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OSA: In the Frontline

Findings of an independent evaluation of the British Lung Foundation project on Obstructive Sleep Apnoea

September 2014

Evaluation Report Reshenia Consulting

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Executive summary

Introduction

The British Lung Foundation (BLF) is one of the UK's leading health charities. It has a strong patient focus, and works for everyone affected by lung disease. It also has strong links with the medical profession. Its main areas of work are to support people affected by lung disease, to promote greater understanding of lung disease, to campaign for change in the nation's lung health, and to fund research into new treatments and cures. In 2008, NICE introduced guidelines about the treatment of Obstructive Sleep Apnoea (OSA), a condition with a high prevalence but little awareness. BLF launched a campaign to address this in 2009/10, with funding initially from Philips Respironics and then also from ResMed. The project ran from 2011 – 2014 and aimed to increase awareness of OSA by targeting both the general public and health care professionals, to find undiagnosed people, to promote OSA as a strategic priority in healthcare provision, and so to improve provision of, and access to, services along the patient pathway for people with OSA.

An independent evaluation was carried out by Reshenia Consulting at the end of the project. It focused on the OSA project's awareness raising and information work, researching both the outputs and the outcomes of the project, and considering the successes and the challenges faced. The evaluators also investigated changes in services and the development of service pathways, leading to improvements in the quality of life for people with OSA.

Evaluation findings

Overview

A huge amount of activity has taken place over the three years of the OSA project, including the production of materials about the condition aimed at different audiences, surveys to establish its prevalence, events and media activity to promote greater understanding. From a starting position of an “*appalling*” information deficit, stakeholders reported that by the end of the project, there had been “*incalculable*” progress in raising the profile of and awareness about OSA. The OSA project produced clear, well evidenced and reliable data, tailored to the different readers within a wide range of audiences including patients, providers and politicians. The BLF had a presence at industry and health care professional events, and devised a number of ways to engage with patients, e.g. through Breathe Easy groups and events, and via the Epworth Sleepiness Scale online which was used by over 40,000 people over the first three years that it was on the BLF website.

The project was viewed as well-organised and comprehensive. Further, the role and the reputation of the BLF itself, and the fact that it prioritised this issue, was reported to have given increased credibility to the issue of OSA. BLF was described as an “*honest broker*” that is respected within the health field, which brings a breadth of experience and has a genuine and demonstrable connection with patients and patient groups. It was described as a ‘trusted brand’, and so its materials were also trusted and valued.

Well researched and designed materials about OSA

The evaluators heard consistent reports about the quality of the BLF materials about OSA, which were described as attractive and professional. The materials promoted consistent and clear messages about OSA, and patient groups appreciated being able to distribute them to their members. The quality of the materials was reported to have been significant in enabling the project to achieve its aim of increasing patient and public awareness and the understanding of OSA symptoms and prevalence among the public and among health care professionals.

Piloting an approach to raise awareness: the County Durham Campaign

An intensive campaign took place in County Durham between May and August 2013, to pilot an area-based approach to raising awareness. A local steering group was set up, which included commissioning managers, GPs, and secondary care and health care professionals: the added value of this network is still being experienced today. Four events were run in a variety of venues across the county, chosen for their high footfall: supermarket pharmacies, an outdoor market place and a shopping centre. 1050 'at risk' households were contacted via telemarketing, to inform people about the campaign events. Two OSA awareness sessions were held for GPs after the events. Approximately 10,000 campaign leaflets and 600 posters were distributed across County Durham and Darlington, with 31 community venues displaying the materials. A large number of people used the Epworth Sleepiness Scale: at the events, about half of those who did received further health advice. There were 128 new referrals to two sleep clinics.

As a result of the campaign, there was a demonstrable increase of awareness of OSA within local Respiratory Networks. An unexpected gain from the campaign was its impact on local services, with ongoing discussions in one CCG in County Durham to develop a service specification for commissioning OSA services which would cover the whole of County Durham. The campaign appears to have been a resource intensive but effective way to deliver elements of the project within a specific geographical area. However, the true impact can only be assessed over a longer period of time.

Evidencing increases in awareness

There was considerable anecdotal evidence that there is greater awareness of OSA at patient level at the end of the project. More patients are being identified, more people are presenting with symptoms, and more sleep studies are being done. Data about increased demand was not gathered systematically through the three years of the project and is an area to build into future work.

The area of least impact was primary care/GPs, despite the production of an information pack targeted specifically at this audience. It was not possible to fully assess the impact of the project on GP awareness, but an industry partner commented that *"amongst all the GPs who have been contacted by or are in contact with the project...now that they know about OSA, they cannot un-know about it."* Because GPs were defined as the *"gatekeepers to get a diagnosis"* they should be considered a target for future work.

Overall, changes in awareness will be evidenced in the main by changes of attitude and behaviour and, as such, are likely to occur over a time period that is longer

than three years. While the evaluators have tracked the activities that went into this goal, it was harder to draw firm conclusions about the impact of the work.

Improving quality of life and enabling higher levels of diagnosis

The OSA project had a strong patient focus, and was informed by BLF's direct engagement with patients, e.g. through the Breathe Easy Groups. Much of the information and tools produced were targeted at patients, e.g. the Epworth Sleepiness Scale on line, which offered a simple mechanism that enabled people to identify and act on their health needs. This is a powerful approach that would be made stronger if respondents who had taken the test were followed up and their outcomes tracked.

The emphasis of the work towards improving quality of life for people with OSA was on enabling higher levels of diagnosis, after which, as one interviewee said, she "*started to live life again*". An online survey of 2000 adults was undertaken in 2011, and again in 2014. This showed a significant increase in awareness of OSA from 57% to 62%. Further awareness work took place through the Breathe Easy groups, and at events in Breathe Easy weeks. BLF staff reported a spin off benefit of the OSA project: it offered a good way to "*start the conversation*" about respiratory health with a large number of people.

Promoting OSA as a strategic priority and improving services

The BLF recognised that diagnosis alone, however, would not improve services. OSA needed to be given a higher strategic priority. To address this, the project produced ten medically approved reports on different key issues such as awareness, diagnosis and treatment, based on a literature review (2011); engaged with health care professionals; and had an active and visible presence at relevant professional conferences. Through this activity, the project manager sent information about the OSA project to over 2000 professionals. The project mounted an active parliamentary and media campaign, engaged with members of the sleep industry (through a Sleep Industry Forum that it set up), and engaged with patients. Throughout its life, the OSA project continued to produce new research, e.g. the sleep clinic patient survey which was the largest survey of people with OSA carried out in the UK, and the OSA mapping project.

The OSA mapping project created a set of maps showing the location of sleep clinics in the UK, and indicated potential OSA hotspots. This information provided powerful ammunition for those who wanted to see OSA having a higher strategic priority in service provision, and has enabled evidenced cases to be made for increased provision in some poorly served areas. In some areas where service improvement has taken place (e.g. Wales and Northern Ireland), the project was cited as one of a number of factors that contributed to service improvement. BLF staff working at a devolved nation or local level and sleep practitioners found that the mapping offered an additional focus, and the project overall gave them additional resources that supported their ongoing work.

Similarly, the OSA charter was perceived as setting out, in simple terms, what a good service looks like. There was no clear data about the impact of this: how many services had adopted it or changed as a result of it. However, stakeholders thought it was a positive output of the OSA project.

Service improvement

Both the quantity and quality of information produced by the OSA project and the networking opportunities it created enabled a dynamic dialogue about the nature of services and their improvement. This finding was tested in a health care practitioners' survey for the evaluation. 48% of respondents either agreed or strongly agreed that they had been able to develop better services. 75% of respondents agreed (49%) or strongly agreed (26%) with the statement that the project "has enabled me to inform and influence other health care practitioners." This indicates the effectiveness of peer to peer dissemination of information and suggests that having key health care professionals as OSA champions and advocates would be worth exploring in future.

Increasing diagnosis: increasing demand

There were significant increases in the demand for services over the three years of the BLF OSA project, at the same time as growing pressures on sleep services. The challenge for the project has been the wholesale change in the structure of the NHS in England, and the UK-wide pressure on NHS resources over the period of the project. It was widely reported that sleep services are really struggling with their patient numbers and the demand. The BLF has been sensitive to these tensions, and about the need for campaigning to also take account of the practicalities of implementation. The project manager responded by making connections between professionals who were working on similar areas of service improvement, enabling examples of good practice to be shared throughout the project. This was an important, if unintended, outcome of the work.

Improved patient pathways

Stakeholders reported a general improvement of patient pathways – more as a result of the increased demand for services and improved levels of care than as a direct impact of the OSA project. However, the BLF promoted the knowledge and shared examples of good practice e.g. by demonstrating the implementation of a new pathway in Oxford at a major conference in 2014. 47% of respondents to the health care professionals' survey for this evaluation reported that they strongly agreed (15%) or agreed (32%) that they had been able to develop better care pathways for patients with OSA.

Reshaping services

With increasing demand came the need to re-shape services. However, during the life of the OSA project, the NHS in England underwent wholesale restructure. Stakeholders in England discussed the real difficulties in influencing CCGs about sleep. Although the situation was different in the devolved nations, all experienced increasing resource constraints over the project period. The OSA project hosted a healthy dialogue and a proactive approach to understanding the importance of sleep services, and successfully gathered a body of data about best practice, and after the end of this project developed information about the economic case for provision.

Factors that influenced the overall success of the project

A range of issues were raised about the OSA project that were not directly linked to its core aims but which contributed to its effectiveness.

New organisational relationships: making the most of each contribution

The OSA project enabled people with wide ranging concerns about OSA/sleep to build new partnerships. These were with:

- other organisations in the sleep and the respiratory field,
- health care professionals who are more involved with sleep and OSA than with respiratory medicine in general,
- patients,
- industry partners
- Advisory Group members.

In all areas, these partnerships enabled new areas for dialogue, and so opened doors. Industry partners view the project as a good example of cooperative working, and Advisory Group members found that it offered fertile ground for sharing and shaping good practice leading to service improvement. Many of the relationships developed through the OSA project continue, leaving a lasting (if uncharted) legacy.

Working across the four nations

One challenge for the OSA project was implementation across four nations, each with its own government structures, healthcare system, policies and priorities. Overall, the BLF made good connections between national policy and local delivery, in part by making the most of local opportunities for awareness-raising. The OSA project should be recognised and celebrated as a good example of a project that had both a distinct 'four nations' focus and a UK wide perspective. Many national charities and organisations are not flexible or responsive enough to be driven by local opportunities but the BLF did achieve this with the OSA project.

The quality of project management

All the stakeholders interviewed for this evaluation were clear in their praise for the organisation of the project, and the quality of the project management. There was universal praise for the way the project manager, Judy Smith (Harris), tackled her role. Several people spoke about how quickly Judy became known as 'that sleep woman', generating the high quality information that the project has been praised for, raising the issue of OSA in forums across the UK, and developing the networks that enabled progress with the project and the issue. Large and complex projects succeed through the input of many partners. However, it was clear throughout the evaluation that the role that Judy played, the way she played it, the personal skills she brought to the project and to the BLF, and the expertise that she generated about OSA were significant factors in the success of the project.

Project legacy: what next for OSA?

The OSA project has achieved beyond its expectations. It succeeded in getting OSA 'onto the radar', but without the resources to maintain this level of intensity, there is concern that it will not stay there. There was an acknowledgement among BLF staff that the exit strategy for the OSA project was not as well worked out as anyone

had wished it to be. This learning is already being applied to the BLF's project development process. The ongoing work on the health economics of OSA was widely recognised as a positive outcome from the project. This will be essential in order to engage with commissioners – a task described as challenging but essential to achieve change at a strategic and service delivery level.

BLF could build further on the OSA work through even wider partnerships. OSA is an issue that makes connections beyond the respiratory community, for example with organisations working with linked conditions such as diabetes. Some stakeholders believe that BLF would be “*knocking at an open door*” if it made approaches to organisations such as Diabetes UK, with a view to further developing or sustaining the project. This approach should also be considered by the BLF in future projects.

Recommendations

This is a summative evaluation conducted at the end of the BLF's three-year OSA project. Internally, BLF is looking at developing more systematic approaches to evaluation throughout the life of its projects. Both within and beyond BLF, there is agreement that there is work still to do on OSA. The evaluation identified the following areas for potential development by project partners and supporters:

1. The OSA project's mapping of services against prevalence of risk is valuable and continues to be used but it needs to be regularly updated, particularly as services change. Partner organisations / funders could undertake to refresh the map, ideally on a three-yearly basis.
2. The material produced by the OSA project is highly valued by stakeholders and has contributed to raising awareness but it needs to remain current to be effective. Funding should be identified to enable the BLF, or a partner organisation, to update the OSA project material as is appropriate.
3. Linking with organisations that focus on related health conditions, such as diabetes and OSA co-morbidities, to develop collaborative projects would be an effective way to build on the impetus created by the OSA project.
4. There is an ongoing need to raise awareness of OSA in primary care, especially with GPs and practice nurses. A peer to peer dissemination model may be effective and organisations working to raise the profile of, and provision for, OSA should explore this cost-effective approach.
5. Finding and developing OSA champions is a key factor in sustaining the legacy of the project. Organisations working on OSA should identify ways to link OSA champions to existing networks, and for those networks to support them, and harness and coordinate their drive, even if this is limited to specific localities.

1 Background and context

1.1. The British Lung Foundation and the evaluation of the OSA project

The British Lung Foundation (BLF) is one of the UK's leading health charities. It has a strong patient focus, and works for everyone affected by lung disease. It also has strong links with the medical profession. The BLF has three main areas of work:

- Supporting people affected by lung disease
- Promoting greater understanding of lung disease, and campaigning for change in the nation's lung health
- Funding research into new treatments and cures.

The BLF sees each element as supporting the others. The organisation structures its work in ways that recognise research, communications and patient support as equally valuable, with each informing the other. It has a genuine commitment to working with patients, and to enabling their participation in its work. The values behind this approach mean that the BLF places emphasis on the quality and accessibility of the information it produces, and on its communications work.

In 2008, NICE introduced guidelines about Obstructive Sleep Apnoea (OSA), a condition with a high prevalence but little awareness. BLF launched a campaign to address this in 2009/10.

This evaluation was commissioned in November 2013, towards the end of the BLF's three year project on OSA, and took place between January and July 2014. It has been carried out by Reshenia Consulting, a partnership of independent consultants that specialises in organisational development with charities. Reshenia has extensive experience of undertaking project evaluation and research at a local, regional and national level and has carried out evaluations for national charities such as Age UK, the British Red Cross and Shelter.

The focus of the evaluation was on the OSA project's awareness raising and information work. The evaluators also investigated changes in services and the development of service pathways, leading to improvements in the quality of life for people with OSA.

1.2. Methodology for the evaluation

1.2.1. Initial methodology

Reshenia Consulting's methodology was developed to focus on the impact of the BLF's OSA work, both within the BLF and in terms of changes to OSA awareness and service provision. The evaluation aimed to look at both the

outputs and the outcomes of the project, and to consider the successes and the challenges faced. The approach was to first analyse the BLF's OSA resources and the literature about OSA. The majority of the evaluation was then to be structured around primary, qualitative research/data gathering with key stakeholders, based on an agreed evaluation framework and focussing on the outcomes and impact of the project.

1.2.2. Elements of the evaluation

To become familiar with the issues about OSA, and the OSA project, Reshenia Consulting carried out an outline literature review, focusing on policy and service delivery issues. The evaluators also reviewed and analysed the activities of the project: this analysis drew predominantly from BLF literature and reports.

To gather the views of stakeholders about the OSA project, the evaluators carried out a range of semi-structured interviews with BLF staff throughout the UK, members of the OSA project Advisory Group, individual patients and representatives of patient groups, and health care professionals who have engaged with the project over its life. A focus group was run with members of the Sleep Industry Forum, and semi-structured telephone interviews carried out with industry partners who were not able to attend that session. A full list of interviewees is at Appendix A.

Questionnaires were emailed to health care professionals on the BLF data base. 94 were returned. 41% of respondents (39 individuals) gave their professions as sleep specialists; 21% (19 individuals) were nurses; and 2% (2 individuals) were GPs. The rest varied from pharmacists to respiratory consultants to physiologists. Some were in support groups and one was an industry professional. A second questionnaire for patients was published on the BLF website for the organisation's active web community. Responses were gathered over two weeks at the end of June/beginning of July. There were 29 responses to this survey. The questionnaires are at Appendix B

1.2.3. Challenges

During the life of the OSA project, the BLF itself underwent a significant strategic review followed by a major organisational restructure. This has had wide ranging impacts, including a new approach to evaluation. At the start of the OSA project, the BLF's own mechanisms for impact assessment were not well developed.

Further, a challenge at the heart of this evaluation was that the focus of the work was on raising awareness of OSA. Such change will be evidenced in the main by changes of attitude and behaviour and, as such, are likely to occur over a time period that is longer than three years. While the evaluators have tracked the activities that went into this goal, it was harder to draw firm conclusions about the impact of the work.

It is always difficult to conduct a summative evaluation close to the end of a programme, and evidence of change was further complicated by the changes to the structure of the NHS in England and the resourcing of the NHS across the UK. The Reshenia Consulting team has had to rely on bringing together a wide range of views expressed throughout the conduct of this evaluation. Taken together, they can be seen to provide a snapshot of the impacts of the BLF's OSA work.

2. OSA and the BLF work to address it

2.1. Obstructive Sleep Apnoea, and why it was a priority for the BLF

Obstructive Sleep Apnoea (OSA) is a sleep disorder in which the airway closes, causing a person to stop breathing repeatedly during sleep. If untreated it can occur hundreds of times in a night leading to daytime sleepiness, increased risk of road traffic accidents linked to sleepiness, and other serious health problems. The extent and severity of the airway collapse, and the level of associated symptoms determines the severity of the OSA. It is associated with obesity, high blood pressure, heart problems, stroke, diabetes and depression, and its prevalence has risen significantly over the last two decades. It is very common and affects individuals in all age groups.

However, OSA is poorly understood by both the general public and the medical profession, resulting in low levels of awareness of the condition and considerable under-diagnosis: it is estimated that up to 80% of people with OSA are undiagnosed. Up to 4% of middle-aged men and 2% of middle-aged women in the UK have OSA with symptoms. 15% - 20% of people aged 70 and over are estimated to have the condition. OSA also affects up to 3% of children. OSA can impact significantly on quality of life and public health, and cause significant healthcare costs, particularly if diagnosis is delayed.

OSA was defined as a priority by the BLF because of this level of under-diagnosis. In 2009/10 the condition was under the radar, although the NICE guidelines on OSA were introduced in 2008, and there was an NHS target of 18 weeks' referral to treatment for lung disease. BLF staff realised that treating OSA could be seen as a 'quick win' in delivering against this target, although existing referral pathways and lack of services were making the target difficult to achieve. Furthermore, OSA was identified as a respiratory disease that is of high prevalence, and that responds very well to treatment. It was recognised in the respiratory medical field as a problem, but there was a low level of patient awareness about it.

2.2. The OSA project: aims, objectives, funders

In 2010 the BLF secured external funding from Philips Respironics for a new three-year OSA project which ran from 2011 - 2014. Additional funding was secured from ResMed after the first year of the project. The aim of the project was to enable the BLF to proactively develop an awareness-raising campaign targeting the public and health care professionals in order to improve both the diagnosis and treatment of OSA.

In the first two years the OSA project had four key objectives. These were:

1. To promote OSA as a strategic priority for the BLF, Department of Health and governments across Scotland, Wales and Northern Ireland

2. To help increase awareness of OSA among the public and health care professionals
3. To help to find undiagnosed people with OSA and improve their quality of life
4. To help to improve OSA services across the UK.

In year three, the emphasis was on embedding the BLF's OSA activities by focussing on two main objectives:

- To help increase awareness of OSA to the general public and health care professionals, especially primary care, to find undiagnosed people and improve their quality of life
- To promote OSA as a strategic priority in England, Scotland, Wales and Northern Ireland, in order to improve provision of, and access to, services along the patient pathway for people with OSA.

The OSA project was led by a full-time project manager, Judy Smith (Harris), with input from a UK-wide Advisory Group.

2.3. Context: sleep services across the UK

Although OSA affects patients in the same way across the four nations, the policy context, structures and service provision is quite different and has changed over the life of the project in different ways in each nation. Overall there is rising demand for services, with resultant funding and resource issues in some areas. There is a need for much greater GP awareness and an increased role of GPs in care pathways, particularly as GPs in England are also commissioners now.

England: In 2013 the NHS in England experienced probably the biggest and most fundamental structural change in its history, with the creation of local Clinical Commissioning Groups (CCGs). A direct impact on the OSA project was the loss of a clinical lead at the Department of Health.

From April 2013, OSA services are mainly commissioned through the 211 CCGs. Within the English regions, the BLF's Service Development Managers have had to establish relationships with a plethora of commissioning managers, at the same time as the people coming into those posts were establishing their own roles and the CCGs themselves have been establishing their own identities and working practices. This structural change creates challenges around engaging with the NHS for any national charity with limited regional capacity. There is also concern that the profile of conditions such as OSA could be lost amidst a myriad of competing and higher profile priorities, leading to further fragmentation in the provision of sleep services in England.

NICE guidelines on Continuous Positive Airway Pressure (CPAP) use were produced in 2008 but are only guidelines. There are no agreed 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 wellbeing and there has been investment in sleep services with a full polysomnography (PSG) sleep service announced, linked to the Northern Ireland OSAHS strategy being redrafted.

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. The Welsh Government reaffirmed their commitment to including OSA in the Respiratory Health Delivery Plan published in 2014.

For more detail about the structure of delivery of sleep services, see Appendix C.

3. Evaluation findings and discussion

A huge amount of activity has taken place over the three years of the OSA project. The main activities and achievements have been summarised in Appendix D. The project focus was refined through the project period, and by the third year the emphasis of its work was focussed on two main objectives:

- To help increase awareness of OSA to the general public and health care professionals, especially primary care, to find undiagnosed people and improve their quality of life
- To promote OSA as a strategic priority in England, Scotland, Wales and Northern Ireland, in order to improve provision of, and access to, services along the patient pathway for people with OSA.

The findings of the evaluation provide evidence of the ways in which the project addressed these objectives. This section of the evaluation report outlines the elements of work that contributed to each objective, and draws on the primary research carried out for the evaluation to evidence the ways in which the OSA project achieved its objectives.

3.1 Increasing awareness

3.1.1 An overview

Stakeholders from all groups commented that at the start of the project, the knowledge of OSA at all levels – patients, carers, and service providers – was “*appalling*”. There was little understanding about the condition and how to manage it. It was too often seen as a ‘niche problem’ and one that was not serious. The connections and co-morbidities between OSA and other conditions were not well known.

BLF delivered a range of outputs to address this issue. These include:

- **An online snoring survey of 2000 adults** in April 2011, which identified that 57% of people who snore loudly, or whose partner snores loudly, had heard of OSA. The survey looked at how many people went to their GP, and were subsequently referred to sleep clinics, and started to highlight areas of need.
- **The Breathe Easy Week, June 2011** during which a **survey** was carried out of 3061 people, and local Breathe Easy groups held 158 events all over the UK, linked with 65 pieces of national and local media coverage. BBC Breakfast coverage was particularly effective.
- **The online pictorial Epworth Sleepiness Scale** was uploaded onto the BLF website in June 2011. Over the life of the project more than 40,000 people took the scale online, enabling many to seek medical

advice or help. Findings data was presented at the British Thoracic Society conference at the end of 2012.

- **The BLF's OSA website pages** were redesigned in 2011 and developed over the life of the project. The OSA website pages have also been featured and supported by other websites and organisations such as NHS Choices, British Heart Foundation, the Stroke Association and many others.
- **Printed OSA information for patients** was developed, including a leaflet that was distributed to sleep clinics across the UK. Orders reached 10,000 per quarter in 2012.
- **Campaign materials**, including an OSA stand-up banner and campaign poster were used at conferences and events from 2012 onwards.
- **Press and media coverage:** Throughout the life of the project there were 215 pieces of both national and local media coverage including newspaper, radio, television and on-line reports.
- The **County Durham OSA awareness campaign** took place between May and July 2013.

The overwhelming majority of interviewees said that there has been *“incalculable”* progress in raising the profile of and awareness about OSA over the project period. This was achieved by producing clear, well evidenced data for a wide range of audiences including patients, providers and politicians.

The project overall was viewed as well-organised and comprehensive, and thus was able to:

“raise the profile of OSA more than anything else that's been done in the UK.” (Health care professional)

This was achieved through consistently delivering reliable information to the project's audiences, by the BLF having a presence at industry and health care professional events, and by devising a number of ways to engage with patients, e.g. through Breathe Easy groups and events, and via the Epworth Sleepiness Scale online. The quality and range of BLF information was cited as having been particularly important in achieving the project's goals.

BLF staff developed an approach within the organisation that aimed to ensure that the information outputs were clear and integrated. They were careful that all the information presented consistent messages about OSA and its treatment. They aimed to provide information at the right level for each audience, from patients to parliamentarians, and that was appropriate to each medium, from web pages to technical reports. Within the BLF, staff reported that the approach developed for the OSA project was effective, and

it will be applied to other projects and campaigns. The majority of external stakeholders also reported that they found the OSA information very valuable.

One of the factors behind the effectiveness of the project was the role and the reputation of the BLF itself, and the credibility that was given to the issue of OSA because the BLF took this lead role.

BLF was described as an *“honest broker”*, and as a *“significant and reputable organisation”*. The involvement of an organisation of this calibre *“gave greater credibility to the issue of OSA”* within the health field. Stakeholders interviewed for this evaluation reported that the BLF brings a breadth of experience, and connects lung health and breathlessness to the wider health agenda. As well as professional networks, it has a genuine and demonstrable connection with patients and patient groups. It was described as being *“like a three-legged stool”*, recognising research, communications and patient support as equally valuable, with each informing the other. For example, the Breathe Easy group networks are seen as demonstrating the practical approach the BLF takes to engage with patients. This raises an issue that extends beyond the OSA project, but which links back to the value of locating the OSA project within the BLF.

The reputational value, as well as the quality of the information produced as part of the OSA project, was reported to have had an impact on increased awareness in many sectors about the condition, and promoted good practice in its management.

3.1.2 BLF information materials about OSA

“I see them everywhere, when I go to hospitals... I see the BLF logo everywhere.” (Industry partner)

A strong view expressed in all elements of this evaluation was that the BLF materials about OSA have been very significant in enabling the project to achieve its aim of increasing patient and public awareness and the understanding of OSA symptoms and prevalence for the public and among health care professionals. The materials were described as attractive and professional, *“the covers make you want to pick them up”* and once you do, the information inside engages the reader. Respondents to the health care professionals’ survey commented that the project had produced:

“excellent educational leaflets encouraging increased awareness amongst patients.” (Health care professional)

Others described the information as *“supportive”*, *“unbiased”* and *“accurate”*. Interviewees also reflected these views, although two interviewees thought that some of the patient information was too lengthy and that this reduced its accessibility. However, patient groups said that they really appreciated having it and being able to distribute it to their members.

Some stakeholders said that one of the benefits of the BLF information derived from the independence of the source. Members of the Sleep Industry Forum were among the stakeholders who said that the BLF, as an independent organisation which provides information materials for patients, has created a 'trusted brand' which other organisations are not able to do. Staff working in Sleep Units were pleased to have *"this high quality information"* as an additional resource for their patients. They also thought that the independence of the BLF added to its value. Patients and carers interviewed agreed that BLF information is trusted because it is both independent and because it places patients at its core. There was an acknowledgement that the information materials were well regarded and effective where they were used.

3.1.3 GP awareness

Many of the stakeholders who contributed to this evaluation thought that the area of least impact was primary care/GPs, despite the production of an information pack targeted specifically at this audience. This is supported by the health care professionals' survey. Only 2% (two individuals) responding were GPs, which suggests that it is a group that still does not engage significantly with OSA. Many of the interviewees made the same point:

"GPs are not very good at picking up on sleep issues. When you go to the doctor feeling really tired, there are so many other things it could be."
(Patient)

"There is still a lot of ignorance out there even amongst medical professionals - especially GPs." (Sleep centre physiologist)

GPs were defined as the *"gatekeepers to get a diagnosis"* and as such, a target for future work. Nevertheless, the increase in patient numbers being referred to and attending sleep clinics over the past three years was cited as evidence of increased awareness of OSA. It is not possible to say that this is a direct result of the BLF OSA project, particularly as the BBC's major documentary *"Good Night Britain"* was broadcast in November 2012. This also had an impact of the number of referrals. There is no data to quantify how many GPs became better informed about OSA as a result of the BLF's work. However, one stakeholder commented that the project has left permanent legacy in primary care:

"Amongst all the GPs who have been contacted by or are in contact with the project...now that they know about OSA, they cannot un-know about it." (Industry partner)

3.1.4 Raising awareness on a whole area basis: the County Durham Campaign

Piloting an approach to raise awareness

The aim of the campaign in County Durham was to raise awareness across a large geographical area. It followed on from a similar campaign, “Love Your Lungs” which sought to find undiagnosed people and to build partnerships with CCGs. County Durham was chosen as an area where statistically there was a high risk of OSA and so a campaign could have a strong impact; and by choosing an area where existing sleep services were few or stretched, a campaign might result in more, and better, services. The BLF’s Service Development Manager for the NE, Yorkshire and Humber, Bev Wears, approached the CCGs in N Durham; Durham Dales, Easington and Sedgfield; and Darlington, and used her contacts to pull together a local steering group. We have described the campaign in some detail, to enable future learning about this approach.

Campaign activities

The campaign took place between May and August 2013, and featured four awareness events in community settings during June, where individuals were given the opportunity to use the Epworth Sleepiness Scale. Anyone scoring highly or showing clear symptoms of OSA was then directed to sit with a specialist nurse from a local sleep clinic, and those at risk were referred to their GP and signposted to local support services. A variety of venues were selected which would provide the highest footfall, including supermarket pharmacies, an outdoor market place and a shopping centre. The venues were spread across the three CCG areas to ensure the campaign was available county-wide.

Telemarketing to ‘at risk’ households was undertaken to increase the reach of the campaign, with calls taking place a week before the events. Following the events, two OSA awareness sessions were held for GPs: one was a professional learning session at an existing GP education event; the other was a session as part of a general respiratory event organised by a pharmaceutical company.

The local steering group

The local steering group involved commissioning managers, GPs, and secondary care and health care professionals. There was a great deal of willingness to be involved with a campaign, partly because, as discussed above, it was being run by a national organisation with a high profile but also because of the kudos of being involved in a pilot project. The steering group offered added value because it was the first time many of these professionals had sat together round a table and talked about sleep. Bev Wears commented:

“For some it raised issues – a Nursing Sister from one of the hospitals was there, and commissioning managers hadn’t talked to nursing staff before. Primary care and commissioners seemed to have no idea of the scale of the problem or even what sleep services existed, or of the link between OSA and other long-term health conditions.”

There was some anxiety among the group members about whether the current service would be able to cope with raised levels of demand if the campaign succeeded, but discussions with the OSA project manager largely resolved this.

Outputs of the campaign

- Approximately 10,000 campaign leaflets and 600 posters were distributed across County Durham and Darlington
- 1050 households were contacted through telemarketing, following which 299 OSA information packs were sent to interested respondents
- 31 community venues displayed the campaign materials
- The campaign was promoted on the BLF website homepage from 15th May until 13th June which linked through to the event page: a total of 141 people came to the page directly and 311 came through the advert on the homepage.

Outcomes of the campaign

There were a number of tangible outcomes:

- 125 people used the Epworth Sleepiness Scale at the events: of these, 50% were advised to sit with one of the team of nurses at the event, and 57 were referred to their GP
- The number of people using the Epworth Sleepiness Scale online following the campaign also increased: there was a marked increase in the total number of people taking the test in July in comparison to June (619 to 1100)
- Website results for the Epworth Sleepiness Scale were analysed from September 2012 – September 2013: the results show that across the year 38 people from County Durham used the Scale throughout the campaign months of May, June, July and August, with the highest number in June when the events took place
- There were 128 new referrals to two sleep clinics (University Hospital N Durham and Darlington Memorial Hospital) over the period July – September 2013: for the same period the previous year, there were 67

- In July 2013 (i.e. the month following the events) the referral rate of 51 at these two sleep clinics was the highest in any month between April 2012 and September 2013.

The County Durham campaign demonstrated an increased awareness at Respiratory Networks of OSA and sleep services, evidenced for example by Sunderland RN and County Durham and Darlington RN including an item on OSA at their recent meetings. An unexpected gain from the campaign was its impact on local services. Discussions are continuing at Durham Dales, Easington and Sedgefield CCG about putting together a service specification for commissioning OSA services which would cover the whole of County Durham. The campaign appears to have been a resource intensive but effective way to deliver elements of the project within a specific geographical area. However, the true impacts can only be assessed over a longer period of time.

3.1.5 Patient awareness

There was considerable anecdotal evidence that there is greater awareness of OSA at patient level at the end of the project. More patients are being identified, more people are presenting with symptoms, and more sleep studies are being done. The evaluation data from Co Durham, Birmingham and North Yorkshire supports this. However, data about increased demand was not gathered systematically through the three years of the project.

3.1.6 Impact on the BLF

The strength of the awareness raising work of the OSA project has brought the BLF to the attention of new audiences – both patients with sleep issues, and health care professionals in the sleep field. It has established the BLF as a major player in the sleep arena: the BLF has been described to the evaluators as the leadership organisation on OSA. The project manager was regularly described as “*that sleep woman*”! The BLF’s parliamentary team has worked with MPs to increase awareness at policy level, and continues to receive questions from MPs about OSA. The quality of publications has been significant in promoting the profile of the BLF in the devolved nations. The level of activity and the project outputs have benefited the BLF, although there are concerns internally and externally about how to maintain this profile after the project funding has come to an end.

3.2 Improving quality of life for patients

3.2.1 Acting as a voice for patients

As stated above, the BLF has a genuine commitment to working with and for patients. Several stakeholders said that the BLF has acted as a voice for OSA patients, and that no-one had done this before. A strong message came through all elements of this evaluation that the BLF starts with “*what’s best for patients*” and so it puts itself in the shoes of patients, and that its

delivery flows from that start point. It has a track record in providing patient-based information. This was enhanced with the OSA project (as discussed above); and through direct engagement with patients through the Breathe Easy Groups. Some of the patients interviewed for this evaluation also said that the BLF enables patients to have a voice in the system.

This approach was demonstrated in the OSA project by, for example, the OSA Patient Survey, and its promotion of the Epworth Sleepiness Scale. This was uploaded onto the BLF website, and over 40,000 people have used it over the life of the project. This simple mechanism shows how the OSA project provided information that would enable people to identify and act on their health needs. By backing this up with patient information (on paper and online), the project worked to support higher levels of OSA diagnosis, which in turn can have significant positive impacts on the quality of life for people with OSA. Reflecting the comments of all of the patients interviewed for this evaluation, one said that after she had her diagnosis, she “*started to live life again*”. Unfortunately, there was no tracking of respondents after they had done the test.

3.2.2 Enabling higher levels of diagnosis

The emphasis of the work towards improving quality of life for people with OSA was on enabling higher levels of diagnosis. The approach taken was to focus on snoring (as well as sleepiness) as an initial identifier of potential OSA. An online survey of 2000 adults was undertaken in 2011, and again in 2014. This showed an increase in awareness of OSA of 5%. The greatest increase in awareness was in the North East of England, where the BLF ran a targeted awareness campaign in 2013 (see above). Further awareness work took place through the Breathe Easy groups, which were identified by patients as valuable ways to promote awareness of OSA, and to support people seeking diagnosis. BLF staff commented that a spin off benefit of the OSA project was that it offered a good way to “*start the conversation*” about lung health with a large number of people.

“It’s much easier to approach someone and ask if they or their partner snore, than if they cough...You can have a laugh about it. It enables positive and proactive engagement.” (BLF staff member)

3.3. Promoting OSA as a strategic priority and improving services

3.3.1 An overview

The activities that focused primarily on increasing the strategic priority of OSA were:

- **Reviewing the literature and research findings about OSA (2011)**, the results of which were distilled into ten medically approved reports on different key issues such as awareness, diagnosis and treatment.

These formed the basis for the BLF's position statements and informed their campaigning and awareness raising activities.

- **Engagement with health care professionals** to understand OSA from a health care practitioner's perspective. The BLF also met with and attended a large number of conferences involving sleep medicine organisations, groups and professional bodies, resulting in over 2000 professionals receiving information about the BLF's OSA project.
- **Engagement with the sleep industry** through the Sleep Industry Forum which was formed in 2011 and continued to meet regularly throughout the life of the project.
- **Engagement with patients:** individual interviews with 32 people with OSA took place in 2011 to understand the issues faced by patients.

While there was some overlap with all of the activities, in terms of their primary outcomes, the activities most closely related to improving services for people with OSA were:

- **The BLF's 10 point OSA charter** which was launched in July 2012 as a key campaigning tool
- **The OSA mapping project** which was completed in 2012 and published in 2013, creating a set of maps showing both the location of sleep clinics in the UK and indicating potential OSA hotspots based on the prevalence of OSA risk factors
- **A sleep clinic patient survey** which was the largest survey of people with OSA that had been carried out in the UK
- **A policy and parliamentary campaign** that ensured that all MPs were emailed when the OSA charter was launched, and through which there was a great deal of dialogue with MPs throughout the life of the project
- **A BLF OSA e-action** was launched at the end of 2012 and has resulted in 400 contacts about OSA with parliamentarians across the four nations by their constituents
- **A web community poll** in January 2013 to establish awareness and experience of OSA services
- **The GP's information pack**
- **The BLF's OSA in Children booklet**

- **A follow up online snoring survey of 2000 adults** in 2014
- **Information produced about the patient pathway** to identify the elements of an effective sleep service. BLF has promoted this as good practice across the four nations.

The most visible outputs, and those which were reported as having made a positive impact on the delivery and development of OSA services, are discussed below.

3.3.2 OSA mapping project

Most of the stakeholders interviewed for this evaluation reported on the impact of the OSA mapping project. For example, it has enabled evidenced cases to be made for increased provision in poorly served areas. As stated above, it provided the rationale for the focused work in County Durham. In some areas where service improvement has taken place (e.g. Wales and Northern Ireland), the project was cited as one of a number of factors that contributed to service improvement. Interviewees commented that these improvements *“would have happened anyway”*, but local BLF staff and sleep practitioners found that the project offered an additional focus, and additional resources that supported their ongoing work:

“What we were already doing was boosted by the quality of input from the OSA project.” (BLF staff member)

Interviewees reported that successes in the form of increased or improved service provision were achieved more quickly and efficiently because of the OSA project.

The mapping information provided powerful ammunition for those who wanted to see OSA having a higher strategic priority in service provision. For instance, in Scotland it has demonstrated the inequity of resources across the country and has been used by smaller Health Boards to argue for more resources. Industry partners responded that the mapping data has *“enabled greater understanding of where to target”* the market which, up to the time of the production of the map, was *“a bit of a mystery”*. Overall, stakeholders believe that the BLF has started a wide-ranging move towards service improvement. However, stakeholders said that while the mapping work continues to be used, it needs to be regularly updated – particularly as services improve – and there was no clarity about how this would happen, or who would resource this in the future.

3.3.3 OSA charter

OSA was described as ‘a Cinderella’ within respiratory services. The charter was perceived as setting out, in simple terms, what a good service looks like. This provided support to patients and practitioners working to improve services. There was no clear data about the impact of this: how many

services had adopted it or changed as a result of it. However, stakeholders thought it was a positive output of the OSA project.

3.3.4 Working towards better services

Overall, the evaluation found that the quantity and quality of information produced by the OSA project, as well as the different ways in which the project brought together people working in and using sleep services (e.g. the OSA conference held in February 2014), enabled a dynamic dialogue about the nature of services and their improvement. This finding was tested in the health care practitioners' survey, which questioned the impacts of the OSA project. 48% of respondents either agreed or strongly agreed that they had been able to develop better services.

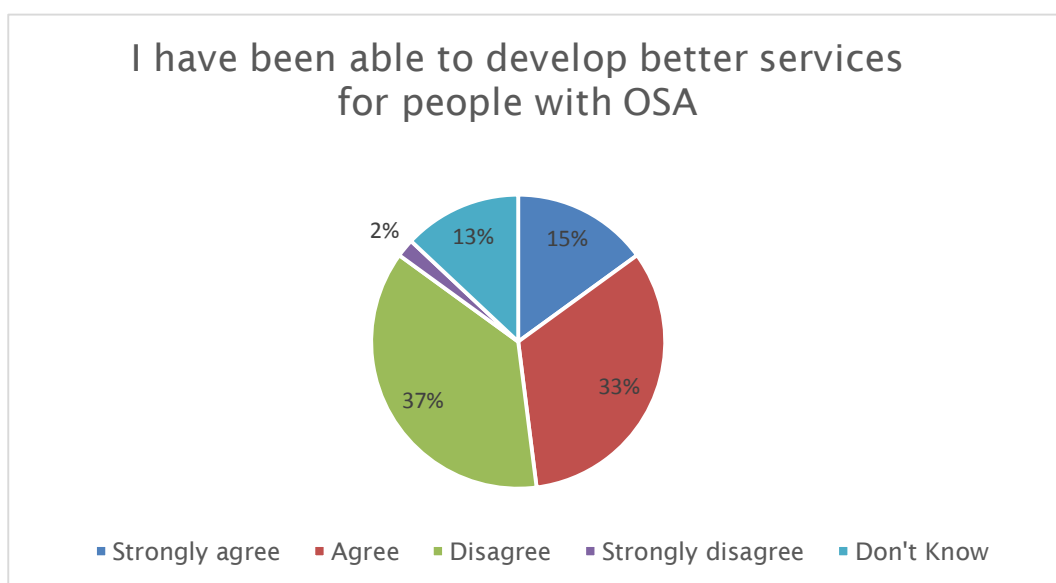


Table 1: Percentage of health care practitioners able to develop better services for people with OSA

One respondent commented:

“The project has moved OSA into the frontline of healthcare, where it rightly belongs, given the major co-morbidities.” (Health care practitioner)

Highly significantly, 75% of respondents agreed (49%) or strongly agreed (26%) with the statement that the project “has enabled me to inform and influence other health care practitioners.” This indicates the effectiveness of peer to peer dissemination of information and suggests that having key health care professionals as OSA champions and advocates would be worth exploring in future.

This influence translated into service improvements in some areas. Stakeholders related these in part to the OSA project.

The British Lung Foundation's OSA project has enabled me to inform and influence other health care practitioners

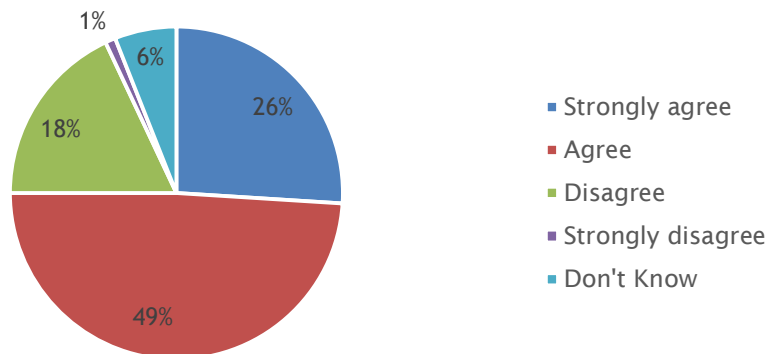


Table 2: Percentage of health care practitioners enabled to inform and influence other health care practitioners

Case Study 1: Northern Ireland

The number of sleep services, and specialist staffing, has increased in Northern Ireland. In Belfast, the Health Board has adopted the business case for a new clinic. Funding has been allocated, and the delivery resources (staffing and space) are being put in place. In other areas, services are also developing.

The increased services came about due to sustained work by practitioners and campaigners in Northern Ireland. The BLF supported this work by providing resources, information and awareness raising materials drawn from their UK-wide OSA project. Further, as an independent, national organisation with a good profile and reputation, the BLF was able to engage with politicians and the media, running a significant parliamentary reception on OSA at which Health Minister Edwin Poots announced the introduction of polysomnography testing in Northern Ireland.

In this way the BLF was one of the key players that helped to increase and develop further services through involvement in rewriting guidelines, discussions with commissioners about service planning, attendance at respiratory board meetings, and involving Breathe Easy support groups to provide a patient voice.

3.3.5 Increasing diagnosis: increasing demand

Most of the stakeholders interviewed reported significant increases in the demand for services over the three years of the BLF OSA project. However, a number of stakeholders discussed the growing pressures on sleep services. The challenge for the project has been the wholesale change in the structure of the NHS in England, and the UK-wide pressure on NHS resources over the period of the project. A practitioner in a sleep clinic reported that:

“Our service has been forced to change (and continually look at changes) due to increasing demand. We also have to cope with expanding the service as the number of patients on long term therapy increases”

It was widely reported that sleep services are really struggling with their patient numbers and the demand. The BLF has been sensitive to these tensions, and about the need for campaigning to also take account of the practicalities of implementation.

Several stakeholders reported that one of the more subtle impacts of the OSA project was the way in which the project manager made connections between professionals who were working on similar areas of service improvement, enabling examples of good practice to be shared throughout the project.

“She knew that someone else was trying to do what I was trying to do, so she put us in touch with each other. The support from the BLF, and the contacts with people trying the same solutions was invaluable. Not only was I less isolated, but we could refer to each other, and quote another example of good practice.” (Sleep service practitioner)

The evaluation has identified examples of the impact of increased demand on services, and how services are responding to this increase.

Case Study 2: Birmingham

In Birmingham, Consultant Clinical Scientist Brendan Cooper reports that more GPs in the area are aware of the Sleep Service at University Hospitals since the BLF's OSA project began. Staff workload has increased by 40% in 12 months and OSA represents much of this increase: *“We used to have 20% of resources spent on OSA, and now it's about 60%.”*

Raised awareness of the cases being diagnosed rather than just the severe ones, as had been the situation before. The Sleep Service is also able to do more preventative work with the rising number of individuals whose sleep study has had a negative result:

“We can give them advice on weight gain and lifestyle, and also advise them that if they don't take action they may develop OSA and the treatment will be CPAP. We explain what this entails and point out that whilst CPAP is very effective, it's not completely pleasant and could be avoided.”

3.3.6 Improved patient pathways

Stakeholders also reported a general improvement of patient pathways – more as a result of the increased demand for services and improved levels of care than as a direct impact of the OSA project. However, the BLF promoted the knowledge about such matters. The BLF conference in February 2014 shared examples of good practice and demonstrated the implementation of a new pathway in Oxford. 47% of respondents to the health care professionals’ survey for this evaluation reported that they strongly agreed (15%) or agreed (32%) that they had been able to develop better care pathways for patients with OSA.

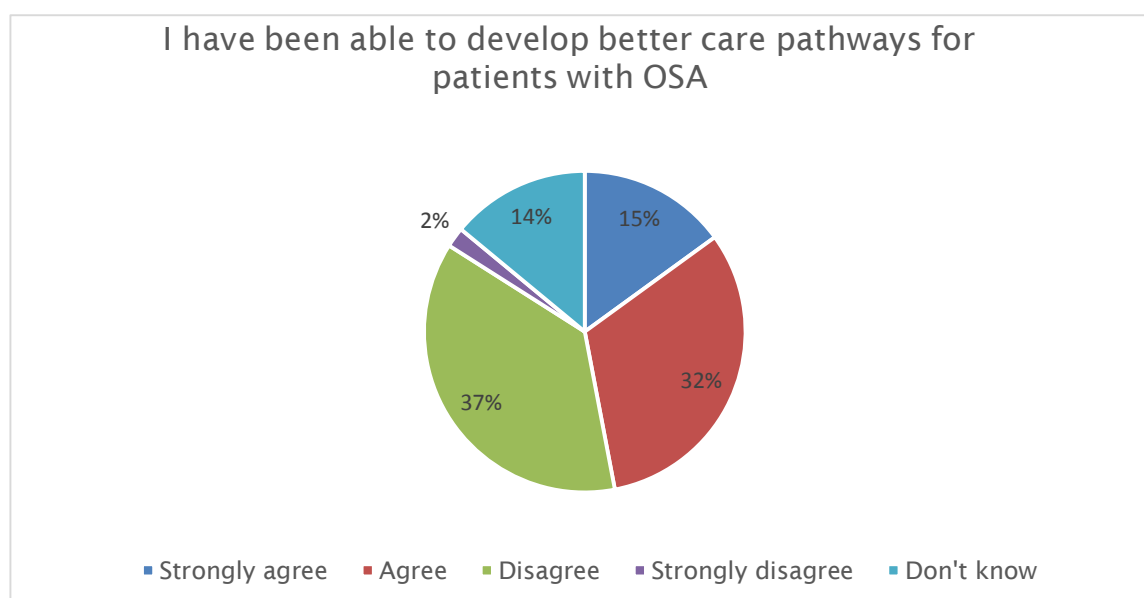


Table 3: Percentage of health care practitioners able to develop better care pathways for patients with OSA

3.3.7 Reshaping services

With increasing demand came the need to re-shape services. However, during the life of the OSA project, the NHS in England underwent wholesale restructure. During the period of the project, the central DH lead role in relation to sleep was abolished, and Clinical Commissioning Groups were established. All the stakeholders in England interviewed for this evaluation discussed the real difficulties in influencing CCGs about sleep. Generally, their priorities are “*the biggest illnesses – COPD and cancer*”, and sleep was described as being “*increasingly under the radar.*”

The OSA project was reported to have hosted a healthy dialogue and a proactive approach to understanding the importance of sleep services, and to have successfully gathered a body of data about best practice. This should be available in the future, along with the BLF-developed resources about good commissioning of sleep services. In the latter stages of the project, a focus on the health economics of OSA provision was developed,

and a separate piece of work was commissioned. Although this was outside the scope of the OSA project (and therefore outside this evaluation), stakeholders were excited by it and keen to see the results.

The NHS in the devolved nations did not experience the same changes that took place in England. In Wales, OSA became part of the National Framework for the NHS. Although work towards this was being led by the BLF in Wales and was under way at the start of the OSA project, the project provided additional resources and support for this action. Similarly, it became a priority in the strategic framework for all Health Trusts in Northern Ireland. In Scotland, stakeholders reported that the Health Boards are beginning to take OSA seriously, and recognise that more resources are needed in order to meet the waiting list targets that still exist in the NHS in Scotland. There was synergy between the work in the devolved nations and the UK wide campaign. These successes in the devolved nations created a UK-wide profile for OSA, and demonstrated the potential of the project to influence policy and provision. In Scotland, OSA has been added to the curriculum at Glasgow University's Medical School.

Case Study 3: Glasgow

Medical students at Glasgow University now do a respiratory block of study as part of their core curriculum during their third year of training. Because of the OSA project's work in raising awareness of the high numbers of undiagnosed OSA patients, this year's cohort of year three students have been the first to receive a lecture specifically on OSA. This has been delivered by Eric Livingston, a consultant Respiratory Physician at the Glasgow Royal Infirmary and Chair of the Scottish Sleep Forum. Eric believes that the BLF's OSA project has been very good for Scotland: the research and publicity materials have resulted in OSA being taken seriously, and the waiting list targets are acting as a driver for prioritising resources.

"All this means that more people are being trained in OSA. The OSA lectures at the University are a new development since the BLF's work here."

3.3.8 Achieving lasting change

All interviewees who are engaged at a strategic level discussed the challenges that have come about because of the structural changes to the NHS in England, the lack of resources for new services in the NHS across the UK, and the consequent changes to service development and commissioning.

Although there is a statutory obligation to provide a service (i.e. CPAP) to patients with moderate and severe OSA, anyone below that threshold is not seen as a priority, despite the evidence that earlier intervention can prevent longer term problems. Some of the medical experts interviewed bemoaned the fact that sleep is not on mainstream medical school curricula. However, the evaluators found that this has changed in Glasgow, in part through the involvement of key individuals with the BLF's OSA project (see case study 3).

Several interviewees discussed the importance of promoting a wider (than among sleep specialists) understanding of the co-morbidities with OSA, and highlighted that the BLF has worked with professionals to achieve this. Health care professionals interviewed for this evaluation stressed the need to recognise the links between OSA and other conditions such as obesity and diabetes. One interviewee commented:

“BLF have made the point but commissioners aren't listening because they're in disarray – anything new is seen as just a problem.” (Health care professional)

Overall, stakeholders expressed high levels of concern about the slow process of getting OSA onto CCG agendas, let alone priorities. One interviewee (sleep professional) feared that *“it might take a spate of road deaths where lorry drivers with OSA fell asleep at the wheel”* to make a difference to the allocation of resources to OSA services. Several stakeholders discussed the need for an emphasis on *“the fact that it's a treatable problem”*, that it is *“easy and cheap”* to treat, and that other health conditions are addressed by treating OSA. There was enthusiasm for the ongoing BLF work on the health economics of treating OSA as a way to further the case for increased resources for sleep services. However, there was concern about what will happen to OSA when it no longer has the BLF as its constant champion.

3.4 Factors that influenced the overall success of the project

3.4.1 Developing new organisational relationships: making the most of each contribution

Stakeholders from different sectors reported that the OSA project had enabled them to build new partnerships. BLF staff reported that these relationships included increased links with ARTP and with a wide range of health care professionals who are more involved with sleep and OSA than

with respiratory medicine in general. The BLF's working relationship with industry partners was also acknowledged by both. This was reported to have enabled new areas for dialogue, and so opened doors.

3.4.2 The Advisory Group

These relationships supported work in the devolved nations and English regions. For example, BLF staff who work in areas beyond London were encouraged to identify their local contacts who could join the UK-wide OSA project Advisory Group. In this way, the Group gained from the expertise of specialist practitioners, and the areas from which these practitioners came gained from the connections with the national organisation and each other. They also gained profile for their services. It was noted that Judy also supported the networks across the UK. She would "jump on a plane" to get to meetings wherever they were held. It was described as unusual for London-based staff to do this, and stakeholders said that it added value to their work, as well as giving greater intelligence and experience to the UK-wide work and supporting the development of a close, national network based on trust and partnership working.

Advisory Group members described examples of good ideas coming out of the advisory group and then being applied to other areas of work. It enabled a sharing of information about good practice – another way in which the OSA project fostered service improvements. Many of these relationships continue, leaving a lasting (if uncharted) legacy.

3.4.3 Working with industry

The industry partners interviewed for this evaluation saw the project as a good example of cooperative working. One commented:

"We can achieve more together... each of us has a different expertise, and we can all add to a whole that is bigger than each of our own areas."

Interviewees discussed the benefits to them of working with a charity such as the BLF. The BLF's reputation and independence have been commented on earlier in this report: both make it an attractive partner for industry. In addition, the BLF is able to lead and coordinate this kind of campaign in a way that an individual company cannot without being seen as being motivated by self-interest or a drive for more sales. And there are limits to the nature of partnerships between companies before they are seen as forming cartels. Overall, industry partners were, therefore, very pleased with the way the project worked, and how it worked with them.

However, it was noted that funding for charity relationships and projects is becoming increasingly difficult to find. With the diminution of NHS funding, industry has less money for these partnerships. This raises issues about how the BLF can best manage its relationships with industry funders,

including the need to be clear about the expectations of partners and being able to demonstrate the impact of the funding. The BLF should also acknowledge openly the value of bringing people together and of providing networking opportunities within the structure of the project. Some interviewees commented that it is cheaper to network through charity advisory groups or networks, than to pay for a stall at a specialist conference. At the same time, the BLF needs to be clear about its costs in providing these opportunities.

3.4.4 Working across the four nations

One challenge for the OSA project was implementation across four nations, each with its own government structures, healthcare system, policies and priorities.

There were issues about how and when to recognise and respond to the specific priorities in the devolved nations and this did not always fit well with the timetable for English or UK-wide awareness raising work. For example, Wales and Scotland both have their own Communications Officers who picked up on specific opportunities. There was potential for the policy focus and timings of the BLF HQ in London to undermine actions in the devolved nations. This risk was mitigated by the project manager regularly visiting Wales, Scotland and Northern Ireland and liaising closely with BLF staff working outside London. The outcome was that the BLF made good connections between national policy and local delivery, in part by making the most of local opportunities for awareness-raising.

The OSA project should be recognised and celebrated as a good example of a project that had both a distinct ‘four nations’ focus and a UK wide perspective. Many national charities and organisations are not flexible or responsive enough to be driven by local opportunities but the BLF did achieve this with the OSA project.

3.4.5 The quality of project management

All the stakeholders interviewed for this evaluation were clear in their praise for the organisation of the project, and the quality of the project management:

“The whole idea was brilliant – good concept and the project was driven very well.” (Advisory Group member)

There was universal praise for the way the project manager, Judy Smith (Harris), tackled her role. Several people spoke about how quickly Judy became known as ‘that sleep woman’, generating the high quality information that the project has been praised for, raising the issue of OSA in forums across the UK, and developing the networks that enabled progress with the project and the issue. Large and complex projects succeed through the input of many partners. However, it was clear throughout the evaluation

that the role that Judy played, the way she played it, the personal skills she brought to the project and to the BLF, and the expertise that she generated about OSA were significant factors in the success of the project.

4. Project legacy: what next for OSA?

4.1 Overview

Many of the stakeholders who contributed to this evaluation were saddened and frustrated that the project was ending. There was a recognition that the project had achieved beyond its expectations, but a real concern that, having got OSA 'onto the radar', it will be important to maintain this level of intensity in order to keep it there. Many stakeholders were aware that there is a strong will to carry on working together on OSA, and that the project had brought so many people together to achieve improvements. The view that "*we've only just started*" was expressed in different terms by many interviewees.

There was an acknowledgement among BLF staff that the exit strategy for the OSA project was not as well worked out as anyone had wished it to be. This learning is already being applied to the BLF's project development process. However, the ongoing work on the health economics of OSA was widely recognised as a positive outcome from the project. This will be essential in order to engage with commissioners – a task described as challenging but essential to achieve change at a strategic and service delivery level.

4.2 Developing ongoing and wider partnerships

Different stakeholders believe that the BLF will be able to build further on the OSA work through even wider partnerships. OSA is an issue that makes connections beyond the respiratory community, for example with organisations working with linked conditions such as diabetes. Some stakeholders believe that BLF would be "*knocking at an open door*" if it made approaches to organisations such as Diabetes UK, with a view to further developing or sustaining the project. This approach should also be considered by the BLF in future projects.

5 Conclusions and recommendations

5.1 Conclusions

5.1.1 Increasing awareness

There was a consistent view from everyone interviewed that there has been a significant increase in awareness of OSA over the three years of the project. This is demonstrated by the number of referrals, an increase in media coverage and patients referring to the BLF information when they visit sleep centres.

There is clear evidence of greater awareness at patient level, for example from data collected in County Durham, Birmingham and North Yorkshire and from an online survey of 2000 adults that showed a 5% increase in awareness in 2014, compared to 2011 when the project began. The greatest increase in awareness was in the North East of England, where the BLF ran a targeted awareness campaign in 2013. Anecdotally, more patients are being identified, more people are presenting with symptoms, and more sleep studies are being done.

The most difficult audience to influence proved to be GPs and primary care providers. However, the increase in referrals to sleep clinics is some indication of impact on this key group. An important factor was the reputation of the BLF whose backing for OSA gave weight and credibility to an issue that had previously been overlooked in the healthcare field.

The effectiveness of the awareness raising activities was underpinned by the range and quality of information and printed materials produced by the BLF. They were well-designed, clear, attractive and informative and as a result people picked them up and read them.

However, the budget and timeframe for the project meant that it was not on a scale or over a long enough period to bring about long term attitudinal change. Several interviewees commented that projects whose main objectives are about awareness-raising need longer than three years to demonstrate change. A member of the Advisory Group compared sleep services and the awareness of them to a super-tanker which the BLF, through the OSA project, had managed to stop, but which would need more years and more resources to turn around.

5.1.2 Improving quality of life

The BLF has successfully acted as a voice for OSA patients, something that patients felt had not been done before. The OSA project had direct engagement with patients through the Breathe Easy Groups. Some patients reported that they felt empowered by the BLF to have a voice and therefore some influence in the health system.

The County Durham campaign offers an insight into the synergies that the OSA project created. By raising awareness of OSA in an area identified by the mapping exercise as high risk, project activities led to an increase in people being diagnosed; and from this, to the identification of the need for better patient pathways.

The OSA project's emphasis on increasing diagnosis by focussing on both snoring and sleepiness was successful. Over 40,000 took the online Epworth Sleepiness test and 7% (2800 people) of those experienced excessive sleepiness. The OSA patients' survey in 2013 found that being diagnosed and treated for OSA had a highly significant positive effect patients' wellbeing.

5.1.3 Promoting OSA as a strategic priority and improving services

The context and structures for influencing health policy have changed significantly during the life of the project, particularly in England. It is a challenge to work with and influence 211 CCGs who have other pressing priorities. This situation is likely to be further exacerbated when health and social care are brought together.

The situation in the devolved nations is different. In Wales, OSA is now part of the National Framework for the NHS. Similarly, OSA became a priority in the strategic framework for all Health Trusts in Northern Ireland. In Scotland, Health Boards are beginning to take OSA seriously, and recognise that more resources are needed in order to meet the waiting list targets that still exist in Scotland. These successes in the devolved nations demonstrate the potential of the project to influence policy and provision.

The mapping and information the project has produced is powerful ammunition for those who want to see OSA having a higher strategic priority. The mapping project, for instance, has demonstrated inequity of resources across Scotland and has been used by smaller Health Boards to argue for more resources.

This evaluation has identified both perceptions of improvements in some sleep services, and evidence of actual improvements. A survey of health care practitioners for the evaluation found that 48% agreed or strongly agreed that they had been able to develop better services as a result of the OSA project and 47% agreed or strongly agreed that they had been able to develop better care pathways for patients with OSA.

The project successfully brought together people working in and using sleep services (e.g. the OSA conference held in February 2014) and this enabled an important dialogue about the nature of services and their improvement. 75% of health care practitioners who responded to a survey for the evaluation agreed or strongly agreed that the project had enabled them to inform and influence other health care practitioners, highlighting the effectiveness of peer to peer approaches

The OSA project also encouraged and supported professionals to work together to promote OSA. The role of key people who act as OSA champions and enthusiasts can be significant, as the Glasgow case study illustrates.

5.1.4 Learning for the BLF about managing the OSA project

The project worked effectively on both a UK-wide basis and across the four nations. The commitment to taking this issue seriously in planning and delivering the project has paid dividends and has been greatly appreciated by those working in the devolved nations. The BLF has been flexible in understanding that local priorities and timetables sometimes need to take precedence over national campaign activities.

It is crucial to have an effective project manager with the right mix of skills, particularly people skills. The Advisory Group was helpful but it was composed of busy people so the hands-on and proactive role of the project manager was vital.

With hindsight the project might have been more effective over a five year timeframe. Three years is too short a period over which to achieve attitudinal change, and to form a cohesive alliance that will carry on working together when the funding comes to an end.

Planning for the end of the project and developing a strategy to continue its legacy could have been started earlier. The project is highly regarded internally and externally and there is a real desire to see the BLF continuing the work on OSA and concern that if it does not, OSA patients will lose out in future.

5.2 Recommendations

This is a summative evaluation conducted at the end of the three-year OSA project. Therefore a small number of recommendations are made which focus primarily on sustaining the legacy of the project.

1. The OSA project's mapping of services against prevalence of risk is valuable and continues to be used but it needs to be regularly updated, particularly as services change. Partner organisations / funders could undertake to refresh the map, ideally on a three-yearly basis.
2. The material produced by the OSA project is highly valued by stakeholders and has contributed to raising awareness but it needs to remain current to be effective. Funding should be identified to enable the BLF, or a partner organisation, to update the OSA project material as is appropriate.

3. Linking with organisations that focus on related health conditions, such as diabetes and OSA co-morbidities, to develop collaborative projects would be an effective way to build on the impetus created by the OSA project.
4. There is an ongoing need to raise awareness of OSA in primary care, especially with GPs and practice nurses. A peer to peer dissemination model may be effective and organisations working to raise the profile of, and provision for, OSA should explore this cost-effective approach.
5. Finding and developing OSA champions is a key factor in sustaining the legacy of the project. Organisations working on OSA should identify ways to link OSA champions to existing networks, and for those networks to support them, and harness and coordinate their drive, even if this is limited to specific localities.
6. Internally, the BLF needs to develop a systematic approach to evaluation and better ways to measure the impact of its work. Future projects should develop mechanisms at the start for gathering impact data (e.g. about increased demand for services) that can be implemented throughout the life of any project. These mechanisms need to include a way of appraising the impact of the BLF, as well as other influences. In the longer term, this will give the BLF valuable insights into how to deliver its core aim of improving services for patients. It will also give the organisation better material to use to demonstrate to funders the impact of their investment in BLF projects.

Appendix A: List of stakeholders interviewed

BLF Staff

Nessie Blair, Service Development Manager (Northern Ireland)
James Cant, Head of BLF Scotland and Northern Ireland
Clare Cox, Director of Communications and Fundraising
Michael Laffan, Digital and Marketing Manager
Chris Mulholland, Head of BLF Wales
Dame Helena Shovelton, former Chief Executive, BLF
Bev Wears, Service Development Manager (North East, Yorkshire and Humber)
Steven Wibberly, Director of Operations and Innovation
Penny Woods, Chief Executive

Industry partners

Michele Avoni, Dolby Vivisol
Teri Challier, Philips Respironics
Fiona Hamilton, Dolby Vivisol
Tamara Lewin, ResMed
Rachel Stimpson, Philips Respironics
Deborah Wainwright, Fisher and Paykel

Advisory Group members

Martin Allen, Respiratory Physician, Stoke-on-Trent, and previously DH clinical lead on OSA
Brendan Cooper, Consultant Clinical Scientist, Birmingham University Hospitals, and current President of ARTP
Jim Horne, Head of the Sleep Research Centre, Loughborough University
Eric Livingston, consultant Respiratory Physician at the Glasgow Royal Infirmary and Chair of the Scottish Sleep Forum
Andy Meredith, Director of Sleep Services at Conquest Hospital, E Sussex
Jaynie Pateraki, Advanced Nurse Specialist, Sleep and Home Ventilation at York Sleep Centre
Stephen Spiro, retired: previously Head of Respiratory Medicine at University College Hospital, London
Adrian Williams, Chair of Sleep Medicine and Professor and Consultant Physician at Guy's and St Thomas's Hospital, London

Other stakeholders

Nicky Baker, Sleep Apnoea Nurse Specialist, Plymouth Chest Clinic
Victoria Cooper, Principal Respiratory Physiologist, Salford Royal Hospital
Gill Hawkes, OSA Patient and Support Group coordinator
Brian Reynolds, OSA Patient; Breathe Easy Group member
Pat Reynolds, OSA Carer, Breathe Easy Group member
Allan Robins, Humber Sleep Apnoea Support Group
Chris Rogers, Sleep Apnoea Trust Association
John Stradling, Emeritus Professor of Respiratory Medicine
Majella Tuohy, Consultant, Regional Respiratory and Sleep Physician (NI)

Appendix B: Evaluation tools

Healthcare practitioners' survey

Reshenia Consulting is carrying out an independent evaluation of the British Lung Foundation's 3 year Obstructive Sleep Apnoea (OSA) project that finished earlier this year.

We would like to know your views about the project. Please take a few minutes to do this short survey (only 12 simple questions) and help us find out what impact it has had on healthcare professionals.

The survey is anonymous and will inform an evaluation report produced by Reshenia Consulting. A summary of the findings will be published on the British Lung Foundation (BLF) website in 2014.

Thank you very much for your help. If you have any queries or need assistance please contact [Error! Hyperlink reference not valid.](#)

1. What is your job role?

GP

Nurse

Sleep specialist

Other (please specify)

2. Which of the four nations do you work in? (select all that apply)

England

Scotland

Northern Ireland

Wales

3. Overall, how would you rate the BLF's OSA information, both online and printed?

Very good

Good

Poor

Very poor

Don't know

4. The BLF's OSA project has increased my awareness and understanding of OSA

Strongly agree

Agree

Disagree

Strongly disagree

Don't know

5. The BLF's OSA project has enabled me to inform and influence other healthcare practitioners

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- Don't know

Thinking about the BLF's OSA project, please tell us what impact it has had on your work.

6. I feel more confident dealing with OSA

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- Don't know

7. I have been able to help diagnose OSA for more people

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- Don't know

8. I have been able to develop better care pathways for patients with OSA

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- Don't know

9. I have been able to develop better services for people with OSA.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- Don't know

10. Overall, what impact has the BLF's OSA project had on your healthcare practice?

11. Overall, what impact has the BLF's OSA project had on outcomes for your patients?

12. Is there anything else you would like to add?

Appendix C: The structure of delivery of sleep services

When the OSA project began in 2011 interviews were carried out with 23 professionals working in sleep clinics across the UK to find out about the structure of sleep services and how OSA was diagnosed and treated at that time.

The BLF found that there is no professional sleep qualification and there was no consensus about which discipline OSA ought to sit within. Some professionals felt that OSA should fall within the scope of respiratory services, while others suggested it should either be a separate discipline or that it belongs in ENT. However, most settings were run by respiratory professionals, with some being led by nurse managers or nurse consultants, or technicians. Some clinicians felt strongly that sleep clinics should provide a service for the whole spectrum of sleep disorders, with OSA as one of the conditions treated.

There was a wide variation in the assessment and diagnostic facilities and protocols used in different settings, although most clinics had some kind of fast-track arrangement for people who drive for a living. There was also variation in the timescales for assessment and treatment, with the time between sleep study and treatment ranging from one day to two weeks. Some clinics offered more options for less straightforward cases, such as full PSG, particularly if there were co-morbidities, or if the home study had not been conclusive. Others referred to another setting for follow-up. Some settings had arrangements with primary care to carry out some assessment and diagnostic work.

The most common treatment was CPAP but there were huge differences across sleep clinics in both the approach to CPAP set-up and management, and the amount of time spent on CPAP education. Dentists can play a role in assessment and treatment of OSA in milder cases or for people who do not tolerate CPAP. Some clinics said they were unable to get oral devices/mandibular advancement/repositioning devices on the NHS for their patients. Bariatric surgery can be the best and most cost-effective treatment for very overweight patients and orthognathic (jaw) surgery can be successful for carefully selected patients. There were no agreed thresholds for intervention in children, although they can be given CPAP treatment.

Follow-up services varied hugely and included drop-in sessions, face-to-face appointments and a telephone helpline service. Some clinics discharged their patients after the first year, while others see them annually for life. A telemedicine approach was being considered in Scotland, enabling consultations to happen via a video link.

There are no agreed requirements for service delivery or staffing levels across the four nations and as a result there are differences, gaps and inequalities in service provision. In 2012 the BLF responded to the fact that there was very little data about OSA by mapping both the location of sleep

services in the UK and potential OSA hotspots based on the prevalence of OSA risk factors. This enabled a ground-breaking comparison of OSA high risk areas against known sleep services.

Areas of relatively high predicted prevalence estimates were Wales, the North East, and large parts of East Anglia and Lincolnshire. Large urban areas in England and Scotland, and the Home Counties were the areas with the lowest predicted prevalence estimates.

The total number of identified sleep units was 289. Of these, 50 centres offered polysomnography whilst other centres offered limited studies, pulse oximetry screening or CPAP services.

The results revealed a concerning mismatch between predicted healthcare requirements and service delivery. 66 health areas had no sleep centres whilst one large urban area had nine. Most UK sleep centres are in large urban areas characterised by younger populations with limited co-morbidities. People in areas with no sleep centres, but near an urban area, had a shorter travel distance to access sleep services. Others in more rural areas or islands had far greater distances to travel to the nearest available sleep service.

Appendix D: Main activities and achievements of the OSA project

A huge amount of activity has taken place over the three years of the OSA project. The main activities and achievements are summarised below in chronological order, to give a sense of the development of the project over the three years.

A review of literature and research findings about OSA was undertaken in 2011 and the results distilled into ten reports, which were medically approved, on different key issues such as awareness, diagnosis and treatment. These formed the basis for the BLF's position statements and informed their campaigning and awareness raising activities.

An online snoring survey of 2000 adults in April 2011 identified that 57% of people who snore loudly, or whose partner snores loudly, had heard of OSA. 11% of people who snore loudly had been to their doctor about it, 27% were referred to a sleep clinic and 18% were given CPAP treatment. Loud snorers in the West Midlands reported the highest rate of referral to sleep clinics (49%), while Yorkshire and Humberside had the lowest referral rate (8%). More people in Wales knew about OSA than anywhere else in the UK.

The Breathe Easy Week survey of 3061 people in June 2011 found that 49% of respondents were loud snorers, 46% struggled to stay awake during the day and 62% did not wake up feeling refreshed. Less than a quarter of respondents had spoken to their GP about their snoring and tiredness. 59% had heard of OSA and 5% had been diagnosed with it.

During Breathe Easy Week in June 2011, BLF Breathe Easy groups held 158 events all over the UK, linked with 65 pieces of national and local media coverage. BBC breakfast coverage was particularly effective.

Engagement with health care professionals: 23 interviews were conducted in 2011 with people who worked in sleep clinics, to understand OSA from a health care practitioner's perspective. The BLF also met with and attended conferences involving sleep medicine organisations, groups and professional bodies such as the Association of Respiratory Technology and Physiology, the British Sleep Society, the British Thoracic Society, NHS Lung Improvement, the Association of Respiratory Nurse Specialists, the British Society of Dental Sleep Medicine, the Sleep Apnoea Trust Association (and affiliated patient groups across the country), and many more. This resulted in over 2000 professionals receiving information about the BLF's OSA project.

Engagement with the sleep industry: the Sleep Industry Forum was formed in 2011 and continued to meet regularly throughout the life of the project to share information and best practice.

Engagement with patients: individual interviews with 32 people with OSA took place in 2011 to understand the issues faced by patients. These found that there was wide variation in the time it took for people to be diagnosed with OSA and to be referred to sleep clinics and other services. The majority of patients interviewed had CPAP machines, and although their experiences varied, three quarters reported positive outcomes as a result of their treatment.

The online pictorial Epworth Sleepiness Scale was uploaded onto the BLF website in June 2011. Over the life of the project more than 40,000 people took the scale online: 22% scored more than 11, indicating sleepiness, and 7% scored 19 or more, indicating excessive sleepiness. A scientific poster on the Epworth Sleepiness Scale results was presented at the British Thoracic Society conference at the end of 2012.

The BLF's OSA website pages were redesigned in 2011 and developed over the life of the project to include the Epworth Sleepiness Scale; a video of a man having an apnoea in his sleep; an OSA infographic; updated information about symptoms, assessment, treatment and management; information for drivers and GPs; and information about OSA in children, including a video of a 3 year old having an apnoea. The OSA website pages have also been featured and supported by other websites and organisations such as NHS Choices, British Heart Foundation, the Stroke Association and many others.

Printed OSA information for patients has been developed including a leaflet that was distributed to 50 sleep clinics across the UK, with orders through the BLF website increasing to 10,000 per quarter in 2012. A patient information pack was produced with information about signs and symptoms, referral, assessment, treatment, and living with OSA.

Campaign materials, including an OSA stand-up banner and campaign poster with the strap-line 'how deep is your sleep' were used at conferences and events from 2012 onwards.

The BLF's 10 point OSA charter was launched in July 2012 as a key campaigning tool. The main messages in the charter are that people with OSA and their families have a right to access screening, diagnosis, treatment, information, and ongoing support. The charter called on governments in the UK to make OSA a priority by increasing awareness levels, data collection and research, and on employers to arrange for employer screening for those employed as drivers or in vigilance-critical roles.

The policy and parliamentary campaign ensured that all MPs were emailed when the OSA charter was launched. The BLF attended the three major party conferences in 2012 and this led to over 25 meetings with MPs and six questions on OSA being asked in Parliament. A parliamentary reception was held at Westminster in April 2013 and was attended by 28 parliamentarians. In Northern Ireland, an OSA awareness event was held at Stormont in

September 2013. The BLF was also involved in the Department of Health's working group on OSA.

BLF OSA e-action was launched at the end of 2012 and has resulted in 400 contacts about OSA with parliamentarians across the four nations by their constituents.

Press and media coverage was an ongoing part of awareness-raising activity. Throughout the life of the project there were 215 pieces of both national and local media coverage including newspaper, radio, television and on-line reports. A BBC breakfast item in October 2011 led to a huge increase in the number of people taking the online Epworth Sleepiness Scale test.

The OSA mapping project was completed in 2012 and published in 2013, creating a set of maps showing both the location of sleep clinics in the UK and indicating potential OSA hotspots based on the prevalence of OSA risk factors, including obesity, diabetes, age, high blood pressure and sex (males) across the UK. In 66 health areas there were no known sleep clinics, while in one large urban area there were nine. Many sleep clinics were located in urban areas where predicted OSA risk was lower because the population was younger than in rural areas. The maps highlighted that access to specialist sleep services varied depending on where you live.

A web community poll of 200 people in January 2013 found that 64% of people had heard of OSA but did not have it. 12% had been diagnosed with OSA and of these 33% had received good training in how to use their equipment and received regular check-ups. 50% were happy with their treatment.

An Information pack for GPs was launched in February 2013 at NHS Improvement's Respiratory Learning event. The pack included a leaflet, poster and GP OSA guide.

A major OSA awareness campaign took place in Co Durham between May and August 2013. This involved a press campaign, sending information to over 250 local venues, engaging local health care professionals and directly contacting over 100 'at risk' households by telephone. The campaign culminated in four events where people could take the Epworth Sleepiness Scale and access specialist support if they needed it.

The OSA patient survey in 2013 was the largest survey ever undertaken of people with OSA. 53 sleep clinics across the UK promoted the survey to their patients and 2,671 questionnaires were completed. Pre diagnosis, only 44% of patients had heard of OSA. 11% had fallen asleep while driving and 2% had had a road accident while driving. 4% of patients later diagnosed with OSA were initially told by their GP that nothing needed to be done.

Following diagnosis 92% said they were given some information about OSA, but only 56% received written information. 22% had to drive regularly for

work but only 62% of drivers and only 68% of those who drove for a living were told to inform DVLA about their OSA diagnosis.

Around three quarters of respondents started treatment within one month of their diagnosis. CPAP was given to 92% of patients and 75% of people were positive about their treatment. Almost all respondents said CPAP was the best treatment, that they were currently using CPAP seven days a week and had received training and support to use their CPAP equipment. Overall, being diagnosed and treated for OSA had a highly significant positive effect on patients' wellbeing.

The BLF's OSA in Children booklet, based on the BLF's award-winning website information, was launched at the British Sleep Society's 25th anniversary meeting in October 2013.

The online snoring survey of 2000 adults in 2014 was an update of the survey originally done in 2011 and showed that awareness of OSA had increased by 5% from 57% to 62%, and for men had increased by 10% from 49% to 59%. Awareness levels improved in every area in the UK except the East Midlands. Awareness levels remained highest in Wales at 75%. The area that had the greatest increase in awareness levels, from 55% in 2011 to 72% in 2014, was the North East of England, where the BLF targeted awareness campaign took place in 2013.

The BLF OSA conference in February 2014, in partnership with the Association for Respiratory Treatment and Physiology, was the first UK conference on OSA and marked the end of the project. The event was an opportunity to share examples of effective clinical practice and mechanisms to support people with OSA from across the UK, and to discuss how to ensure that OSA remains a priority in the future.

Identifying the elements of an effective sleep service: the patient pathway: Over the life of the project, the BLF has established the components of an effective patient pathway for someone with OSA and has sought to promote this good practice across the four nations.

- i. **Screening and referral:** The BLF identified 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 to increase their involvement in care pathways.
- ii. **Assessment and diagnosis:** The key components of an effective service are good quality referral processes, 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.
- iii. **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 which 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 - primary, secondary and tertiary care - and gives detail about resource and training requirements, key performance indicators, potential funding streams, and locally agreed fees.

- iv. **Management and ongoing support:** As diagnosis and treatment improves, managing the growing number of patients on treatment will become an important priority. There are different ongoing support models, depending on where the tertiary service is offered.

Appendix E: About the consultants

Reshenia Consulting is a partnership of independent consultants who work with voluntary, community and social enterprise organisations and the public sector. We support individuals, teams and organisations to:

- Improve their performance
- Demonstrate their impact
- Develop strategies and action plans

Reshenia is a Russian word for reaching solutions: that is what we help our clients to do. Reshenia Consulting draws on the skills and expertise of freelance professionals, who are all self-employed, to meet the specific needs of each client.

This evaluation has been undertaken by a team of three consultants: Lori Streich, Lin Whitfield and Vicky Redding.

For more information, see our website www.reshenia.co.uk

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