-aged women in the UK, only about one in four people with OSA have been diagnosed and only about half of patients diagnosed have been able to access treatment, untreated OSA syndrome is estimated to cost the NHS £432 million a year
- **quoting guidelines** such as national Institute for Health and Care Excellence (NICE) guidance and specialist professional bodies which support treatment of symptomatic patients based on gradation of severity
- **treatment recommended** by guidelines
- **barriers to service development**, such as low recognition of the problem, inadequate access to services, perceived cost of investigation, perceived cost of treatment
- **challenges presented by NHS structure**, such as lack of holistic patient focused management pathways, lack of national and international guidelines accepting OSA as a major cardiovascular risk factor, disparity of awareness and treatment delivery for ethnic groups, private industry offering diagnostic and treatment services without the involvement of a specialist sleep clinician
- **the need to develop pathways** especially as most of the referrals were coming from GPs, obesity and diabetes clinics – these pathways would enable development of better screening, better collaboration between obesity, diabetes, and sleep clinics in NHS trusts, obesity-diabetes-OSA clinical pathways, support for complex patients, improved collaboration between

primary and secondary care sleep services, and an extended role of the metabolic/sleep physicians/teams to primary care clinics

- **explaining the health economics of OSA**, including research that shows use of CPAP (for a cost-reduction of £973 over 14 years) leads to:
    - 25 per cent risk reduction in mortality
    - 46 per cent risk reduction in cardiovascular event
    - 49 per cent risk reduction in stroke
    - 31 per cent risk reduction in road traffic accidents
    - 12 per cent improvement in health gain
    - impact on quality of life e.g. 24 per cent increase in health status, average lifetime gain of 5.4 to eight QALYs, very favourable cost utility ratio
    - comparison of cost per QALY with other conditions
    - becoming a dominant treatment after two years – improved outcome for less cost

2. What services do we have now?

This stage focusses on who is involved:

- the current roles of primary care providers e.g. screening and case recognition of patients with suspected obstructive sleep apnoea syndrome (OSAS), and screening of high risk co-morbidity patient groups for OSAS, with appropriate referral to secondary care
- secondary care provision e.g. almost all diagnostics and treatment services
- any third sector (private) provision for diagnostics and treatment services

3. What services should we have?

This stage focusses on additional capacity and capability, and a network approach working across sectors (including involvement of voluntary sector):

- **Additional capacity and capability** would include: infrastructure, staffing and training in investigation and treatment; convenient access to specialist facilities for investigation and treatment with facilities provided by each large hospital or group of hospitals; cumulative effect of growing numbers of patients on CPAP, and economies of scale; different requirements will apply to a comprehensive service covering the broad range of sleep disorders; access to full polysomnography (PSG) sleep study for a minority of patients without undue delay or lengthy travel; patient follow up
- **Network approach:** A regional service specification is proposed to provide current best practice across all those involved

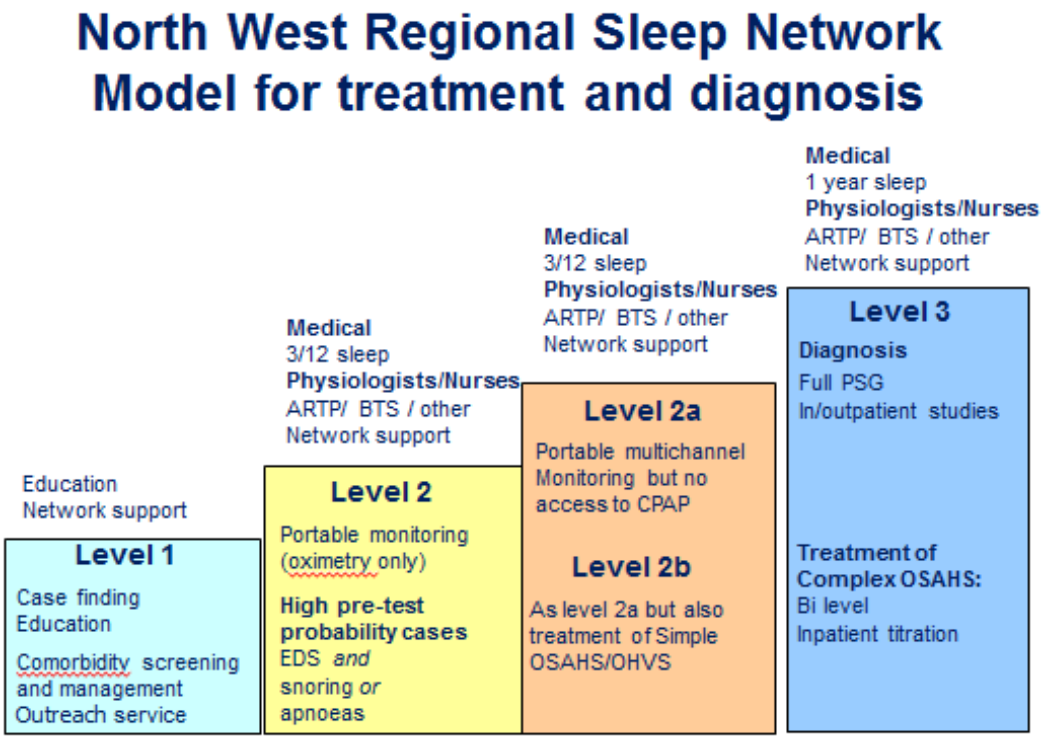
4. Proposed solution

This stage focuses on the development of a service specification (based on recommendations from NICE, British Thoracic Society (BTS), Primary Care Respiratory Society (PCRS) :

- **Primary care roles**: screening and case recognition; screening high risk co-morbidity groups for OSAHS; shared care of patient follow up
- **Secondary care sleep service roles**: specific diagnosis and treatment of SRBD; longitudinal patient follow up; equipment maintenance; assessment of treatment compliance/adherence; appropriate support; an outreach service to primary care and other sleep services may also be appropriate; education of the patient, encouragement, attention to detail and time spent with the patient are essential, as prescription of the equipment alone, without such support, is likely to be unsuccessful
- **Resource requirements** for service: staffing levels for consultant, nursing / technical / scientific, secretarial / clerical
- **Training requirements** for staff
- **Key performance indicators**, including patient management, database, CPAP set up, CPAP success, patient satisfaction survey, follow up and trouble shooting, annual review
- **Sleep service network:** a regional network is proposed, with each unit having formal links and with a monitoring remit
- **Funding streams (potential):** a region wide funding stream should be agreed. A possible step wise approach to funding would be as follows:
    - Each clinic visit to be charged at the set Healthcare Resource Group (HRG) code (both new and follow up)
    - In patient sleep studies to be charged under set HRG codes
    - A locally agreed fee for home sleep studies

- A locally agreed fee for a CPAP trial including consumables
- A locally agreed fee for initial CPAP supply (if successful trial) which includes consumables for the first year
- A locally agreed fee annual fee for maintaining a patient on CPAP (to cover consumables, re-titration, replacement, servicing)

Dr O'Reilly presented the model developed in the North West as a result of this approach:



Finally, Dr O'Reilly talked about how this model was used to set up a new sleep and ventilation service at Aintree. The business case that was developed included the following headings:

- executive summary
- strategic context / case for change
- patient and commissioner focus
- project objectives and benefits
- formulation and appraisal of options
- financial analysis
- risk
- the preferred option
- benefits realisation / post project evaluation
- capital funding / procurement
- sensitivity analysis
- appendices

In conclusion, Dr O'Reilly summarised the issues regarding developing a business care:

- The number of patients requiring CPAP therapy is rising
- The number requiring CPAP follow up is rising rapidly (CPAP mountain)
- Need for increased sleep service staffing, training and infrastructure
- Need adapt processes to increase efficiency and quality (Quality, Innovation, Productivity, Prevention QIPP agenda)
- Need to meet sleep service specification and standards

Session 3 discussions – setting up a local service specification

Developing a business case / commissioning

- Dr O'Reilly was asked if the data he presented is available – some of this data is now out of date, and the figures are higher – needs to be re-visited
- The data is compelling – what is the key barrier dealing with commissioners? CCGs are not interested – they tend to say things like "when we get round to it" – they don't understand that OSA underpins a lot of the problems they see as priorities. There is no support for OSA within the national framework
- Sleep services need to drive the change to get sleep services commissioned. There should be top down from Government together with bottom up, although there's no support at Department of Health for respiratory
- Look at the management of other long term conditions (e.g. diabetes, cardiovascular) with costs highlighted to persuade the CCG to consider OSA
- Educate and persuade CCGs and be clear on cost benefits and cost effectiveness of CPAP
- It was mentioned that oral devices offer good compliance early on but in long term not as good as CPAP. Dentists aren't always trained and are therefore unwilling to fit splints. Oral devices are two or three times more expensive than CPAP. Devices can be purchased from the internet but there is no infrastructure to support patients once they have the device and custom made devices are much more effective. There is difficulty in referring for mandibular devices in some areas
- There is an economic argument between the use of autoset and fixed pressure CPAP. Certain patients benefit from autoset and there is a reduced need for follow up but data is required here. With data about patients using autoset devices and those using fixed pressure machines when tendering, this could be built in to the service specification
- Some patients benefit from CPAP but there is also a need to address lifestyle issues e.g. weight

Local networks

- There can be limited links with primary care – these are developing
- In some areas, primary care have become more pro-active, and GPs are sending out appropriate letters
- How to incentivise GPs to seek out patients?
- What about using OSA50 which Prof Stradling mentioned? Some physicians don't like this due to the 50 year cut off, which would rule out younger people – and the STOP Bang is preferred
- Should develop a regional model with level one / two / three – this should be acceptable with others but needs good collaboration
- How do sleep services manage the perceived threat of GP provision? They need to recognise that sleep service cannot manage the numbers so clear protocols must be developed to manage each stage of the pathway including managing stock, i.e. replacement masks, etc. and day to day demands on sleep service. Set up helplines and train staff (? healthcare assistants) to screen phone calls/telephone triage and/or perform routine CPAP set ups (sleep assistant)
- Link with wider network re lifestyle advice, weight management, diabetes – link with other clinics in secondary care

National picture

- Campaigning for a QOF point for OSA – unlikely to be used
- NHS Health Check – have tried to get OSA included and failed
- Need Quality Standards for OSA
- Could you have a Commissioning for Quality and Innovation (CQUIN) payment for OSA?
- Payments for outpatients / overnight pulse oximetry are normally done as part of a block contract – need to look at the payments for outpatients
- Need to get the coding right
- In Wales – most are at level one. There is capacity in secondary care but primary care needs to reconfigure
- The rest of Europe seems to be treating patients entirely in specialist centres. Is this better than looking at delivering services in primary care? Within the current system in the NHS it is felt that there needs to be some primary care screening for appropriate referrals to sleep services. Oximetry screening is followed by appropriate referral to sleep service for sleep study and polysomnography (PSG)

Session 4 – ongoing management

Why is ongoing support important, resources and models available

Four speakers were involved in giving presentations in this session, and were invited to speak due to their different approaches to the issue of coping with an increasing caseload of patients established on treatment.
Professor Adrian Williams talked about how ongoing support is offered at Guys and St Thomas' Hospital Trust (GSTT).
He began by reminding the audience that the success of CPAP depends on various factors, including:

- Liberal access to technicians for troubleshooting
- Dedicated phone line
- Technology available - humidifiers; masks
- Follow up - face to face; remote (smart cards)

Research indicates that the best continued use statistics are at about 80 per cent, and Professor Williams said that at GSTT, continued use is about 60-70 per cent.

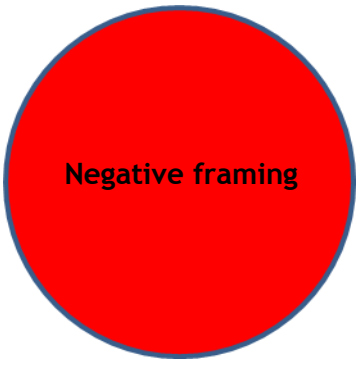
He also highlighted that efforts to improve CPAP use include:

- Choice of patients and alternate treatment e.g. oral appliance
- Streamlining- group vs individual collection (data)
- DNAs- texts can be send to remind patients
- Framing (how data is presented)

The clinic ran a comparison in 2010 of individual versus group training for CPAP set-up and found that group training was more cost effective and also that there was not much difference in compliance rates for CPAP use (defined as over four hours per night) over a 12 month period.

Professor Williams explained how framing information given to patients has an impact on CPAP compliance.

- Using CPAP at least four hours per night will reduce your daytime sleepiness and give you more energy
- If you use your CPAP at least four hours per night, you can experience benefits that may save your life
- Using CPAP at least four hours per night will increase your chances of lowering your blood pressure
- Using your CPAP at least four hours per night decreases the risk of cardiovascular events.
- Using CPAP at least four hours per night will decrease your chances of experiencing sudden death



- If you do not use your CPAP at least four hours per night, you miss the chance to be less sleepy and have more energy.
- If you do not use your CPAP at least four hours per night, you cannot treat your sleep apnoea and not treating sleep apnoea can cost your life.
- If you do not use your CPAP at least four hours per night, you may decrease your chance of lowering your blood pressure.
- If you do not use your CPAP at least four hours per night, you may increase your chance of cardiovascular events.
- You may not decrease the risk of sudden death if you do not use your CPAP at least four hours per night.

Research from 2010 has indicated that negative framing has more impact on CPAP use.
Finally, Professor Williams talked about effective CPAP use being dependent on repeat assessment and sleep study if needed, and that behavioural management of weight and sleep can be implemented to improve compliance.

Next, Jayne Pateraki, advanced nurse specialist at York Hospital, talked about the review service offered there. York, which has approximately 3,000 patients on CPAP, faces the same issues as any other large clinics, where more patients are being put onto therapy and need follow up without

necessarily being supported by an increased staff team. York's approach has been to appoint a team with varied experience and grades, led by a respiratory consultant, and comprising one band seven advanced nurse specialist, three band six specialist nurses (2.23 whole time equivalent), two band three sleep assistants (1.44 wte) with a full time band five and full time admin support soon to be appointed.
Jayne began by summarising that the provision of CPAP involves more than simply issuing a CPAP device and mask: it involves education, support and ongoing care including the monitoring of treatment adherence. This is a shared responsibility between the patient and the sleep clinic.
Follow up comprises the following elements:

- Weight
- Blood pressure (BP)
- Compliance checked
- CPAP users questionnaire is completed which includes Epworth Sleepiness Scale (ESS) score, symptoms.
- Patients are asked for any changes in health status since last seen / change in medication
- CPAP machine plug, pressure and casing are checked
- New equipment is issued
- New follow up appointment is issued
- Discussion takes place about any issues the patient may be experiencing
- Review and refer for oral device as an alternative therapy if struggling

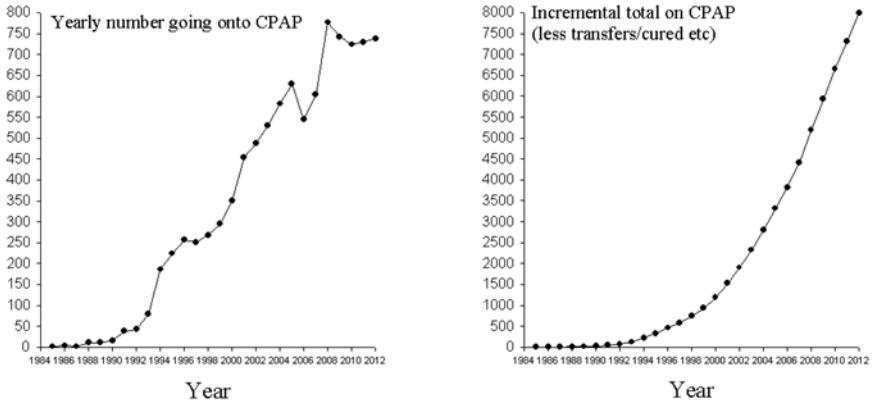
Jayne highlighted problems with patients relocating to York who have not had regular follow up elsewhere:

- Weight increase or weight loss causing pressure issues. Patients have repeat titration studies or pressure altered and diagnostic test ordered whilst using CPAP to ensure it is effective
- ESS score can be elevated
- Mouth dryness requiring addition of heated humidification
- Demotivation - given up
- Non-compliance with therapy
- Developed other health problems leading to mixed / central apnoea not treated by CPAP requiring further investigations
- Very old poorly fitting masks cause leak and sub-therapeutic pressures

She concluded by summarising the problems facing the team at York, namely increasing numbers of new patients, limited clinic space for follow up and CPAP titration studies, and more complex needs of patients requiring time and additional resources.

Professor John Stradling then took to the podium again to present an approach adopted at Oxford University Hospitals, where there are approximately 7,000 patients on CPAP. He aptly named his presentation "coping with the CPAP mountain".
He highlighted the growth in the service with this image:

CPAP prescriptions, Oxford Unit
1984-2012



Professor Stradling reminded the audience that CPAP only becomes cost effective after time on treatment because of the costs associated with diagnosis and treatment set up, and summarised the reasons for CPAP discontinuation:

- inconvenience
- poor mask fit and discomfort
- skin irritation
- mask leaks
- sore eyes
- airway drying
- nasal problems
- noise
- frequent awakening
- claustrophobia
- dislike of CPAP treatment
- partner initiated referral
- sleeping alone
- anxiety
- depression
- concerns over sexual intimacy

Research has shown that the long term pattern of use is established in the first week, and that is it very difficult to predict who will respond well. However CPAP compliance has been shown to be better than compliance with medication for asthma or hypertension.
Professor Stradling introduced technology that can be used by clinics to support patients in the early days on CPAP, which comprises wireless technology used with the CPAP that allows the clinic to remotely monitor CPAP compliance and issues, such as leak. Professor Stradling showed images of ResMed CPAP devices with this technology (other systems are available). He finished by posing this question: can the use of this new wireless technology during the first week of CPAP use increase compliance, reduce costs and thus improve cost-efficacy in OSA?

Dr David Dawson, consultant anaesthetist then presented the model that has been developed in Bradford. The service started in the independent sector and was successful, thereby demonstrating a demand for the service; this demand enabled the team to introduce the service to NHS Trust as a new service. Initially there was no funding to develop service, and there were limited diagnostics available. Dr Dawson had had previous positive experience with the "MOST" (management of specialist therapies) patient service offered by Philips Respironics (other systems are available), and he went on to explain the pathway:

1. Two night respiratory home study
2. Clinic appointment
- Explain OSA
- Go through sleep study
- Explain CPAP
- Measure for mask
- On-line prescription or fax
- Encourage use of 0800 help line

3. Philips phone patient and arrange delivery
4. Follow up phone call at 48 hours
5. Data recall at one week
6. Phone call to confirm results of data recall and to give support
7. Data recall at four weeks, three months and then six monthly
8. Follow up clinic appointment at six weeks
9. If all well no routine follow up

Dr Dawson explained why he is happy to leave CPAP management to a third party in terms of it being a partnership arrangement which gives him access to:

- A wealth of expert clinical advice
- Support in training local staff
- Regular review of patients with alerts if there are problems which the clinic needs to address
- Identification of complex problems and the ability to escalate therapy and track response
- Reporting package which allows audit of the service

Dr Dawson concluded by presenting his view of future services for uncomplicated (so called "barn door") OSA:

- Diagnostic device in primary care
- CPAP therapy set up in primary care
- Oversight by clinicians from secondary care reviewing diagnostic and therapeutic data on-line
- Wireless/ modem data collection
- Patient able to view data on phone/tablet

Those with complex OSA and / or co-morbidities would stay in secondary care.

Session 4 discussion – ongoing support and management, models available

How often to follow up

- Do people need follow up every year? A sub-group are seen every two years in some clinics
- Do you ever discharge?
- Some thought that the patient should be reviewed many times but evidence has shown that when a patient has been put on an autoset device that the treatment is effective at the first week follow up and also the six week appointment

CPAP machines

- It's important to separate issues with the CPAP machine issues from the patients' needs
- Don't need to service the machine every year – it is exempt from Portable Appliance Testing (PAT)
- What is life of the machine?
- Would you ever remove CPAP – only for non-users following a consultant appointment
- There is a reluctance to tie into one CPAP provider. There is a company that will provide whichever machines you want – you decide the models for your service
- The patient's biggest problem is getting the right mask

Tariffs / costs

- There is no tariff funding for receiving the smart card for analysis rather than face to face session – this is open to local negotiation
- There is concern over the cost of masks – in Bristol we have limited it to a choice of three
- There is payment for correct coding of annual appointments in England

Different models

- There are opportunities around a telephone helpline rather than regular follow up
- Telephone consultations were felt to be very time consuming and not cost effective – difficult to close the consultation on the phone. General feeling was that face to face was better
- Can remote monitoring be done? Face to face enables more problems to be identified but there are high 'did not attend' (DNA) rates
- It is important to have a specialist nurse at every clinic
- Reduce DNA with a reminder letter six weeks before the appointment, plus text
- In Blackpool, the Chronos system is used to phone patients for follow up and offer three choices
- Complex patients should always go to secondary care
- What is the role of private providers – especially in follow up? In Scotland the home oxygen provider service is also delivering spare parts for CPAP
- What about support groups? Humber Sleep Apnoea Support Group (HSASG) – all new patients are referred and we provide reassurance – this reduces the number of calls to the clinic. Predominantly emails nowadays. At York, it was thought a support group would be great but there was no interest – it was felt this was due to the big geographical area
- DNA rate can be high – one clinic tried offering an evening clinic, reminder letter and when they are ready, go down to two-yearly follow up
- Patients on CPAP who are non-symptomatic are followed every two years in York. Patients would probably be happy with one year however, some patients haven't been reviewed for years once discharged from the service and this causes some concern. It was felt that it is better to provide education for patients in the early days of CPAP to reassure patient that if they are asymptomatic and the equipment working well then they don't need to be seen
- There are concerns over the time between testing and diagnosis for drivers in some areas. It was felt that these patients should be fast tracked and even two weeks is too long

- David explained that the Bradford service worked well because there were so many untreated/undiagnosed in the community the outsourced part of the service is an adjunct not a replacement to the sleep service in hospital
- It was difficult to move elements of the service into primary care if there is no GP with an interest in sleep
- After triaging oximetry referral, the complex cases should be seen by the specialist service but there is potential for CPAP to be implemented by GP in community. In Bedford they undertake oximetry and overnight study in primary care with consultant reviewing all studies (currently researching this). There was a comment that there needs to be a randomised controlled trial for GP management

Minimum standards – session 5

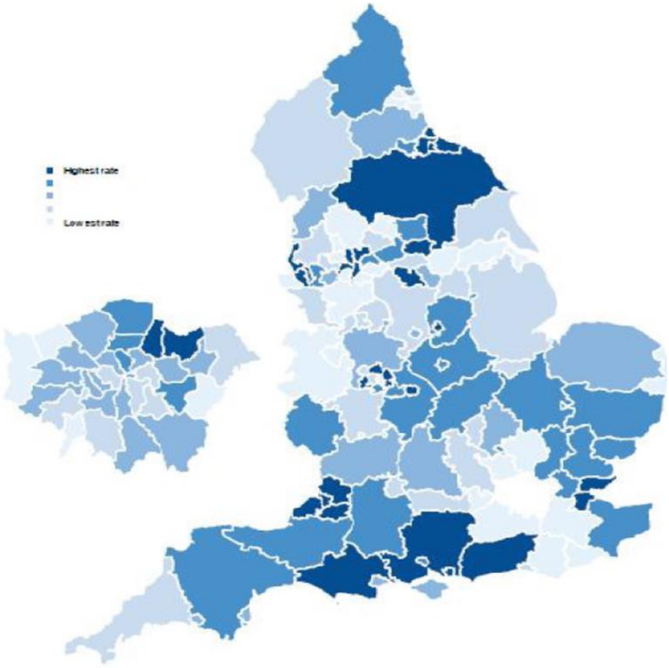
Where are we now across the UK?

During this part of the conference, speakers from the four UK nations each gave a brief presentation about the situation in their own country.

England

Dr Martin Allen began with an overview of the English experience. He summarised the key drivers for care in an international and national context:

- International guidelines from Europe and America
- National information, e.g. from British Lung Foundation (BLF), Association for Respiratory Technology and Physiology (ARTP), British Thoracic Society (BTS), Map of Medicine
- Direction from the Department of Health (DH) – until April 2013, the DH led on commissioning advice, the 18 week "measurement", the respiratory program board. The NICE Technical Appraisal Guidance (TAG) guideline on CPAP treatment was produced
- An OSA working party was set up by the DH in 2012 which included representation from the BLF and other organisations, and which produced a report of recommendations for the respiratory programme board
- Following NHS re-structure, OSA is now the responsibility of local commissioning with some sleep services also in specialist commissioning
- We now have the respiratory alliance, a federation of organisations responsible for driving the respiratory agenda
- The atlas of variation (left) provides useful information of variations in service across England
- Payment mechanisms – for clinics and sleep studies



Dr Martin concluded by talking about codes and sleep tariffs, which he described as being in a mess.

There are no codes for actigraphy and Multiple Sleep latency Test (MSLT), and no true tariff for CPAP titrations

There is a sleep apnoea code of DZ18Z but no procedures are allowed in the coding

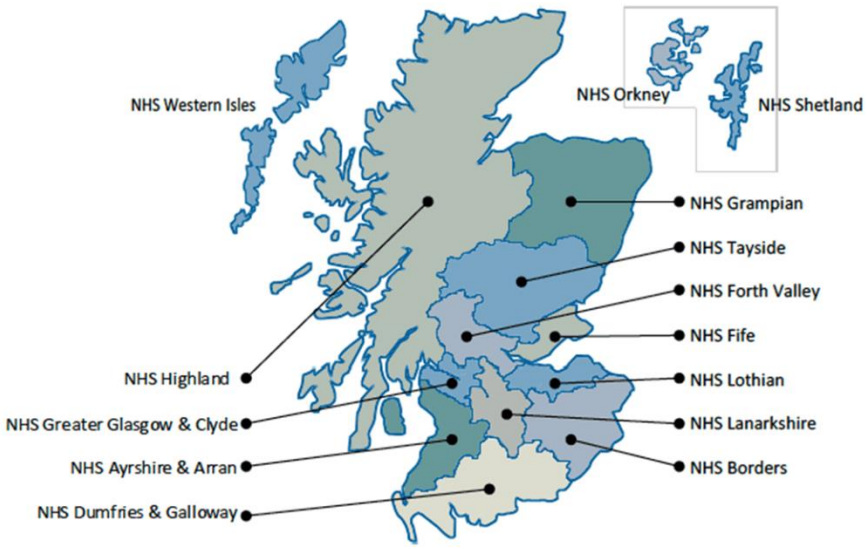
Outpatients Respiratory Medicine	TFC 340
New outpatient	£182
Follow up	£102
Multi-professional N/FU	£241 / £143

Sleep studies (DZ50Z) - there is no payment mechanism for day-case sleep studies, but can these can be coded as an outpatient = £168 (x two)

Scotland

Dr Eric Livingston next talked about the situation in Scotland, on behalf of the Scottish Sleep Forum.

There are two major centres In Edinburgh and Glasgow offering a full range of hospital (PSG) and home based outpatient (respiratory PSG / oximetry) sleep studies and treatment.



Other health boards offer varying degrees of assessment / treatment.

- Borders pass all patients to Lothian
- Ayrshire & Arran / Lanarkshire investigate locally at home then pass equivocal / positive studies to GGCHB
- Tayside/Grampian/D&G investigate at home and treat locally

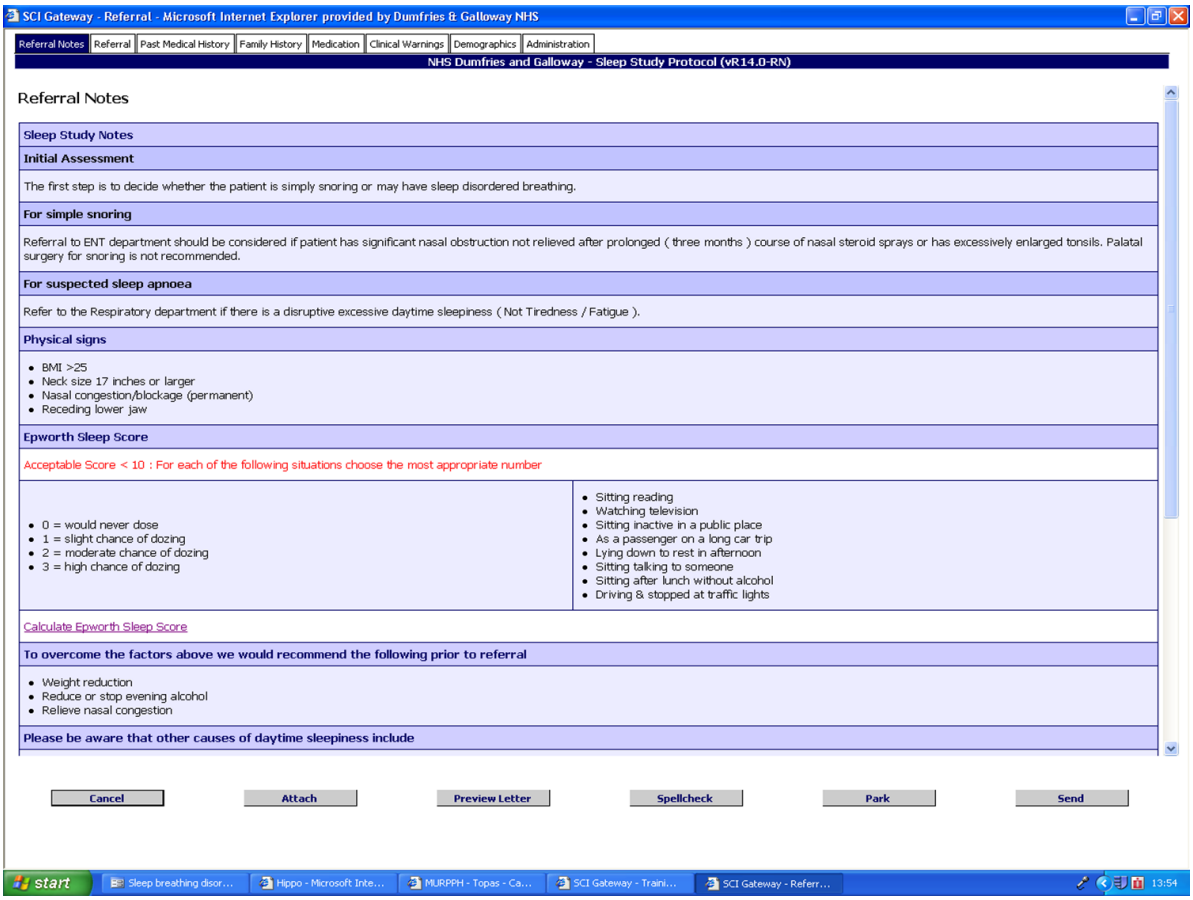
There is significant variation exists across Scotland in the availability of investigation and in the delivery of treatment of OSAS.
Dr Livingston identified the key problems as being:

- Exponential rise in new patient referral numbers for suspected OSAS making compliance with 18 week referral to treatment (RTT) target impossible to achieve in all health boards
- Geographical inequity of access to investigation and treatment
- Technical diagnostic support is a limiting factor even in tertiary referral centres
- Lack of standardisation of current clinical practice

This is placing an unsustainable demand on the current system, and has been exacerbated by initiatives to meet the 12 week new patient referral to first out-patient appointment target.
The current referral to treatment time (initial appointment + diagnostic test + analysis of test result + wait for treatment) for routine OSAS cases was as high as 42 weeks in Edinburgh and 44 weeks in Glasgow.
The Scottish Sleep Forum (SSF) was established in 2008. It is a multi-disciplinary group of doctors, nurses, and physiologists, with representatives from throughout Scotland. It meets twice per year in Stirling.
The aim of the SSF is to develop a safe, efficient, effective, timely, equitable and patient centred service for those suspected of having OSAS no matter where they reside in Scotland. This is in line with the recently published Healthcare Quality for NHS Scotland document.
The SSF has developed minimum standards which focus on five areas:

1. Referral standards
2. Diagnostic and treatment standards
3. Patient review standards
4. National core data set
5. Driving issues

An electronic referral protocol has been devised which is used in some health boards but not all.



The standards were set up through a partnership approach - BLF Scotland organised meeting with the Long-Term Conditions Alliance, and the standards were endorsed by National Advisory Group (NAG) respiratory managed clinical networks (MCNs).
The document was circulated to all chief executives of Scottish health boards with the aim of encouraging health boards to prioritise sleep services and develop sustainable cost effective local solutions to the problems.
The impact of developing the standards:

- Prompted discussion in some of the smaller health boards
- Clinicians feel more supported
- Allowed some clinicians to get funding for local investigation of patients

Dr Livingston concluded by saying that Dr James Cant, Head of BLF Scotland and Northern Ireland, has been instrumental in the development/dissemination of our standards, particularly through his contacts in the Scottish Government and different health boards.

Northern Ireland

Dr Martin Kelly gave an overview of the situation in Northern Ireland.
There are five health trusts looking after a population of 1,799,392. Dr Kelly talked about the BLF's mapping work on OSA which indicates that the areas with the highest predicted prevalence of OSA (calculated from the prevalence of known OSA risk factors) are not necessarily the areas where there are sleep services, particularly in the Northern Trust. The Western Trust has mapped all their OSA patients by postcode.
Prior to 2007, there were very limited

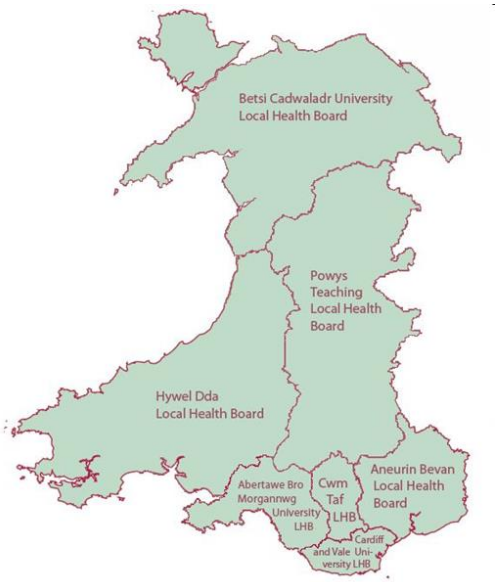
services, in Belfast & Derry only, and with no PSG. This meant that there was a patchy and inequitable access to services; tended to be somewhat Belfast-centric. Also, resources and staff were very stretched.
The service framework for respiratory health and well-being was produced in 2011. Following this, there has been some investment into sleep services and Belfast is about to begin PSG.
Dr Kelly highlighted the problems in Northern Ireland:

- Massive increase in demand – obesity epidemic, increased awareness
- Funding/resources based upon historical estimates of prevalence and demand
- There had been a massive backlog of people to be seen and to commence CPAP – this needed clearing
- Some funding this year – to firefight

Wales

Dr Amit Benjamin gave a presentation about the situation on Wales, on behalf of the Welsh Sleep Group.
In 2009, it was recognised that the service was underdeveloped. In November of that year, sleep representatives from the six health boards met with The British Lung Foundation.
The aims of this meeting were to:

a) establish current service provision;
b) recommend a national strategy with minimum clinical standards in Wales



Using the model developed by the BTS and ARTP, and published in the IMPRESS service specification in 2009, an audit was carried out, which revealed that none of the health boards were meeting the standards recommended, especially with regards to the estimated waiting time from referral to treatment – in three boards this was 30 weeks, three years and "infinite". There was a variable service across Wales, and no specialist centres for more complex cases.
Minimum standards for Wales were devised:

1. All local health boards should provide local facilities for investigation of sleep disordered breathing
2. All acute hospital should have facilities for investigating and treating sleep disordered breathing
3. Any patient diagnosed with criteria accepted in the NICE guidelines for CPAP should be provided with CPAP
4. Each health board should have one specific centre for investigation of complex problems

A hub and spoke, three tier level of care model was proposed.
In 2010, the strategy document for sleep disordered breathing services in Wales was produced and sent to all health boards.
Subsequently, in May 2012, another review was undertaken. The aim of this was to:

- Assess current service provision
- Assess if the All Wales document has had any impact
- Assess deficiencies
- Provide the BLF OSA group with an overview of the Welsh service.

Results, compared with 2009, indicated:

- Continued shortfall in estimated referral to treatment times
- Continued shortfall in estimated referral to diagnosis times
- Continued shortfall in recommended staffing ratios
- Better access to diagnostics
- Better access to CPAP funding

In 2013, the draft of the Welsh Delivery Plan was produced for consultation and this document is due for publication this month. The five year plan provides a framework for action by local health boards and NHS Trusts. It sets out the Welsh Government's expectations of the NHS in Wales to tackle lung diseases in adults and young people wherever they live in Wales and whatever their circumstances".

The document states that the assessment and management of sleep disordered breathing conditions requires an all-Wales network of adequately staffed and equipped sleep laboratories to undertake assessment, overnight sleep studies and the provision of the ventilators (CPAPs) for those with moderate/severe OSAHS. It also sets out that there should also be hospitals identified as providing more specialised sleep investigations for those with complex sleep-disordered conditions (Lewis and Benjamin, 2010).

Proposed outcome for Wales:

- Increase the number of patients with suspected moderate/severe OSAHS who are assessed are treated annually

Health boards will need to:

- Ensure that pathways for the investigation of sleep disordered breathing (SDB) are established to assess and treat patients with OSAH within established RTT
- Undertake a population needs assessment and review current levels of service for SDB against the recommendations of the strategy document for sleep disordered breathing services in Wales 2010

Dr Benjamin thanked the BLF, especially Chris Mulholland, head of BLF in Wales.

OSA in the future – session 7

How do we ensure OSA is a priority?

The final session in the conference involved all speakers from sessions one to eight joining Dr Brendan Cooper on the platform to lead a panel debate and audience participation discussion.

The key points to emerge were as follows:

- Services should be designed for patients and the patient voice must be part of service planning, so that services help the people who need them
- The BLF's "PR machine" should be utilised by service planners, and the work of the BLF should be widely disseminated
- Sleep clinicians being deluged with referrals should not be seen as a problem – it should be part of the solution as it provides evidence of need, therefore raising awareness should not be perceived as a problem by health care professionals
- Sleep clinicians need to work in partnership with other health care professionals and especially with GPs
- Dentists should be encouraged to become more involved with OSA care – the British Association of Dental Sleep Medicine provides training and (in partnership with ARTP) guidance
- Sleep clinicians should work more closely with local GPs to encourage them to be involved with sleep centres and to develop more GPs with a Special Interest (GPwSIs)
- Health care professionals need to commit to put together business cases for commissioners / service planners, especially in small CCGs in England
- Health care professionals in the UK should have a unified approach - there is a need to bring together recommendations into one document which all involved in the BLF's OSA campaign could be involved in producing. This should be clear and precise and should contain BLF resources such as the mapping results, patient survey results
- The solution to engaging GPs and commissioners may lie in "piggy-backing" OSA onto other conditions that they are interested in, which are closely linked to OSA, such as obesity and diabetes, in order to highlight OSA
- Co-morbidities are very "fashionable" at the moment and a priority in England is outcomes around long term conditions – OSA fits with this
- GPs do what they get paid for – we need to consider the incentives for GPs
- Future campaigning could include the theme of the "two week wait" for drivers
- The BLF should continue to campaign

Key takeaway themes

Steven Wibberley, Director of Operations and Innovation at the BLF closed the conference by summing up the key takeaway themes:

1. There is a rise in demand for services
2. There is variation in service provision between and within nations in the UK
3. There is a growing "follow up mountain" of people on treatment
4. There is a need to develop ways to influence and support the commissioning / planning process

Conclusions

This is believed to be the first UK conference on OSA, bringing together experts from across the UK to provide a snapshot of the issues they face, to share innovative practice, and to discuss OSA as an ongoing priority.

The conference enabled participants (speakers and the invited audience) to share experience and expertise, discuss and debate issues between and within nations and along the patient pathway, and contribute to conversations about how to ensure OSA is a priority in the future.

There was some difference of opinion amongst the experts, but also many themes on which there appeared to be broad agreement. Many of the issues they faced were similar although different approaches and models had been adopted.

The patient pathway

Screening and referral – the role of GPs is changing, and in England GPs, through their local CCGs, are now commissioning sleep services as well as having a role in service provision. There is a need to raise awareness of the importance of OSA with GPs, particularly in relation to the link OSA has with associated co-morbidities and traffic collisions. There is a role for expert health care professionals in sleep clinics to provide training and education to their local GPs, and there are BLF resources to support this. There is also a need for some sleep clinics to work more closely with their local GPs and to investigate local pathways in which the role of the GP is clear. This may involve looking at local tariffs and how GPs could be incentivised. When GPs take an active role in screening and referral pathways then this is beneficial to the patient, the GP and the sleep clinic.

Assessment and diagnosis – the key components to a good service are a good quality referral, a subjective assessment of sleepiness, a sleep study and a clinical assessment. A one-stop shop for CPAP set-up can shorten the total patient pathway, especially from diagnosis to treatment, and can reduce concerns about driving. Using an autoset CPAP machine for the initial CPAP trial can be beneficial. Offering group education sessions can allow more patients to be set up and is an efficient approach (especially re "DNAs" – patients who do not attend).

Local specifications for assessment, diagnosis and treatment of OSA – a successful model for developing sleep services is one which demonstrates the need, looks at current service provision, identifies what services should be in place, and offers a proposed structure.
Demonstrating the need involves highlighting the demand for the service, explaining the condition, its prevalence and impact, quoting relevant guidelines and recommended treatments, identifying barriers and challenges, stating the case for local pathways, and explaining the health economics.
Looking at current services needs to include identifying the current roles of different health care professionals and partner organisations / stakeholders.
Examining what services should be available involves identifying what additional capacity and capability would include, such as infrastructure, staffing, training, treatment, access to comprehensive and specialist services. It also involves using a network approach involving primary, secondary and tertiary care.
The proposed solution should be based on current guidelines and local need. It should include the roles of all those in the local network, including primary care, secondary care and tertiary care, and should give detail about the resource requirements, training requirements, key performance indicators, potential funding streams, and locally agreed fees.

Management, ongoing support – there are different models being practiced. Some clinics outsource follow up to another provider through a partnership agreement for uncomplicated, so called "barn door" cases. Some clinics continue annual follow up, others follow up every two years for uncomplicated cases, and others discharge patients once they are established on therapy. CPAP treatment only becomes cost-effective after time, and initial set-up is very important to ensure good compliance - the long term pattern of CPAP use is established in the first week, and that is it very difficult to predict who will respond well. There are many reasons why people stop using CPAP. However, CPAP compliance has been shown to be better than compliance with medication for asthma or hypertension. If the follow up service is provided directly by the sleep clinic, a team approach is needed, to offer technical advice, medical advice, troubleshooting support and a range of choices e.g. face to face, group, phone helplines, text reminders. Negative framing may have more impact on CPAP compliance e.g. if you do not use your CPAP, you will not be treating your sleep apnoea. Use of new technology can help in the early days, whereby CPAP compliance can be measured remotely using a wireless device.

Minimum standards

England – sleep services are, from April 2013, mainly commissioned through the 211 CCGs. The drivers for care are varied, and are informed by national and international guidelines; however there are no minimum standards, and the tariff and coding system needs reviewing.

Scotland – the Scottish Sleep Forum has developed a minimum standards document focussing on referral, diagnosis and treatment, patient review, national core data set and driving issues. This has been sent to all health boards. An electronic referral protocol is in place in some areas.

Northern Ireland – there is a service framework for respiratory health and well-being and there has been some investment recently in sleep services, with the first full polysomnography (PSG) about to start in Belfast.

Wales – sleep provision was audited in 2009, highlighting gaps in service, and in 2010 the Welsh sleep group produced the Welsh strategy for sleep disordered breathing which was sent to all health boards. Four key standards were identified concerning investigation, treatment, following NICE guidance on CPAP and provision of centres to investigate complex cases. A hub and spoke three tier model was introduced. A repeat review was carried out in 2012 which showed some improvements but also highlighted areas of continued concern.

Common themes across the four nations:

- Rise in demand for services
- Service provision varies across the country
- Funding and resource issues are still a problem in some areas
- Need for GP awareness and increased role of GPs in screening and referral
- Need for pathways and networking to clarify the role of all health care professionals
- Need to look at the follow up mountain and how this is tackled

Ensuring OSA is a priority

Emerging themes from the debate were:

Patients at the centre of care – services should be designed for the patient, and the patient voice must be part of service planning. Raising awareness of OSA to help more patients get access to services provides evidence of need. Promoting a two week wait for drivers would alleviate patients' concerns about losing their driving licence.

Working in partnership with others – sleep clinics should work closely with local stakeholders, including GPs, commissioners and service planners, dentists, and other secondary care specialists.

Working together – health care professionals specialising in sleep in the UK, and the BLF should build on this conference and work together in a unified way to produce a clear document with key recommendations.

Commissioning and planning services – locally, health care professionals need to commit to put together business cases for commissioners / service planners, and the BLF's work should be disseminated. Emphasising the association between OSA and key co-morbidities, and incentives for GPs could influence commissioning.

What next?

The BLF will continue working on a range of activities focussing on OSA throughout 2014, with the aim of establishing a programme of OSA activity which becomes "business as usual" and is embedded in the BLF's overall programme to support people with respiratory disease, rather than to continue to offer a specific long term OSA project.
The BLF's OSA work will continue, especially at a local level, to focus on raising awareness of OSA so more health care professionals and people at risk understand the symptoms, and to carry out activities to campaign for improved service provision to enable people with OSA to get the right treatment (the exact level and content of this activity will depend on funding secured).

During 2014, the BLF's activities will include:

To raise awareness of OSA

- Media campaign
- Upload and promote new video of a person with OSA onto BLF website
- Promotion of BLF website
- TNS online survey about OSA awareness – compare with baseline three years ago
- Promote GP screening programmes at a national and local level
- Fundraise for, and carry out targeted OSA awareness / screening campaigns
- Fundraise for and carry out a work-place awareness and screening programme (WASP)

To improve service provision for people with OSA in the UK
The key piece of work for the BLF in 2014 will be to produce a report on OSA health economics, and to develop a commissioning / planning toolkit for OSA services, using existing BLF materials such as the mapping tool, patient survey results and this conference report, plus existing guidelines and research findings where appropriate.
In addition the BLF will:

- Complete and disseminate OSA project evaluation including recommendations
- Report findings from the OSA patient survey
- Complete and disseminate findings and recommendations from BLF OSA conference
- Parliamentary activity - using mapping tool to produce bespoke OSA mapping reports for MPs / parliamentarians as requested or when an interest in OSA is expressed, followed up with meetings and introductions as appropriate
- Regional campaigning – using OSA charter, mapping, and other resources as they become available
- Maintaining a national presence
- Developing an interactive online OSA mapping tool – look into funding opportunities

Specifically as a result of the OSA conference, the BLF will arrange to facilitate a meeting of stakeholders and will facilitate the writing of a document that brings together in one place the evidence for and the tools to develop services for people with OSA in the UK.

Acknowledgements

The British Lung Foundation would like to thank the following:

- OSA conference speakers
- BLF OSA advisory group
- Association of Respiratory Technology and Physiology, particularly Dr Brendan Cooper
- Executive Business Support, especially Jackie Hutchinson
- Conference sponsors:
  - ResMed
  - Philips Respironics
  - Fisher and Paykel

Glossary of acronyms

ARTP	Association for Respiratory Technology and Physiology
BLF	British Lung Foundation
BP	blood pressure
BTS	British Thoracic Society
CCG	clinical commissioning group
CPAP	continuous positive airway pressure
CQUIN	Commissioning for Quality and Innovation
DH	Department of Health
DNA	did not attend
DVLA	Driving and Vehicle Licensing Agency
EDS	excessive daytime sleepiness
ESS	Epworth Sleepiness Scale
GP	general practitioner
GPwSI	GP with a special interest
HCP	health care professional
HRG	Healthcare Resource Group
HRT	hormone replacement therapy
HSASG	Humber sleep apnoea support group
MCN	managed clinical network
MOST	Management of Specialist Therapies
MSLT	Multiple Sleep Latency Test
NAG	National Advisory Group
NHS	National Health Service
NICE	National Institute for Care and Excellence
OSA	obstructive sleep apnoea
OSAHS	obstructive sleep apnoea hypopnoea syndrome
OSAS	obstructive sleep apnoea syndrome
PAT	portable appliance testing
PCRS	Primary Care Respiratory Society
PSA	polysomnography
QALY	quality of life year
QIPP	quality, innovation, productivity, prevention
QOF	Quality Outcomes Framework
RTA	road traffic accident
RTT	referral to treatment time
SDB	sleep disordered breathing
SSF	Scottish Sleep Forum
TAG	Technical Appraisal Guidance
wte	whole time equivalent

Conference programme and speaker profiles

Programme

Time	Session title	Speakers
9.00	Registration	
9.30	Welcomes and introductions	Brendan Cooper, Steven Wibberley
9.35	The Patient Pathway	
	Screening for OSA – the role of GPs	John Stradling, Malav Bhimpuria
	Assessment and diagnosis of OSA – setting up a 'one stop shop'	Maxine Hardinge
	Treatment of OSA – setting up a business case and local service agreement	John O'Reilly
	Management of OSA – why ongoing support is important, and different models available	Adrian Williams Jayne Pateraki Beccy Mullins David Dawson
10.55	Break	
11.10	The Patient Pathway – discussion groups	Facilitated by above speakers
11.50	OSA minimum standards – where are we now?	Martin Allen (England) Eric Livingston (Scotland) Martin Kelly (Northern Ireland) Amit Benjamin (Wales)
12.15	OSA as a priority – how do we ensure it?	Brendan Cooper, chairing an expert panel
12.30	Closing remarks, followed by lunch	Steven Wibberley

The BLF would like to thank ARTP for their help to organise the conference and project funder Philips Respironics and ResMed

Primary conference sponsor ResMed

Philips Respironics

Fisher&Paykel Healthcare

Conference **Speaker Profiles**

Martin Allen – Martin's interest in respiratory problems originated from researching sleep and physiological changes in COPD. He has held many hospital management roles. Martin was a BTS executive without portfolio, and treasurer of the Royal Society of Medicine sleep section. He chairs the respiratory EWG and represents respiratory and sleep medicine on the speciality reference group of choose and book. He is the secondary care consultant on Telford and Wrekin CCG, and he chaired the DH working party on OSA in 2012.

Amit Benjamin – Amit grew up in the valleys of South Wales, and qualified from the University of Wales College of Medicine in 1998. He was appointed as a chest physician at the Royal Glamorgan Hospital in 2008. Amit assisted in writing the *All Wales Sleep Disordered Breathing in Wales* strategy document in 2010. He is very interested in sleep disorders but would like to emphasise that he is not a sleep expert and would advise that all technical sleep questions are directed to the other members of the panel.

Malav Bhimpuria – Dr Bhimpuria is a GP in Huntingdon and while chair of his local commissioninggroup, developed an integrated community sleep studies service for Huntingdonshire, which was modelled on work he had previously done at practice level. An innovative GP and commissioner, he is passionate about patient care.

Brendan Cooper – Brendan is a consultant clinical scientist in respiratory physiology at Queen Elizabeth Hospital Birmingham and Hon. Senior Research Fellow at the University of Birmingham. He has published more than 70 peer-reviewed papers and is a world leader in the drive for quality diagnostic spirometry, having roles at the Department of Health (DH), European Respiratory Society (ERS) and with the American Association for Respiratory Care. He was chair of ARTP for 9 years, and now chairs ARTP Sleep.

David Dawson – David is a consultant anaesthetist at Bradford Teaching Hospitals NHS Foundation Trust. He has a specialist interest in sleep-disordered breathing and has been running clinics for OSA patients since 1998, seeing patients through both the NHS and independent sector. In addition to clinics, David works as a medical advisor to Philips Respironics. He has also set up his own company which offers advice on diagnosing and treating OSA, working with individuals and with companies looking to develop screening programmes.

Maxine Hardinge – Maxine has worked as a consultant physician in the Oxford University Hospitals sleep unit since 2000, and has been involved in service developments for the sleep and home ventilation team. She is clinical lead for the Oxford Respiratory Unit, was respiratory lead for South Central SHA from 2010-13, and is currently chairing the BTS home oxygen guidelines group. She has spoken on OSA at the BTS, Royal Society of Medicine, BMJ Master-class series, BLF and Sleep Apnoea Trust (SATA) meetings. She is committed to providing high quality, patient-centred services.

Dr Martin Kelly – Martin has worked as a consultant respiratory physician at Altnagelvin Area Hospital since 2004. He graduated from Queens University Belfast in 1993 and completed an MD examining aspects of airway inflammation in obstructive lung diseases in 2002. For 12 months, he worked as a senior registrar in New Zealand, combining clinical work and research. He returned to Northern Ireland and took up his present post. Clinical interests include COPD, pulmonary rehabilitation and bronchiectasis. He is developing an EBUS service at Altnagelvin. Research interests include rehabilitation and bronchiectasis. His interest in sleep medicine is very much at the service delivery end of things. As the clinical demand has mushroomed within the trust, he and his colleagues have worked closely with management and commissioners on the challenge of meeting service requirements.

Eric Livingston – Eric is a consultant respiratory physician at Glasgow Royal Infirmary and lead for adult sleep services in Greater Glasgow and Clyde. He has been involved in the Scottish Sleep Forum since its conception and now chairs this group, which has developed minimum standards for sleep services in Scotland, and produced national referral guidance. He has been working with the Scottish Government to improve access to sleep services in Scotland.

Beccy Mullins – Beccy is a registered general nurse and has specialised in sleep medicine for 18 years, much of that time working at the Oxford Department for sleep medicine with Professor John Stradling as a clinical nurse specialist. Today Beccy leads ResMed's clinical services team, working with NHS providers to develop and support clinical pathways for OSA. Beccy also has direct patient involvement and oversight of ResMed centres for healthy sleep in central London and Abingdon.

John O'Reilly – John is a consultant in sleep and respiratory medicine and lead clinician in sleep medicine at the Liverpool sleep and ventilation centre, University Hospital Aintree, and Honorary Lecturer at Liverpool University. His interests include clinical outcomes, quality of life, health economic assessment and service development in respiratory and sleep disorders including OSA. He co-chaired the North West SHA review of sleep services and North West sleep network. He has promoted education and training as an executive committee member of the BSS and is co-organiser of the International Sleep Medicine Course.

Jayne Pateraki – Jayne currently works as an advanced nurse specialist at York Hospital. She leads a team of nurses diagnosing, treating and providing follow-up care for patients with sleep-disordered breathing. She obtained an MSc in evidence-based practice at York University in 2006. She has worked with the BLF on their current three-year project raising awareness of OSA nationally and developing priorities for ensuring that OSA remains a priority for health care provision in the future.

John Stradling – John Stradling is Emeritus Professor of Respiratory Medicine at Oxford University and was director of the respiratory sleep service until 2013. His research on sleep-related disorders of breathing has recently concentrated on its association with cardiovascular consequences. He has published mote than 180 original publications in peer reviewed journals and recently received the 2012 William C Dement award from the AASM for contributions to academic sleep medicine.

Steven Wibberley – Steven is Director of Operations and Innovation at the British Lung Foundation. Steven joined the BLF in 2012 after working at Macmillan Cancer Support. Before moving to the charity sector, Steven had worked in the NHS for more than 20 years, most recently as London Regional Director at NHS Direct.

Adrian Williams – Adrian published a definitive study at Harvard implicating OSA as a cause of SIDS, followed by the first reports of OSA causing hypertension and of oximetry as a diagnostic tool whilst at UCLA, where he became tenured professor of medicine and co-director of the sleep lab. He established the sleep disorders centre at Guy's and St. Thomas' where he is a consultant physician. Adrian is a diplomat of the American Board of Sleep Medicine, a somnologist (ESRS), a founding member of the sleep medicine section of the Royal Society of Medicine and the UK's first chair in sleep medicine at Kings College, London.

Conference list of delegates and speakers

Name	Role
Adrian Kendrick	ARTP
Adrian Williams	Professor of Sleep Medicine
Alaw Holyfield	Sleep Physiologist, Bangor
Allan Robins	HSASG
Amit Benjamin	Consultant Physician
Andrew Meredith	BLF Advisory Group
Anwen Evans	Philips Respironics
Beccy Mullins	ResMed
Bernadette Coleman	Philips Respironics
Bev Wears	BLF
Brendan Cooper	Consultant Clinical Scientist
Caroline Keating	ARTP
Chris Rogers	SATA
Claire Parker	Respiratory Physician, Yeovil
Darren Kershaw	F & P
David Dawson	Consultant anaesthetist
Debi Wainwright	Fisher and Paykel
Deborah Lamont	Sleep Physiologist, Blackpool NHS Trust
Dorothy Price +1	(via ARTP)
Dr Dilys Waller	Lead GP (interest in respiratory)
Emma Braithwaite	ResMed
Emma Spence	ARTP
Eric Livingston	Consultant Physician
Francesca Macdonald	lead CNS for Sleep, Yeovil
Gavin Phillips	ARTP
Graeme Wellard	Intus
Harry Gribbin	Sleep Consultant, S Tees
Hilary Mortimer	Respiratory Nurse Specialist, Devon
Jay Lingwood	(via ARTP)
Jayne Pateraki	Specialist nurse
Jennifer Coulson	ARTP
Jenny Gingles	Public Health Agency
Jillian Baker	Consultant Physician, Nottingham
Jiten Master	Dentist
John Mitchell	ResMed
John O'Reilly	Consultant physician
John Stradling	Emeritus professor
Jose Thomas	Wales
Judy Harris	BLF
Julia Roberts	Principal Physiologist, Bangor
Julian Leggett	NI
Julie Chapman	ARTP
Katie Merrick	BLF
Kylie Russo	(via ARTP)

Laura Knowles	Philips
Laura Liddiard	Senior Physiologist, Plymouth
Lee Radforth	Rotherham General, Senior Physiologists
Lesley Bagnall	SASA
Liz Brohan	Wales
Malav Bhimpuria	GP
Martin Allen	Consultant Physician
Martin Heller	Intus
Martin Kelly	Consultant Physician
Mary Morrell	England
Maxine Hardinge	Consultant physician
Michael Nicholson	Blackpool Hospitals
Mini Travis	Philips
Nicola Walters	
Phil Paice	Philips
Ray Walker	SASA
Richard Hawksworth	(via ARTP)
Rogerio Pereira	Senior Physiologist, Plymouth
Rosemary Fillingham	
Roy Dookun	BLF Advisory Group, BSDSM
Sandra Davies	ARTP
Sophie Bond	ARTP
Stephanie Walker	ARTP
Stephen Tomlinson	Blackpool Hospitals
Stephen Thomas	CPAP Nurse Consultant, S Tees
Steve Russell	ARTP
Steven Wibberley	Director of Operations and Innovation, BLF
Sue Evison	England
Sue Renwick	Liverpool CCG
Tamara Lewin	ResMed
Teri Challier	Philips Respironics
Tim Brown	Philips
Tom Parr	Intus
Tracey Titterington	Blackpool Hospitals
Vasanti Master	Practice Manager
Vikki Cooper	ARTP
Yvonne Lloyd	ARTP