The Optimal Sleep Pathway: Towards better care for patients with sleep conditions

A practical guide to improving the sleep pathway

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February 2025

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Acknowledgements

The optimal sleep pathway (OSP) working group are grateful to the many individuals that co-developed this document including patient representatives and clinicians.
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Clinicians: *Professor Brendan Cooper, Dr Victoria Cooper, Dr Aditi Desai, Dr Dipansu Ghosh, Dr Andrew Hall, Dr Julia Kelly, Dr Sofia Khan, Mr Bhik Kotecha, Elaine Lyons, Dr Swapna Mandal, Dr Alison McMillan, Michael Lang, Dr Julie Lloyd, Sara Parsons, Alex Perkins, Mr Vik Veer, Ian Wheatley and colleagues who supported focus groups and case studies.*

Foreword

The 2021 GIRFT national specialty report for Respiratory medicine[1] identified substantial variation in the delivery of sleep medicine across the National Health Service (NHS). NHS England (NHSE) data[2] demonstrates rising numbers of referrals to sleep services, and a significant backlog following the pandemic. There are a number of barriers to the recovery of outpatient services, including sleep medicine, and workforce is a particular challenge: The 2022 British Thoracic Society Workforce Report[3] highlighted staffing issues across the NHS, and the NHS Long Term Plan[4] identified workforce development as an area for focus.

A NHSE outpatient transformation workstream was commissioned to design an optimal sleep pathway, in order to modernise and improve the patient pathway. The group consisted of a broad range of healthcare professionals, representing all of those involved in the delivery of sleep medicine, alongside patient representatives and members of national organisations, including the British Sleep Society and the Association for Respiratory Technology and Physiology. Focus groups were held with patients and primary care representatives, and a range of case studies were captured, in order to share real world insights into solutions developed by different services across the country.

The working group identified exemplars of good practice and guidance on service improvement, aligned with Getting It Right First Time (GIRFT) aims[5] the NHS Long Term Plan[4] commitments to increase support to primary care, deliver care closer to home and to assist with post-pandemic recovery and with NHSE goals for referral optimisation and increasing patient initiated follow up.[6] It is hoped that this guide will facilitate progress towards improved outcomes and experiences for patients with sleep disorders.

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8th April 2024

RE: Optimal Sleep Pathway

This is a letter of endorsement of the Optimal Sleep Pathway Document.

Sleep medicine is facing a huge range of challenges specific to the speciality. We feel that this high-quality piece of work has captured a broad breadth of challenges and experiences within sleep medicine. The document effectively reflects the views of a wide group of professionals and patients with lived experience of sleep disorders and has given voice to patients who are using sleep services. It provides helpful guidance on how to improve sleep services, regardless of what level of development the services are currently in.

We would support this piece being published on a platform which would encourage service development within sleep services, to help tackle many of the challenges faced by the speciality at this time.

Yours sincerely,

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Executive Summary

Sleep disorders are common, with over 80 distinct primary sleep disorders[6] affecting around a third of the general population in Western Europe.[7] In the UK, 14% of adults are experiencing clinical insomnia in any given year[8] and an estimated 2.5 million individuals are living with obstructive sleep apnoea hypopnoea syndrome (OSAHS)[9] with the latter demonstrating rapidly increasing prevalence due to the ongoing obesity epidemic and an aging population.[10,11] Many of these patients are undiagnosed – data suggest 85% of individuals with OSAHS in the UK are undiagnosed;[12] or experience significant delays to diagnosis – narcoleptic patients frequently experience delays of over 10 years before they receive a confirmed diagnosis.[13] The impact of sleep disorders, particularly when unrecognised and untreated, is significant. Nationally, the UK is predicted to incur a loss of 1.86% of Gross Domestic Product (GDP) due to insufficient sleep and insomnia related workplace absenteeism in the UK amounts to 200,000 lost working days annually.[14]

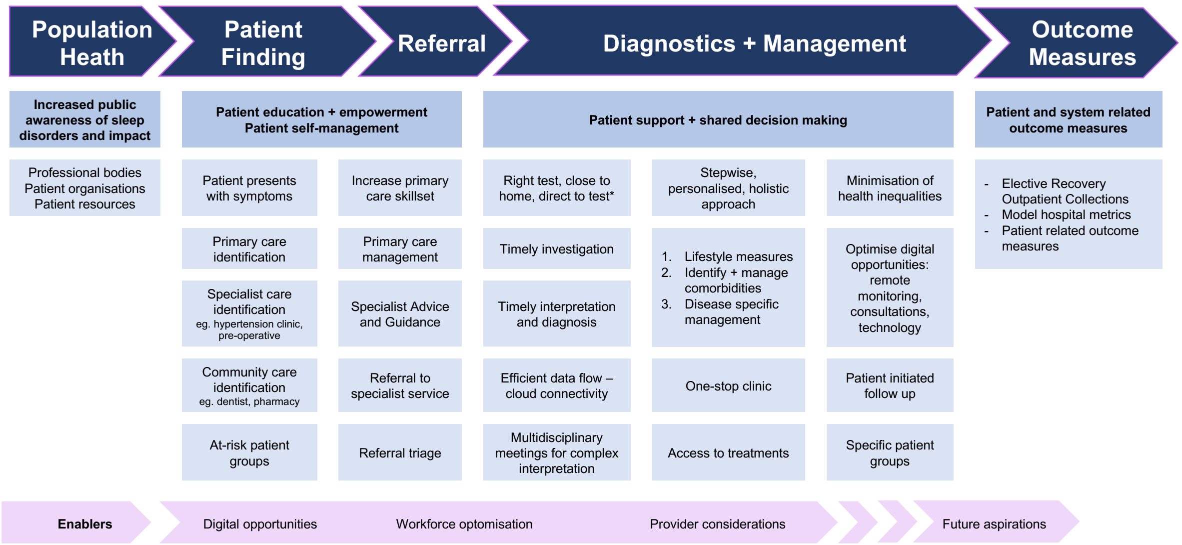
National Health Service (NHS) sleep services are under strain, with rising referrals exacerbated by pathway delays due to the Covid-19 pandemic. In 2021, data from the NHS eReferral services identified an estimated 360,000 referrals into respiratory and sleep medicine services in England,[15] with sleep medicine accounting for one third of all respiratory medicine referrals in many NHS Trusts.[1] The 2021 GIRFT national specialty report for Respiratory medicine identified substantial variation in the delivery of sleep medicine across the NHS.[1] Several sleep disorders are managed predominantly in primary care, such as insomnia and restless legs syndrome. Specialist sleep medicine is delivered by a range of specialities, which may not be comprehensively, or digitally, linked up, resulting in siloed care throughout the patient pathway. These specialities include respiratory, neurology, psychiatry, ENT, dentistry and anaesthetics. The lack of integrated care can result in some patients undergoing duplication of investigations and being disadvantaged by delayed therapeutic decisions.[1,16]

The early identification and treatment of patients with sleep conditions can provide significant economic and social benefits including through reduced healthcare utilisation and improved healthcare outcomes.[17,18,19] Therefore, it is important to improve awareness of sleep disorders, to actively draw patients into optimised and coordinated sleep pathways, so as to ensure timely access to robust diagnostics and effective treatment, maximising efficient use of NHS resources. The NHS Long Term Plan[4] recognised that current models of outpatient delivery are outdated, and the experience of outpatient visits could be improved for many patients. By improving service delivery models, it was estimated that a third of face-to-face hospital outpatient attendances could have been saved by 2023/24, avoiding up to £1.1bn of additional expenditure, reducing unnecessary hospital appointments, and generating a positive environmental impact.[4]

There are plenty of opportunities in the outpatient management of sleep conditions to optimise referral pathways and to ensure patients with sleep disorders are seen in the right place, by the right person, getting it right the first time. Increased personalisation of care and patient empowerment, for example through patient initiated follow up, could improve the patient experience further. There are also many opportunities to use digital transformation and optimisation of the workforce to enable improvements in patient care and in staff efficiency.

This guide, designed by a broad range of healthcare professionals representing those currently involved in the delivery of sleep medicine, and co-developed with patients, provides guidance on improving NHS sleep services end-to-end. The work identifies key enablers for success, to ensure a care pathway for those with sleep disorders which is fit for today and for the future.

An overview of the pathway and its key recommendations can be seen in figure 1.



Population Heath

Increased public awareness of sleep disorders and impact

Professional bodies
Patient organisations
Patient resources

Patient Finding

Patient education + empowerment
Patient self-management

Patient presents with symptoms
Increase primary care skillset
Primary care identification
Primary care management
Specialist care identification
eg. hypertension clinic, pre-operative
Specialist Advice and Guidance
Community care identification
eg. dentist, pharmacy
Referral to specialist service
At-risk patient groups
Referral triage

Referral

Diagnostics + Management

Patient support + shared decision making

Right test, close to home, direct to test*
Stepwise, personalised, holistic approach
Minimisation of health inequalities
Timely investigation
1. Lifestyle measures
2. Identify + manage comorbidities
3. Disease specific management
Optimise digital opportunities: remote monitoring, consultations, technology
Timely interpretation and diagnosis
Efficient data flow – cloud connectivity
One-stop clinic
Patient initiated follow up
Multidisciplinary meetings for complex interpretation
Access to treatments
Specific patient groups

Outcome Measures

Patient and system related outcome measures

- Elective Recovery Outpatient Collections
- Model hospital metrics
- Patient related outcome measures

Enablers
Digital opportunities
Workforce optomisation
Provider considerations
Future aspirations

Figure 1: *Overview of the Optimal Sleep Pathway*

Introduction

Sleep disorders are common, with over 80 distinct primary sleep disorders[6] affecting around a third of the general population in Western Europe.[7] In the UK, 14% of adults are experiencing clinical insomnia in any given year[8] and an estimated 2.5 million individuals are living with obstructive sleep apnoea hypopnoea syndrome (OSAHS)[9] with the latter demonstrating rapidly increasing prevalence due to the ongoing obesity epidemic and an aging population.[10,11] Many of these patients are undiagnosed – data suggest 85% of individuals with OSAHS in the UK are undiagnosed;[12] or experience significant delays to diagnosis – narcoleptic patients frequently experience delays of over 10 years before they receive a confirmed diagnosis.[13] The impact of sleep disorders, particularly when unrecognised and untreated, is significant. Nationally, the UK is predicted to incur a loss of 1.86% of Gross Domestic Product (GDP) due to insufficient sleep and insomnia related workplace absenteeism in the UK amounts to 200,000 lost working days annually.[14]

The impact of sleep conditions

Comprehensive economic assessment of the impact of sleep disorders in the UK does not exist. Available data, however, demonstrate impacted cognitive function[20] and work performance,[21] greater unemployment rates[22] and increased workplace absenteeism[23] with significant economic burden as a result. Nationally, the UK is predicted to incur a loss of 1.86% of Gross Domestic Product, equivalent to up to $40 billion, due to insufficient sleep.[14] Excess social and health-related costs per patient with narcolepsy are over €10,000[24] and insomnia-related workplace absenteeism in the UK amount to 200,000 lost working days annually.[14] Sleep disorders burden healthcare systems: compared to controls, individuals with insomnia have double the likelihood of hospital admission,[17] patients with OSAHS utilise 10-20% more healthcare[18] and patients with narcolepsy have doubled direct medical costs, when compared to controls without a sleep disorder.[19] Undiagnosed OSAHS has an even greater impact: in the year preceding diagnosis of severe OSAHS, patients required twice the number of inpatient days, and incurred twice the healthcare costs, compared to controls.[25]

Sleep conditions commonly co-exist with other conditions, particularly other sleep conditions and cardiovascular diseases. Patients with OSAHS have an increased stroke risk, with worse functional and cognitive outcomes if they do experience a stroke,[26] have an increased association with atrial fibrillation (AF)[27] and experience a tripling in the risk of hypertension.[28] Up to 80% of patients with treatment-resistant hypertension have OSAHS[26] and patients with OSAHS have increased all-cause mortality.[29] Effective OSAHS treatment is proven to improve AF burden[26,27] and reduce blood pressure;[30] whilst antihypertensives can both reduce the severity of OSAHS and blood pressure.[31] OSAHS and central sleep apnoea commonly affect patients with heart failure (HF) resulting in adverse outcomes including increased hospitalisation and mortality,[32,33] but treatment improves ejection fraction.[34]

The social impact of sleep conditions is broad. Interpersonal relationships are often affected: a third of couples sleep in separate beds due to the discomfort of partner's movements in restless legs syndrome[35] and the bed partners of patients living with OSAHS experience physical and mental health impacts[36] and in fact, report a lower quality of life than the patient.[37] The effect of sleep disorders on the patient themselves includes reduced quality of life, particularly when undiagnosed:[38] the impact of narcolepsy on quality of life is comparable to that of Parkinson's disease or multiple sclerosis.[24]

Managing sleep conditions, such as obstructive sleep apnoea, effectively decreases healthcare costs, compared to matched controls who had increasing healthcare utilisation costs during the same period.[39] 2014 estimates suggested that the NHS could save £55 million annually if all people with moderate to severe OSAHS were diagnosed and treated,[12] but with the ongoing obesity pandemic, this number is expected to have increased. If all drivers in the UK with OSAHS were treated, it is estimated that there would be 40,000 fewer road accidents annually,[12] in addition to reductions in work-place accidents, healthcare costs, changes in quality of life, improvements in cognitive function and workplace performance.[40]

There are rising numbers of referrals to sleep services which have limited capacity, insufficient sleep workforce and a lack of support services, driving delays in diagnosis which vary across the NHS.[1] Commissioning differences result in services with variable comprehensiveness, staffing ratios and waiting lists. This further drives geographic variation in patient outcomes, where there is already geographical mismatch between predicted healthcare requirements and current sleep service delivery.[41] Sleep medicine encompasses many specialities, therefore service design differences can result in some patients experiencing siloed care along their care journey. Patients report limited understanding of sleep conditions beyond insomnia within primary care, challenge accessing support for their conditions and issues with access to medications and devices.[42] *For further information please refer to Appendices A to C.*

What is the guide's aim?

The purpose of this guide is to describe how sleep services can be optimised to improve referral and triage, cut down on unnecessary appointments and give patients greater flexibility and control over how they receive care in line with the aims of the NHS Long Term Plan.[4] This guide highlights the necessary elements to achieve these aims. These include an adequately staffed and skilled workforce, appropriate digital support, access to evidence-based treatment options, and improved communication and support between primary and specialist care. As each service is unique, this guide describes overarching principles to support the development and optimisation of outpatient sleep services, so that these can be adapted across different services. The guide also describes aspirations to support the development of services which will be fit for the future. Finally, learning from existing sleep services with established novel working practices is included in the form of case studies which describe how new practices have been embedded in the real world.

Who should read this guide?

This guide is aimed at healthcare professionals who care for patients diagnosed with sleep conditions, and commissioners and providers of NHS sleep services, within England. It is anticipated that this information will also be helpful for services within the devolved nations.

How was this guide developed?

This guide was developed with the involvement and feedback of key stakeholders including patients, clinicians, implementation managers, relevant professional bodies such as the British Sleep Society, British Thoracic Society and Association for Respiratory Technology and Physiology, and organisations that represent the views and interests of people with lived experience of sleep disorders, including the Sleep Apnoea Trust, Hope2Sleep and Hypersomnolence UK.

Experienced sleep clinicians from across the multidisciplinary team co-produced the work with patient representatives with lived experience of sleep conditions. The group explored various elements of the patient pathway from identifying patients, supporting diagnosis and management and assessing outcomes, in addition to looking at various enablers which could support these elements. These areas were looked at within task and finish groups under the oversight of a reference group. Additional focus groups were held to explore various elements in more detail.

1.0 Population health

Greater public awareness of sleep conditions and their impact could empower patients to present to healthcare services in a timelier fashion and be supported to obtain a diagnosis and management quicker. This could thereby mitigate the negative sequalae of sleep conditions on their physical health, mental wellbeing, work productivity and safety.[43-45] Public awareness has historically been driven by professional societies, patient organisations and charities. Governmental public health organisations have championed addressing obesity,[46] an important risk factor for OSAHS, and hypertension,[47] an important sequalae of untreated OSAHS.[31] However there is also an opportunity to increase awareness of the sleep consequences of obesity, the impact of poor sleep on cardiometabolic health, and for a national approach to raise the profile of sleep conditions.

Recommendations	
1	**Increase public awareness of sleep conditions**
Education about sleep conditions, their consequences and the symptoms which should lead individuals to seek medical attention should be enabled through increased public health messaging, targeted advertisements and by supporting the work of national sleep related charities. *See Appendix H for a leaflet designed to raise awareness within community dentistry.*	

The patient perspective[42]

Patients within the working group are keen for the profile of sleep conditions to be raised, through increased information provision at a population level, to try to improve rates of diagnosis and reduce the impact of undiagnosed conditions. They suggested that there is an opportunity to harness current obesity-related health advertising to increase awareness of sleep conditions related to obesity, particularly obstructive sleep apnoea.

2.0 Patient finding

There is a need to improve identification of individuals with sleep conditions to manage them effectively and mitigate the impact of these conditions. Opportunities exist across all interactions with healthcare providers.

Recommendations	
1	**Enhance case finding in primary care**
	Existing care interactions could be used: for example, screening patients at annual review of common sleep co-morbidities such as hypertension or diabetes. Sleep conditions are important differentials for many primary care attendances, such as “tired all the time” and teams should be supported to screen for sleep conditions in these patients.[10]
2	**Increase primary care skillset**
	All healthcare professionals should be aware of symptoms of sleep conditions and how to support patients to access appropriate healthcare. Effective specialist advice and guidance could increase collaboration and knowledge sharing between specialist and primary care clinicians. Further opportunities for clinicians with an interest in sleep medicine are useful: Newcastle Upon Tyne Hospitals NHS Foundation Trust have had positive experience trialling novel “GP with Special Interest in sleep” roles.
3	**Enhance case finding in specialist care**
	Sleep conditions should be proactively considered when patients seek specialist healthcare for conditions commonly associated with sleep conditions, for example complex hypertension,[48] obesity services,[10] or psychological services.[49]
4	**Enhance case finding in community care settings**
	Patients attending community settings could be navigated towards patient education resources and sleep services as appropriate. For example, patients seeking advice or over-the-counter medications to aid sleep in community pharmacies or patients consulting community dentists with snoring with daytime sleepiness.[50] *See Appendix H.*
5	**Enhance profile of sleep medicine**
	Enhancing the presence of sleep medicine within general physician, dental and allied healthcare professional training should increase awareness and experience of sleep conditions and may help tackle workforce challenges, as demonstrated through schemes in psychiatry.[51,52]

2.1 At risk patient groups

It is particularly important to ensure that critical patients are identified, flagged and expedited, or have additional or enhanced monitoring as required. Digitalisation and artificial intelligence (AI) within electronic patient records, could provide functions to actively identify patients who are at greater risk of sleep conditions, and who would most benefit from reduced morbidity by being identified and treated.

Recommendations	
1	**Social deprivation**

Many patients with sleep conditions experience comorbidities that are associated with social deprivation and should be prioritised for identification, in line with NHSE's Core20PLUS5 agenda.[53]

2 Occupational considerations

Patients with important occupational considerations, such as professional drivers, must also be proactively identified, due to the impact of sleepiness on driving safety.

3 Digital case finding

Digital opportunities for case finding exist and should be utilised to find patients at risk. Flags could be enabled within electronic patient records to trigger healthcare professionals to consider sleep conditions if patients have a high-risk clinical profile, for example, patients with metabolic syndromes associated with obesity, or those with hypertension on multiple antihypertensive agents.

There is functionality within existing primary care platforms, to search for specific conditions, and to link the healthcare professional to the latest evidence-based resources; we would advocate more widespread availability of these technologies and for the functionality to be utilised to optimised patient care. Patients could digitally complete screening tests, such as the Epworth Sleepiness Scale,[54] or the STOP-BANG screening tool,[55] which could be linked to primary care and trigger primary care practitioners to facilitate referrals to sleep medicine if there is significant clinical concern. Finally, platforms exist that utilise AI to identify if patients are at risk of more unusual sleep conditions, such as narcolepsy.[56]

See section 7.0 Enablers: Digital

The patient perspective[42]

The patients who co-produced this work also contribute to national patient support organisations which have a crucial role in enabling patient self-management, particularly when the sleep pathway may be inadequately doing so. They highlighted the importance of high quality and accessible information and resources to enable patients to be able to understand and manage their own condition. In particular, clear information regarding notifications to the DVLA for each condition are needed, as well as personalised information to support patients with accessing appropriate healthcare.

3.0 Referral

The figure below represents a symptom-based pathway of care, demonstrating where patients may need to go, and highlighting the importance of processes described later in this guide, such as specialist advice and guidance and centralised triage.

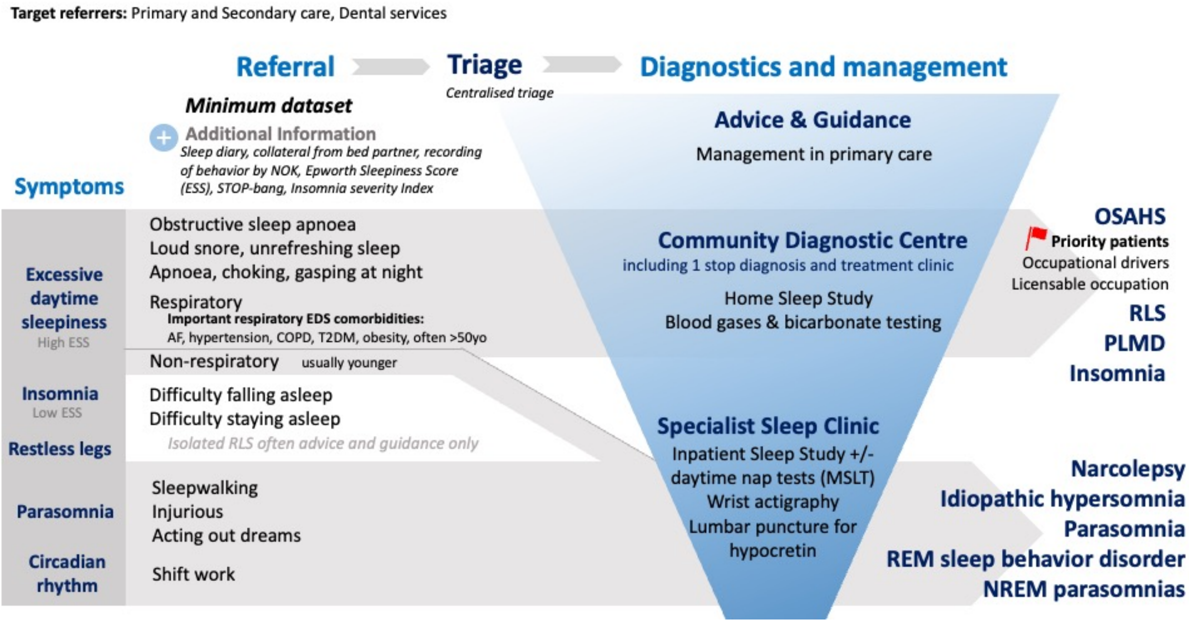


Figure 2: *Symptom based pathway*

3.1 Pre-referral management

There should be a step-wise approach to pre-referral management, with self-management being fundamental. Not all patients will need specialist input but there is a need to optimise pre-referral pathways to ensure that, when necessary, patients have efficient and effective access. Patients should be seen in the right place by the right person first time, and specialists should see patients who have had optimal care before being seen in a specialist centre. NHSE has a programme of work for system-wide pre-referral pathway improvement which includes advice and guidance and referral optimisation.[57]

Recommendations	
1	**Patient resources to enable self-management**
Patients should have resources to enable self-care, including the ability to take decisions in response to observations from self-monitoring and support with problem-solving, for example, NHS patient information websites, local patient literature, access to support groups, and support with informed decision making when making choices about their care.	
2	**Patient organisations**
Individuals should be directed to patient organisations, such as Hope2Sleep, Sleep Apnoea Trust, Narcolepsy UK, RLS-UK and Hypersomnolence UK, which provide valuable support to patients living with sleep conditions.	
3	**Primary care management**

Patients should have a holistic clinical assessment including screening tools. Many sleep conditions can be managed effectively in primary care, with no requirement for specialist diagnostic or treatment intervention. Primary care professionals should be supported to manage these patients effectively where possible. Current resources include NICE clinical knowledge summaries and the "FAQ" function within specialist advice and guidance platforms, which should also be kept updated to enable GPs to access locally relevant management and pathway advice. We would also support the creation of web-based learning tools and webinars to increase opportunities for knowledge sharing.

3.2 Specialist Advice and Guidance

Specialist advice and guidance (SAG)[57] enables enable primary and community services to have better clinical support about sleep disorders and the resources they need to diagnose, treat and support more patients closer to home. This reduces the need for onward referral and/or can ensure referrals are made to the right place in a timely fashion. SAG enhances the pre-referral stage of the patient pathway by providing continued digital access to specialist clinical advice via NHS electronic referral system (NHS e-RS). A SAG request is submitted to a specialist sleep service, and a response given by a specialist. Reasons for obtaining SAG include advice on a treatment plan and/or the ongoing management if a patient; clarification or advice regarding a patient's test results; advice on the appropriateness of a referral for a patient. This allows the sharing of relevant clinical information enabling the referring clinician to seek advice from a specialist prior to or instead of referral.

It also ensures that specialists will see patients who have had optimal care across the pathway before being seen in a specialist service. SAG provides improved continued access to specialist clinical advice for primary care. Alongside community diagnostic centres (CDCs), this should better support primary and community services to diagnose, treat and support more patients closer to home, and to ensure efficient navigation to the most appropriate clinical pathways. This should improve patient experience and reduce unwarranted variation.[58] SAG processes already exist within respiratory and neurology services: there were over 51,000 respiratory SAG requests in November 2021[59] with data suggesting that a quarter were diverted from a specialist care appointment.[60] However, there is no sleep-specific data and opportunities exist for optimising sleep SAG.

Recommendations

1 Models of SAG

There are multiple SAG models. The model used within a particular service is for local determination and should complement standardised referral pathways. SAG can be delivered pre or post referral but must be prior to a booking being made. Once the response has been received by the referrer, the patient and clinician can make a shared decision about the available choices, treatment plan and provider. When using NHS e-RS, SAG conversations can be converted to a referral, removing the need for the request to be returned to the referrer for them to take this action.
Pre-referral models include the following specialist delivered SAG services:

- e-RS advice and guidance

- virtual review services offered by specialists or experts working in the community or primary care (eg. services where primary care practitioners such as GPs with extended roles, or first contact practitioners with suitable training and qualifications deliver SAG)
- independently provided platforms delivering SAG to primary care colleagues

Post referral models include referral assessment or triage services. These models provide a specialist-led assessment of a patient’s clinical referral information to support a decision on primary care management or the most appropriate onward clinical pathway. These models are best enabled by standard referral forms and the use of digital platforms which can help guide the referrer.

Responses can be synchronous, for example via a telephone call, or asynchronous enabled electronically through the e-RS platform or other local routes, for example a dedicated email address where there is agreement from all stakeholders.

2 Broaden referrers

Currently, SAG is usually requested by general practitioners and provided by specialist sleep services, except for insomnia, for which SAG can also be delivered through the primary care IAPT service and community mental health teams. Better integration and use of SAG can be achieved through expanding the range of primary care healthcare professionals that may request SAG, by ensuring that that appropriate training and governance structures are in place.

3 Timely response

Efficient responses, recommended to be within two working days, will ensure timely clinical decision making and minimise delays to onward referral if this is required. However, it is recognised that this should be agreed locally to reflect local service needs and systems and adequate time allocated in providers’ job plans to deliver within any set timeframe.

4 Funding

SAG must be adequately remunerated to ensure that there is adequate workforce cover to respond to SAG requests timely, and to balance SAG workload against other clinical activity. Local service providers and commissioners should decide how local SAG services will be established, analysed, and scaled to demand.[61] Upcoming changes in funding with aligned payment incentives (API) to aid movement away from block contracts will provide an opportunity to ensure that SAG is recognised. API guidance acknowledges the role of SAG services, and the blended approach of fixed and variable funding will enable funding proportionate to the amount of SAG activity undertaken.[62]

4 Resourcing

Adequate workforce resourcing is essential to deliver effective sleep SAG services. The following tasks comprise SAG services and therefore service planning should acknowledge and accommodate the following:

- Viewing referral letters and additional attachments, eg. patient drug history
- Reviewing additional information in the patient record, eg. test results
- Reviewing literature and performing evidence-based searches for complex cases
- Typing or digitally dictating a suggested diagnosis and management plan where appropriate, or, recommending specific investigations in primary care
- Converting the SAG request to a referral and indicating the priority
- Development of agreed educational resource that takes account of local provision
- Attaching documents / guidelines / web-links

- Phone calls to primary care or patients for complex cases requiring urgent clinical intervention eg. fast tracking professional drivers or concerns about respiratory failure
- Ensure remuneration for SAG activity through appropriate commissioning

5 Monitor outcomes

Measuring and evaluating SAG services regularly highlights good practice, supports benchmarking, and informs opportunities for system improvement. This helps ensure services are meeting local requirements, quality standards, ensure sustainability of the service and ultimately improve outcomes for patients.

6 Provide FAQs

Providing FAQs as part of the SAG provision will help manage numbers of requests and provide rapid support to primary care. Through interval auditing of the service, as above, other FAQs could be added to the list. Generic SAG FAQ's can be found on FutureNHS with other support tools and resources.

Members of the working group and primary care focus groups advised the following core sleep SAG FAQs:

- Insomnia management advice
- Advice regarding restless legs diagnosis, investigations and management
- Change in symptoms in a patient with a known sleep condition not under specialist care
- Navigating the correct diagnostic pathway for patients presenting with symptoms of sleep disorders
- Advice for non-injurious parasomnia eg. isolated sleep paralysis or occasional sleepwalking
- Management or adjustment of stimulant or sedative medication or a potential side effect of medication for a patient not under specialist care.
- Advice regarding difficult snoring
- Recommendations regarding provision of mandibular advancement devices

Specialist services may also offer local resources, for example a sleep diary.

7 Digital optimisation

Digital and information technology should support the effective delivery of SAG and include the provision of two-way communication between sleep services and primary care providers.

3.3 Referral to specialist service and referral triage

How referrals are managed will depend on how a sleep service is structured. Given the variety of specialties involved in sleep services, referrals may be received by each specialty, or be centralised. The ability for referrals to be passed onto the most appropriate specialist is important when services are segregated. Effective and timely triage is enabled by sufficient information being available for the specialist to review. This needs to be balanced against the time-pressures within primary care and the need for succinct referral forms with the ability to automatically pull through information from the primary care patient record.

Recommendations

1 Minimum dataset

Referrals should contain a minimum set of information to enable effective triage. The working group have recommended this in figure 3. Where possible, information should pre-populate from the primary care system, to minimise time spent completing referral. If the patient already has a known sleep disorder, but there is concern that patient has an additional sleep diagnosis, we recommend the use of SAG in the first instance.

2 Centralised referral system

Centralised systems would enable all sleep referrals, including those for CDCs and highly specialist services, to be quickly sent to the right service, and in some cases, direct to test. Services should have processes in place to ensure that cases are sent to the right part of the service at the point of referral, for example, patients with likely parasomnias or narcolepsy should not be triaged to CDC-led investigation pathways, and some cases of probable OSA could be triaged direct to test, or to a one-stop clinic.

3 Timescale and triage

Specialist services should perform diagnostic testing on all individuals with sleep conditions within 6 weeks of referral. Those with vigilance critical occupations and those for whom alertness is critical for safety, should be prioritised for treatment. This aligns with NICE guidance that patients with OSAHS and increased occupational risks, should be prioritised for treatment.[63]

4 Digital optimisation

Robust digital processes are necessary to gather information before referrals are screened, to enable patients to be triaged and placed onto appropriate diagnostic and treatment pathways. Systems should operate so that all available information from primary care records can be pulled through to avoid duplicate processes, and this information should then be able to be sent onwards for further specialist referrals. This information could be usefully supplemented by the inclusion of further information from patients, obtained digitally via electronic questionnaires.

Figure 3: *Minimum dataset for referral to sleep service.*

It is recommended that this minimum dataset is expanded and adapted to local services.

Minimum dataset for referral to sleep service	
Sleep symptoms	
1	Daytime sleepiness – eg. unable to get through the day without sleeping, Epworth Sleepiness Scale >10
2	Snoring
3	Nocturnal apnoeas, choking, gasping, breathlessness
4	Unrefreshing prolonged night time sleep
5	Restless legs +/- nocturnal movements noted by partner
6	Sleep walking, acting out dreams +/- injury
7	Insomnia condition – inability to initiate/maintain sleep
Other symptoms	
1	Nocturia
Important co-morbidities	
1	Obesity
2	Hypertension
3	Type 2 diabetes
4	Atrial fibrillation
5	Chronic obstructive pulmonary disease
6	Neurological conditions eg. Parkinson's disease
Occupation	
1	Shift work
2	Licensable or vigilance critical occupation e.g. HGV driver
Drug history	
1	Stimulants
2	Sedatives
3	Anti-hypertensives
4	Excess alcohol/caffeine
Clinical data	
1	Body Mass Index and weight
2	Blood Pressure
You may wish to consider asking the patient to obtain the following	
1	Sleep diary – a local sleep diary could be made available to the referrer via the SAG platform or the sleep service website.
2	Collateral from bed partner, or advise patient to bring bed partner to sleep clinic appointment
3	Video recording of behaviour by bed partner or family

4.0 Diagnostics

The priority is to ensure that the most appropriate investigation is performed first time and is interpreted in a timely way by an appropriately trained healthcare professional. Investigations can be healthcare-based or home-based: we recommend home-based sleep studies as a routine, unless there are patient-related reasons to undertake the test in hospital, including patient preference. Some studies can only be performed in specialist sleep services and/or in healthcare environments.

Recommendations

1 Investigations

The OSP working group recommend home-based sleep studies as a routine, unless there are patient-related or clinical reasons to undertake the test in hospital, including patient preference.

2 Community diagnostic centres (CDCs)

CDCs could enable investigation of some sleep conditions in a convenient way, closer to patient's home. Home-based testing kits could be coordinated via CDCs, however specialist sleep services should complete more complex diagnostics and treatments.[64]

3 One stop clinics

One stop clinics allow assessment, investigation, diagnosis and treatment within one care opportunity, and could be facilitated by the use of home-based sleep diagnostics. Benefits of this include minimising the length of time to treatment start, reduced costs and opportunity for sleep assessment, closer to patients' homes.[65]

4 Specialist sleep services

Patients will benefit from sleep centres which have access to a range of allied specialities, which may include psychology, neurology, psychiatry and ENT teams.[66] Management of some sleep conditions requires the expertise of multiple specialties beyond sleep medicine, for example bariatric services. Patients with rarer and/or neurological sleep conditions are likely to need clinicians linked to specialist centres. These centres should have sufficient concentration of expertise and caseload, while being as local as possible to the patient.[1]

5 Access to Multidisciplinary Team Meetings

There should be access to an appropriately staffed and skilled MDT for complex diagnostics interpretation.[66]

6 Diagnostic testing for OSA

OSA diagnostic testing is variable and can be home or healthcare-based. Centres may offer oximetry or respiratory polygraphy for first-line testing, influenced by clinical preferences and local commissioning agreements. NICE advises home respiratory polygraphy as a first-line investigation, or oximetry if there would be diagnostic delay due to limited access to respiratory polygraphy.[63] Supporting evidence for this strategy is lacking, as reflected by NICE not mandating polygraphy replace oximetry when it is already embedded in a service.

Recommendations

1 Diagnostic standards

We advocate that diagnostics used within the sleep pathway should fulfil the following criteria:

1. All services should have access to cost-effective diagnostics that enable providers to deliver accurate and timely diagnostics effectively and economically
2. Sustainability should be considered, for example, the sustainability and footprint of disposable kit should be considered alongside the convenience. Small re-useable kits will facilitate this and avoiding disposable kits will reduce electrical waste
3. Devices should be appropriate for the requirements, for example, ensuring diagnostic tests rather than screening tests are used to diagnose accurately and cost effectively
4. Diagnostics should have validated efficacy, with adequate sensitivity and specificity
5. Consideration should be made for the maintenance of equipment, for example, some trusts may prefer to rent diagnostic kit to avoid the responsibility of having to maintain it
6. Diagnostic equipment should be compact and robust to ensure it can be safely sent to patients cheaply, for example, within a standard sized envelope with a standard postal charge
7. Equipment should be easy to use by the patient and /or their carers
8. Equipment should fulfil the digital technology assessment criteria[67]
9. Diagnostic equipment should comply with NICE recommendations for minimum standards for medical devices[68]
10. Data should be easily synchronised with the electronic patient record and across all healthcare providers involved in the patient journey
11. Devices should not clear study data unless they have been downloaded
12. Devices should have the ability to identify when a test has been unsuccessful and, in the case of sleep studies, be able to perform second-night testing when required

2 Utilising digital opportunities

Regardless of where the investigations have taken place, there should be cloud-based connectivity to enable investigations to be interpreted as efficiently as possible.

3 Access to Multidisciplinary Team Meetings

There should be access to an appropriately staffed and skilled MDT for complex diagnostics interpretation.

4 Use of digital screening tools

Some patient screening tools and requirements, such as sleep diaries, and electronically hosted questionnaires, for example the insomnia severity index[69] and the Epworth Sleepiness Score,[54] are helpful and should be used. These have additional benefits in that they can send reminder prompts to patients to ensure that they maintain cooperation. These screening tools must be securely stored, and data must be exported in a way that is useful and can link in with the patients electronic patient record.

5 Reviewing patients’ own devices

Patients may use their own devices to provide additional information. For example, relatives may video nocturnal movements or snoring and apnoeas as evidence, or patients may have their own devices such as smart watches or phone apps which can provide helpful collateral information. Although these are usually not quality or diagnostics assured, and have a limited evidence base, they are often important to patients and so we recommend healthcare professionals engage with patients to support them with using these devices in a helpful manner to support their sleep health. Whilst the information captured might help direct patients towards engaging with sleep services, and should be acknowledged, eg. in clinic letters, formal diagnostic studies should always be performed.

6 Performing diagnostic testing for OSAHS

The priority of OSA diagnostic testing is to ensure that an accurate diagnosis is achieved (or excluded) in a robust and timely manner. Current practice in home diagnostic testing for OSAHS is variable. Some sleep centres offer oximetry as the first-line test and others offer respiratory polygraphy. This will be influenced by clinical preferences and local commissioning agreements.

NICE advises home respiratory polygraphy as a first-line investigation, or oximetry if there would be significant diagnostic delay due to limited access to respiratory polygraphy.[63]

This is based on the theoretical potential for polygraphy to reduce requirements for further investigations, thereby improving cost-effectiveness and increasing efficiency of movement through the pathway. However, supporting evidence for this strategy is lacking, and the NICE guidelines reflect this uncertainty by not mandating that polygraphy replace oximetry when it is already embedded in a service.[63] Oximetry is less sensitive and specific than respiratory polygraphy, but it is more accessible and has other potential efficiencies, especially in likely severe OSAHS. Polygraphy equipment is more expensive and the set-up and analysis of polygraphy requires staff of a higher banding (usually 5-6) compared to oximetry. In reality, the clinical and cost effectiveness of either test will depend on how it is used within a clinical service and the epidemiology of OSA in the referral population.

A future research priority should be to directly compare different diagnostic strategies using both types of tests including, for example, exploring the validity and role of automated polygraphy scoring.

Whichever entry-level home test is used, their limitations must be recognised by the clinical service. Escalation to inpatient polygraphy and ideally polysomnography should be available for use when required. Consideration should be made to ensure that there is adequate workforce to perform the chosen diagnostics and, when this requires higher banded roles, that there is adequate support staff to ring-fence more specialist skills.

5.0 Management

This section describes important considerations for the treatment of sleep conditions. The aim is not to dictate to clinicians with significant and relevant expertise how to manage their patients, particularly when evidence for recommendations may not be strong. Instead, the aim is to support clinicians in ensuring all patients with sleep conditions have equal access to high quality care.

Recommendations

1 Lifestyle advice

Optimising lifestyle choices is important for all individuals with sleep conditions, particularly weight management in those with co-existent sleep conditioned breathing and for all sleep conditions, the broad health benefits of smoking cessation and alcohol reduction. Each sleep condition and patients require specific and personalised sleep hygiene advice. Digital patient resources include NHS Sleep Problems[70] and NHS Every mind matters.[71]

2 Identify and manage other contributing factors

Sleep conditions are associated with a broad range of comorbidities which should be diagnosed and managed to optimise clinical outcomes and quality of life. In particular, the management of commonly co-existent psychomorbidity[72] through availability of counselling and support. Sleep conditions can cluster[73] resulting in patients experiencing more than one sleep condition, generating specific issues, for example there are often concerns about using medications to aid sleep in patients with sleep conditioned breathing.

3 Personal safety

Patients with sleep conditions characterised by impaired alertness should be educated about lifestyle adjustments that may help maintain personal safety and the safety of others. Examples include avoiding undertaking unsupervised tasks that have potential for injury if an individual were to fall asleep, such as taking a bath or operating machinery.

4 Patient and bedpartner support

Patients should be empowered to self-manage their condition through the provision of accessible patient information, identification of support networks and navigation to sleep condition specific patient organisations. Local and online courses providing more information on these conditions would be welcomed. Research has evidenced the negative impact of sleep conditions on bed partners and relationships,[36,37,74,75] therefore bed partners should also be signposted to support when required.

See D-G for patient information leaflets.

5 Patient passports

Patient passports enable patients to inform healthcare professionals of their conditions.[76] These could be particularly helpful for patients whose sleep condition, or its management, is less well known. For example, a passport for a patient with type 1 narcolepsy could explain their cataplexy, including how it manifests, common triggers, and how to manage a cataplectic episode. Patients using mandibular advancement devices may benefit from patient passports to optimise interactions with community dentists.

6 Patient registries

Rare diseases affect less than 1 in 2,000 people.[77] People living with these diseases frequently experience delays to diagnosis[13] and access to effective treatment, complexity in care delivery and significant adverse impacts on many aspects of their lives.[78] Several sleep conditions are considered rare. Collaborative networks could support the development of evidence-based clinical practice guidelines, controlled pharmacological studies and multidisciplinary research.

7 Treatment supply and cessation

Several medications used in management of sleep conditions are controlled drugs requiring frequent repeat prescriptions and in which sudden discontinuation can result in withdrawal syndromes or debilitating symptom rebound.[79] Robust systems are required to prevent misuse of medications, minimise patient inconvenience and avoid accidental interruptions to treatment. Shared care agreements should be discussed as soon as the patient is stable on their medication.[80]

8 Drivers with excessive sleepiness

Patients should be managed in line with DVLA guidance,[81] particularly those with occupational requirements. A new offence of driving with blood levels of controlled drugs (including some hypnotics) above specified limits was introduced in March 2015, which patients should be made aware of, and driving safety advice provided.[82,83]

9 Conception, pregnancy and breastfeeding

Patients should be informed of any risks, particularly teratogenicity, of therapies prior to conception and if breastfeeding. Some treatments have specific advice, for example the Medicines and Healthcare products Regulatory Agency advises that Modafinil should not be used during pregnancy and women of childbearing potential must use effective contraception during treatment and for 2 months after stopping Modafinil.[84] Oral contraceptive efficacy is affected by interactions with some of the medications used to treat sleep conditions. Patients should have expert counselling to choose an effective contraceptive to ensure that there is no risk of conception.[85] Patients should be reminded to inform obstetrics teams of their diagnoses, as they may require enhanced antenatal care.

The patient perspective[42]

Several **challenges** associated with treatment of sleep conditions were highlighted:

- Difficulty accessing personalised information or advice about their condition, particularly for those with rarer conditions. For example, providing psychological support for patients with idiopathic hypersomnolence requires an understanding of the condition, and the support received following referral to general psychological services may not be informed or disease-specific enough to be helpful.
- Issues in accuracy of DVLA notifications.
- Challenges in accessing personalised treatments, for example those with OSAHS to be supported to find alternative treatments to CPAP when it is not tolerated.
- Difficulty explaining diagnoses to others, including employers. Studies have shown patients with excessive daytime sleepiness can be stigmatised as “lazy” or unmotivated,[86] and the workplace stigma these patients experience is associated with reduced function[87] and elevated rates of unemployment.[86]
- Sleep conditions are commonly misunderstood within social care settings, resulting in difficulty obtaining benefits and social support.

The patients had the following **recommendations**:

- Counselling and support should be available for all patients who need it to help them to come to terms with their diagnosis, its implications and minimise impact on quality of life.
- Occupational health support to optimise functional capacity at work and to help employers understand the nature of their sleep condition and necessary adjustments required to comply with the Equality Act 2010[88] and DVLA requirements.[81] Examples of adjustments include avoidance of difficult shift patterns, later start times or facilitating scheduled napping.
- Referral to specialist help groups or social workers should be available to support and advise patients on important matters such as career selection, accessing social support and applying for adjustments at work.

5.1 Challenges in treatment of sleep conditions

1 Mandibular advancement device (MAD) access

Multiple types of MAD exist including bespoke precision devices (fitted by dental specialists) and semi-bespoke MADs which are not always titratable and may be less effective,[89] but provide a MAD option in areas where under provision in dental sleep medicine limits use of bespoke devices. Reduced variation should diminish the need for semi-bespoke options. Remote monitoring of MAD may be evidenced in the coming years, allowing remote assessment of compliance and treatment outcome measures. MADs need regular replacement, usually between 1 and 5 yearly, and there should be capacity for provision of replacement devices.[90]

See Appendices D and E.

2 Use of sedating medications in obstructive sleep apnoea

A Cochrane review examined the impact of the use of opioid, hypnotic and sedating medications in patients with OSA and found no change in AHI, but found reduced minimum oxygen saturations with some agents and concluded they should be used with caution in OSA.[91] A case-control study demonstrated increased risk of OSA among 3,000 patients treated with benzodiazepines, particularly with higher doses.[92] Further research is needed.

3 Medication access

Medication access issues, including significant variation in regional formularies, leading to unwarranted variation and inequity was frequently highlighted. In some conditions, such as idiopathic hypersomnolence, medications are prescribed “off-label” subject to the healthcare professional’s expertise, trust policy and formulary guidelines. High quality clinical research should help resolve these issues, although UK consensus guidelines may be a more realistic first-step.

Some medications have strict limitations in use, such as melatonin which was previously more widely available. Longer-term use is now limited to specialist services through the use of shared care agreements due to limited primary care access. Its use therefore is often unlicensed or off-label and patients may access medications via alternative sources, which are less well monitored or regulated and cannot be endorsed by specialists. The working group would support reappraisal of access to melatonin, including reviewing previous concerns around prescribing costs of melatonin compared to current resourcing requirements of shared-care agreements and referrals to specialist services.

4 Access to cognitive behavioural therapy for insomnia (CBTi)

	CBTi has documented challenges in availability, related to traditional delivery of CBTi being via face-to-face therapy and there being limited available therapists to provide treatment.[93] Digital CBTi platforms exist which could help bypass barriers to accessing to face-to-face CBTi access and has been shown to be more cost effective than medications.[94] Digital CBTi has been commissioned nationally within Scotland,[95] whereas CBTi can be variably accessed via IAPT in England due to diverse commissioning agreements
5	**Delay to diagnosis**
	Many sleep conditions have delayed presentations. For example, patients with non-REM parasomnias may not seek support until they or someone close to them has been injured or had a near miss, or are experiencing excessive daytime fatigue due to night-time disturbance. Following presentation, minimising the impact of the condition should be prioritised
6	**Future opportunities for disease surveillance**
	Patients with REM behaviour conditions are at risk for developing neurodegenerative conditions,[96] however there are currently no neuroprotective interventions to slow or stop the development of these conditions, therefore monitoring is not yet advocated.[97] It would become a priority should there be advances in preventative, decelerating or curative treatment options for α-synucleinopathy conditions.

5.2 Management of specific patient groups

Managing drivers

Drivers with excessive sleepiness, particularly those with occupational requirements, should be managed in line with DVLA guidance.[81] Further advice is provided by the British Thoracic Society.[98] We welcome recent changes the range of personnel eligible to complete DVLA paperwork and hope that this will reduce inconvenience to patients.

There is evidence that the use of sedative hypnotics is associated with a doubling of the risk of motor vehicle accidents.[99] A new offence of driving with blood levels of controlled drugs (including some hypnotics) above specified limits was introduced in March 2015, which patients should be made aware of.[83] Advice should be given to patients on driving safety in relation to the use of medications, for which guidance exists.[83]

Managing patients of childbearing and breastfeeding potential

Pregnancy impacts each patient and their sleep condition differently. Patients should be central to decision making processes with their sleep specialist and any other relevant experts (eg. specialist pharmacist, GP, obstetrician, psychiatrist). Patients should be reminded to inform the obstetrics team of their diagnosis, as they may require enhanced antenatal care.

Teratogenic risk
Patients should be informed of any risks, particularly teratogenicity, of therapies prior to conception. Some treatments are considered more important to avoid than others, for example the Medicines and Healthcare products Regulatory Agency advises that Modafinil should not be used during pregnancy and women of childbearing potential must use effective contraception during treatment and for 2 months after stopping Modafinil.[84]
Pharmacokinetic interactions

Oral contraceptive efficacy is affected by interactions with some of the medications used to treat sleep conditions. Patients should have expert counselling to choose an effective contraceptive and ensure that there is no risk of conception.[85]
Breastfeeding
Some medications should be avoided during breast feeding due to significant breast milk excretion.

6.0 Follow Up

Whilst some sleep conditions are short-lived, may require management, and resolve, for example acute insomnia, others require long-term management. Current models for long-term follow up of patients are suboptimal for many patients. Opportunities exist to improve how longer-term follow up is delivered, and to provide it in a more personalised way. These opportunities include changing the way we conduct consultations and harnessing digital technology to deliver virtual consultations. Digital opportunities also exist in remote monitoring and patient portals. The scheduling of follow up can be improved too, and appointments arranged for times of clinical need, rather than routinely.

The use of face-to-face consultations is essential in certain scenarios, such as for facial assessment when considering mandibular advancement devices, or for full neurological examination in patients presenting with REM behaviour disorder. However, telemedicine is an opportunity to fundamentally improve patient access, quality, efficiencies, experience, and drive sleep medicine's evolution to ensure services are fit for the future. This is often performed via virtual platforms, including the NHS platform Attend Anywhere, in addition to the use of telephone. Virtual consultations have increased significantly since the pandemic and, whilst there have been rapid improvements and progress in remote consultations, they are imperfect[100,101] and can exacerbate digital inequities, and the impact on healthcare outcomes is not fully assessed[102]. The change in delivery of care has also resulted in an increased administrative burden.

Recommendations	
1	**Ensure necessary infrastructure to deliver quality consultations**
	Healthcare professionals delivering virtual consultations require a physical space to perform this work. Shared offices are common and can mean that providing confidential healthcare is a challenge. Although clinic rooms remain available, the available space may be insufficient for demand or may have been repurposed. Protected space to perform consultations with due care to privacy and to ensuring disturbances are minimised should be provided for all virtual consultations.
2	**Communication**
	Communications between patients and providers should be effective and bi-directional. Patients must be able to participate in their care, and digital services can help facilitate this. For example, providing patient portals or email contacts would enable patients who work and are less likely to be available during time of routine elective care, to have increased access to healthcare. Patient ownership of records and feedback on their care, through providing feedback to patients on their treatments or further utilising apps such as the NHS app, could improve patient empowerment.
3	**Patient initiated follow up**
	Patient initiated follow up (PIFU) is an initiative whereby a patient (or their carer) can initiate their follow-up appointments as and when required, for example when symptoms or circumstances change.[103] PIFU pathways are already successfully embedded within sleep medicine services: Sandwell and West Birmingham Hospitals NHS Trust has ~70% of patients with OSAHS on CPAP therapy on PIFU pathway and audit data suggests 10-25% of patients on PIFU pathway contact the service annually.

See Appendix I for a case study regarding Sandwell and West Birmingham's use of PIFU in sleep service; and appendices L and R for other PIFU case studies.

The patient perspective[42]

Patients highlighted that when PIFU was not adequately explained and consented for, patients sometimes felt "abandoned" or that they were no longer under specialist care. This demonstrates the importance of providing clear information and leaflets with contact details, ensuring informed consent and supported shared decision-making processes to ensure that patients fully understand PIFU.

6.1 Patient Initiated Follow Up (PIFU)

6.1a Patient selection

PIFU could be across the full range of sleep conditions, and within many groups of patients. However, lessons learnt from services that have implemented PIFU, emphasise the importance of appropriate patient selection, and starting with "easy win" cohorts first. Given the large numbers of patients involved, it is therefore often logical to implement PIFU in CPAP pathways first. In this patient group, those with OSAHS using CPAP therapy for 12 months who are confident in CPAP use, have experienced an improvement in or resolution of excessive daytime sleepiness and have good adherence to the agreed patient management plan would potentially be eligible for PIFU. Good adherence to therapy would constitute a regular pattern of CPAP usage that results in symptom control. Patients with other sleep conditions being considered for management on a PIFU pathway would be expected to have a similar level of disease control prior to being enrolled on a PIFU pathway. Non-condition specific criteria for selecting patients for PIFU are given in the national PIFU guidance.[104] *Please see Appendices I, L and R for case studies regarding PIFU in sleep services.*

Recommendations	
Suitability for a PIFU pathway should be determined through a careful assessment of clinical need, risk and patient capacity.	
Patient groups who may not be eligible for PIFU	
1	**Occupational risk**
	Those with high-risk occupations, for example professional drivers or those with vigilance critical occupations, may not be able to enrol on a PIFU pathway. DVLA and other professional and legal requirements, mean patients in these occupations with sleep disorders should have annual review.
2	**Poor adherence**
	Patients who are not confident with CPAP therapy, or struggle to adhere to the agreed patient management plan would not be appropriate for PIFU as they require clinical input to support their care and/or an alternative treatment strategy. Likewise, patients with residual sleepiness, or inadequate symptom control, should not enrol on PIFU as they also require clinical support.
3	**Patient preference**

	Some patients may prefer a more traditional approach to management, or may wish to be seen at intervals for reassurance. Patient choice is integral to the success of a PIFU pathway, therefore it is essential that patients are given enough time to understand a PIFU pathway, and have the option to decline PIFU in favour of regular appointments.
4	**Patient risk**
	Patients with progressive conditions with a likelihood of deterioration should not routinely be commenced on PIFU. If this form of follow up is to be considered, individual risk assessments should be undertaken and regularly reviewed to determine suitability and minimise risks.
5	**Comorbidities**
	Comorbidities should be taken into account, such as other sleep conditions or severe and/or enduring mental health conditions. Individuals who may be less able to effectively undertake self-management or contact the service when needed may not be appropriate for a PIFU pathway.
6	**Communication**
	Some patient groups may find it more difficult to contact the service should problems occur (for example, those who are not digitally confident or enabled, or those with limited access to a telephone). Some patients may be less able to communicate their needs (for example, those with additional learning needs, health illiteracy, a language barrier or sensory impairment). Some patients can be supported through their carers to engage in PIFU, provided that the carer is also involved and consulted in the shared decision-making process, and their role is explicitly acknowledged[105].
See Appendix U for a detailed equality and health inequalities assessment which further highlights groups who might require more support, or for whom PIFU may be unsuitable.	

6.1b Designing a PIFU service

Recommendations	
1	**Ensure consistency**
We recommend organisations adopt a consistent approach for PIFU, and it is important that this is tailored to the needs of each specialty and adapted to suit the service's case mix. The local sleep medicine clinical team should have overall responsibility for the development of clinical guidance, risk stratification protocols and standard operating procedures (SOP) relating to the implementation and delivery of PIFU within their service. Local clinical protocols should include clinical criteria for patient selection and exclusion; prompts for patients to contact the service; ideal and maximum waiting times for response from the service and for subsequent appointments; identification of the staff members who are responsible for allocation of PIFUs; how patients who request an appointment will be managed and how contacts with the service will be communicated to the GP. SOPs should ensure that all staff are clear about roles and responsibilities.	
2	**Ensure safety**
There should be safety-nets established and where possible and helpful, remote monitoring options should be provided (for example, in individuals using CPAP therapy). Guidelines should be developed, and clinicians should receive adequate training and support to facilitate shared decision making.	

6.1c Service delivery considerations

Recommendations

1 Contacting the service

Patients should be able to easily and reliably access the service to request advice or a consultation, through whichever method(s) are felt to be the most locally appropriate. Consideration and appropriate accommodations should be made for patients with different communication needs and preferences.

Telephone contact lines are likely already established in centres providing CPAP therapy for patients to request more consumables.

Some services use email, which may be feasible but there are GDPR considerations. Emails from non-NHS servers containing patient information would require patient consent. This could be overcome by a service agreement so that patients understand they are sharing personal information.

Local websites/weblinks may be a convenient method, should the local service infrastructure be able to provide this.

There are also examples of “drop-in” services, provided either physically or virtually where patients can speak directly with healthcare professionals as needed, through clinics allocated for example, weekly. *See Appendices M and N.*

2 Reasons to contact the service

Patients may contact services for a variety of reasons. This could include:

- Change in symptoms or clinical status, for example significant change in weight
- Equipment/technology issues or replacements
- Issues with mask fit
- Patient wishing to end therapy
- Advice, for example travel advice
- DVLA-related queries

3 Triage of patient contacts

Patient contacts should be triaged in a timely fashion to determine what action is required, for example telephone advice, distribution of paperwork or equipment, or an appointment. Response times should be in line with the local trust or provider’s policy and appropriate to the degree of clinical urgency. Appointments may be conducted by telephone, virtually or face-to-face, depending on the query. Services may use junior or non-clinical team members to staff telephone lines, with the support of appropriate triage tools and training.

4 Timescales

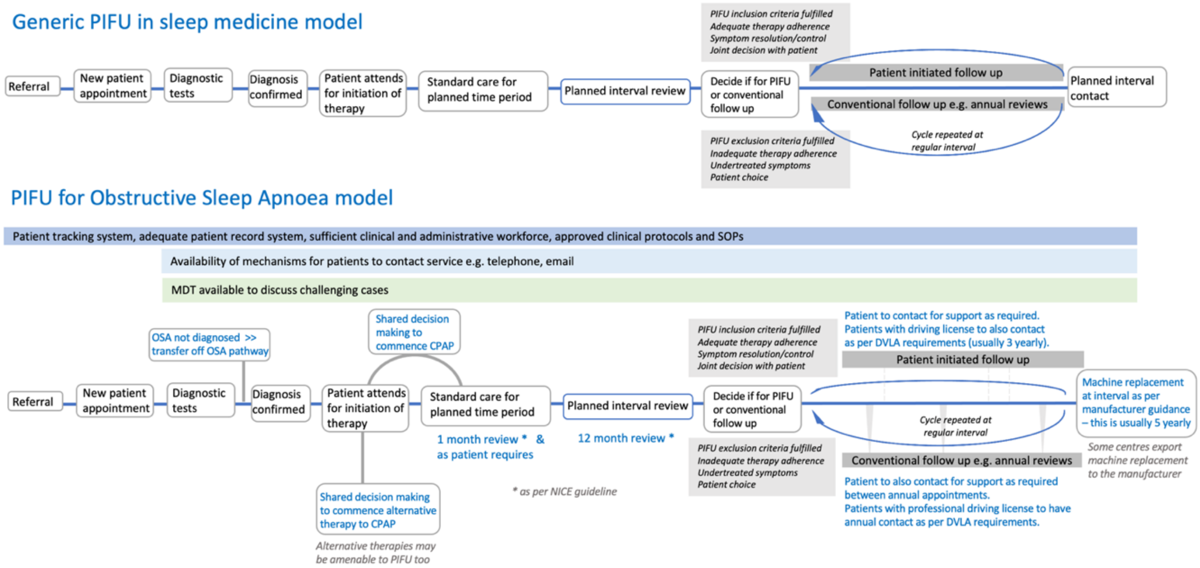
Patients on therapies should remain under PIFU for the duration of their therapy, although some patients may need to move off a PIFU pathway in certain circumstances. Several services who have CPAP PIFU services start PIFU after approximately 12 months of CPAP therapy, provided they have sufficient adherence to the agreed patient management plan. Patients need device replacement at regular intervals as advised by the manufacturer, or as per contractual agreements. The timeframe for this depends on multiple factors, including the specific device and hours of usage. There are also interval requirements for review as described by the DVLA: annually for occupational drivers and three yearly for all drivers.

See figure 4 for pictorial representation of proposed timescales.

5 Digital opportunities

Within CPAP PIFU services, remote monitoring can support clinicians to understand device usage and issues with the therapy. It may be particularly helpful when commencing therapy and over the first 12 months of treatment as there is a high drop-out rate during this time. The use of available, and locally customisable, technology should support PIFU delivery.

Figure 4: *Possible PIFU timeline for management of OSA on CPAP therapy*



6.1d Patient considerations

Recommendations

1 Shared decision making

Shared decision making is particularly important when deciding whether a PIFU pathway is right for each individual patient and to provide personalised care. Patients (and/or their carers) should have the opportunity to discuss the healthcare aims, benefits, and any risks associated with being placed on a PIFU pathway. They should be provided with clear and readily accessible information about when and how to initiate contact with the service, and sufficient information about self-management of their treatment and of their condition. Possible approaches for this include information stickers attached to patient devices and/or providing patients with patient passports.[76] Trusts should ensure that any patients who require additional time or tools to understand PIFU are supported.

2 Patient resources

Patients can be encouraged to access local resources, NHS Choices, and patient support and information groups. The role of patient organisations, including those detailed above, should be recognised for the significant volume of patient support that they provide. Patients utilise these organisations for support on a range of issues along the diagnosis and treatment pathway and anecdotally may choose to consult these organisations rather than their treating service.

3 Documentation

When a shared decision not to enrol on a PIFU pathway is made, it should be flagged on the patient record so that other members of the team, or other healthcare teams, can clearly understand why the patient is not on a PIFU pathway. This decision could and should be reviewed, for example if a patient is subsequently successfully established on therapy and wishes to commence PIFU.[42]

6.1e Risk considerations

Overall, it is expected that PIFU would likely have a positive impact on all patients as it reduces the need for routine outpatient attendances when they are not required and enables routine appointment slots to be provided to those most in need.

Recommendations

1 Patient individualisation

PIFU should not be implemented in a "one size fits all" model, as this could exacerbate health inequalities. Generic risks associated with the use of PIFU are highlighted in the NHSE PIFU handbook.[104] Sleep pathway-specific risks are of reduced adherence to treatment and the consequences thereof, for example road traffic accidents related to uncontrolled daytime sleepiness. This is the rationale for advising that those patients who are struggling to engage with therapy should not be considered for PIFU. DVLA legal requirements mean that patients who drive must seek bi- or tri-annual consultation. A national Equality and Health Inequalities Assessment (EHIA) for PIFU in sleep medicine is available in Appendix U, which provides a risk assessment across all areas of potential health inequalities and protected characteristics. A local EHIA should be conducted by all trusts or providers before PIFU is commenced.

2 Minimise exclusion

To minimise exclusion, for example of those with poor digital literacy or sensory disability, there should be different means to contact the service, for example via phone, text and email. There should also be consultation options to minimise inequalities, for example by offering face-to-face or telephone calls, rather than only video calls. Patients should be asked their preferred means of communication and information should also be shared as a non-digital copy. All patient literature should be patient-appropriate, not require a high reading age, and be available in other accessible formats. All patient literature should be non-discriminatory and include diversity in images.

3 Monitor for unintended consequences

In order to monitor health inequalities and to ensure that specific patient groups are not excluded, feedback on the service should be obtained to ensure that it is working effectively for patients and clinicians. The service should be audited to ensure that patients from all groups are initiating follow-up appointments. Patient feedback should be encouraged.

7.0 Enablers: Digital

Recommendations

1 Digital opportunities to identify patients

There is functionality within existing primary care platforms to search for specific conditions and can be used to identify and highlight risks. Flags could be enabled within electronic patient records to trigger healthcare professionals to consider sleep conditions if patients have a high-risk clinical profile, such as those with metabolic syndrome associated with obesity, those with refractory hypertension, or occupational drivers.

2 Data to be linked and flow across boundaries

Seamless data links between all part of the patient journey, from primary care to specialist care and CDCs would support efficient triage and avoid duplication of investigations. Cloud-based connectivity enables investigations to be interpreted efficiently, regardless of location of test. Some diagnostics enable this already, such as spirometry, demonstrating feasibility and could serve as a blueprint for enabling data flow with sleep studies.[106] *Please see Appendix J for a case study on CPAP data download to patient record.*

3 Digitalised treatment

Where appropriate, digitalised treatment should be encouraged, for example evidence based digitally delivered cognitive behavioural therapy for insomnia (CBT-I).[107]

4 Remote monitoring

Remote monitoring has a useful role in the management of sleep conditions,[108,109] particularly if seamless integration of data between treatments such as CPAP, and patient records is enabled. Patient self-monitoring of symptoms or physiology, such as blood pressure, could be facilitated by patients self-entering results into patient portals for both primary and specialist providers to access. Evidence demonstrates that telemonitoring-feedback in CPAP therapy may result increased adherence to that therapy.[110] The OSP working group recommend that all CPAP devices have continuous remote monitoring functionality, and that costs for these services should be equitable. *See Appendix J for case study on CPAP data download to patient record.*

5 Automation

Opportunities for automation should be embedded, but should not result in inefficiency in the pathway or increased waste. The Long Term Plan, highlights the use of intuitive tools to capture data as a by-product of care to be used in ways that empower clinicians and reduce the administrative burden.[4] Examples include automatic download of CPAP data, or blood pressure recordings which could be analysed by AI algorithms that flag patients with sub-optimal management. Care should be taken however, as machines may trigger alerts for many reasons, for example if the patient takes off their mask this will flag as mask leak. Whilst data is useful, steps should be made to minimise the numbers of alerts when there is no clinical need and/or no clinically relevant data is generated. Other opportunities include providing patient prompts, reminders or information. For example, reminding patient to order CPAP consumables; patients on stimulants to be reminded about the importance of contraceptives. This is currently unfeasible manually due to large volumes of patients and issues with manual extraction of data but having to link into individual machine to access data. However, the need for this will increase due to greater remote management of patients with proposed PIFU pathways.

6 Two-way communication

Communication channels should be straight forward, bi-directional and enable patients to easily contact the service themselves if needed. Patients should be able to provide information, such as completing digital questionnaires, which are then linked into primary and specialist services electronic patient records. Some CPAP machines enable the treating team to communicate with patients with messages displayed on the machine, however the patient is not able to respond to these comments. Other platforms, such as patient portals, enable patient to contact into the service.

7 Use of digital screening tools

Sleep diaries, and electronically hosted questionnaires, for example the insomnia severity index[69] and the Epworth Sleepiness Score,[54] are helpful and should be used. These have additional benefits in that they can send reminder prompts to patients to ensure that they maintain cooperation.

8 Adequate reporting outcomes

Current reporting of activity is insufficient,[1] therefore digital pathways should have the functionality to gather accurate information and trigger outputs, such as reporting requirements and metrics. Where possible, data should be openly available to enable research and to aggregate metrics about NHS performance and services.[4]

9 Optimise patient engagement

Digital technology can be used to maximise patient engagement. Examples include sending digital patient reminders, questionnaires or assessments, or the use of patient engagement apps. CPAP apps provide automated feedback and links to further information and troubleshooting advice. Patients should be given control over their medical records.[4]

10 Digital technology to improve workforce experience

Changes in clinical practice and working patterns require appropriate, robust, IT infrastructure and equipment to enable staff to perform remote virtual and telephone consultations, wherever they are located with remote log in.[111] Processes to embed novel technology within practice should be streamlined to enable efficient service developments and to ensure that healthcare professionals are not distracted from patient care trying to navigate blocks to service improvements.

11 System level investment

Sleep medicine services are not the only services with ambitions for improved digitalisation. Unified process across a system will be more effective than fragmented processes.

12 Health inequalities

Measures to avoid and monitor digital inequality should be taken to ensure that inequalities are not worsened by any digital changes.

13 Increase efficiency and efficacy of the sleep pathway

Digital technology should increase efficiency however multiple examples exist where technology designed to improve patient pathways instead complicates the delivery of care. Digital opportunities to apply best practice,[112] for example with the use of artificial intelligence, digital-guided consultations and linking healthcare professionals to the latest evidence-based resources, also have a role in reducing unwarranted variation.[4]

14 Digital consultations

Whilst face-to-face consultations are essential in certain scenarios, telemedicine can improve patient access, quality, efficiencies, experience and drive sleep medicine's evolution to ensure services are fit for the future.[113] Studies demonstrate the effectiveness of remote consultations effectively delivering cognitive behavioural therapy for insomnia.[114] However, digital consultations are imperfect[100,101] and can exacerbate digital inequities, and the impact on healthcare outcomes is not fully assessed.[115]

15 Workforce to deliver digital care

The impact on workforce requirements of greater digitalisation should be adequately assessed and support services grown to maximise opportunity. Our experience is of recent changes in delivery of care, expedited by the pandemic, has resulted in increased administrative burden. For example, for patients receiving CPAP therapy, replacement consumables may have been previously been absorbed within annual face-to-face appointments, however with increased pivoting to virtual appointments, consumables must be sent by post to patients, or arrangements made for patients to collect equipment.

16 Infrastructure to deliver digital care

Healthcare professionals should have access to all of the necessary platforms and electronic records in order to be able to provide efficient and holistic care. Platforms need to work well without glitches and with reliable and fast internet connectivity to reduce connection issues and lag within video consultations, which can impact upon the patient and healthcare professional relationship.[100] Services should consider enhanced digital and technology solutions to improve the delivery of sleep care.

17 Data usage

Historical data is stored by CPAP device manufacturers and is not usually routinely available to patients or treating healthcare practitioners. Patients should be able to have access to their own data should they want it and to support evidence of adherence for DVLA requirements. Historic data should also be made available for sleep centres to audit over time, in order to examine population level adherence and examine links within patients struggling with the therapy. There should also be functionality to push or pull data, so that prescriptions can be changed outside of the once-daily data exchange time. This would allow these population groups to be more proactively monitored to optimise their therapy.

8.0 Enablers: Workforce Optimisation

Workforce issues within sleep medicine have been highlighted through the BTS workforce report[3,116] and GIRFT respiratory report.[1]

Recommendations	
1	**Encourage a multidisciplinary workforce**
	Multi-professional sleep teams facilitate high-quality care in a timely and cost-effective way[117,118] and are established in many sleep departments. Further expansion is required, for example increased access to psychologists and lifestyle support professionals for greater holistic care and expanded sleep dental services to reduce inequality in OSA care. Multiprofessional workforces should be enabled and supported through adequate training opportunities and support for all.
2	**Ensure appropriate workforce for an expanding speciality**
	Sleep medicine has significant recruitment and retention challenges,[1,3,4,116,119] whilst having expanding patient numbers.[120] Realistic future workforce planning with adequate funding and appropriate job planning will help ensure sleep service re-design is future-proofed and deliverable. GIRFT recommendations to increase physician trainee numbers[1] is supported but also requires parallel recruitment of other healthcare professionals. Very lean staffing ratios may result in service sustainability issues, therefore staff:patient ratios should be regularly assessed and considered as services evolve. The ARTP toolkit[121] identifies staffing numbers required according to levels of service activity, and the British Lung Foundation calculator[122] advises rates of OSAHS per CCG and therefore necessary workforce to provide care to those patients.
3	**High quality support services**
	Administrative and support staff optimise patient throughput, support patient contacts and enable clinical sleep staff to complete clinical work. Current inadequate numbers of administrative staff[1] and impractical ratios of qualified to non-qualified staff[120] need review, particularly as services expand and as ways of delivering care evolve.
4	**Development of Band 2-4 roles**
	The Respiratory GIRFT report identified insufficient numbers of physiologists within many sleep services and recommended the appointment of band 2-4 physiology staff.[1] These band 2-4 roles facilitate more senior and skilled team members to deliver more complex tasks.
5	**Opportunities to enhance job satisfaction**
	Career development pathways should be improved to minimise staff attrition[1,4] and be in line with other professional groups, such as pharmacy services. Staff should be encouraged to engage with audit and research and have training opportunities widely available with protected time for continuing professional development provided within their job. Dedicated and planned time for CPD with corresponding availability of a budget will enhance engagement, satisfaction and ultimately retention.[79] This should be included within job planning and terms and conditions to ensure that there is capacity for staff to be released.
6	**Development of qualifications**
	Interprofessional and multi-professional education and practice leads to improved patient outcomes, enhanced safety and quality of care.[123] To enable further development of band

2-4 roles, relevant qualifications[1] should be devised to support proposed expansion of services in a standardised way.

7 Standards of practice

Sleep professionals of different bands perform similar roles in different services; with differences in remuneration. Agreed standards of practice and standardisation of roles would be helpful.

8 Appropriate job planning, prioritising staff wellbeing

Effective job planning can match clinical capacity to predicted clinical demand, resulting in positive impacts on patient outcomes and staff morale.[124] Sleep professionals frequently perform multiple different tasks or roles within a single session. For example, staff may spend time reporting, issuing therapy and running diagnostics within the same session. Careful job planning should ensure that there is sufficient capacity to complete all the necessary tasks, particularly relating to the time-consuming reporting of sleep investigations. Centres should avoid models of care resulting in one staff member managing exclusively complex cases: a varied patient mix will balance the staff members' mental and physical workload and retain skills in the workforce. Multi-professional team meetings can share the burden of decision making and allow for discussion of complex cases.

9 Community diagnostic centres

It is expected sleep diagnostics will be included within some CDCs, which could exacerbate existing staffing issues. Comprehensive workforce structure and number planning is important, including workforce rotation between community/CDC and specialist care settings. Some CDCs may be delivered by non-NHS providers, however adequate information sharing and staff training standards is important.

10 Enable staff to work at the upper limit of their competence with confidence

Healthcare professionals are often currently performing tasks that could be undertaken by more junior members of the team or by administrative staff.[!] This has historically been driven by workforce gaps and an impractical ratio of qualified to non-qualified staff,[120] limiting service capacity. Ensuring that staff members are working at the top of their skillset will optimise capacity within the service and ring-fence more senior, experienced, and trained staff to complete more complex tasks. This requires structured training and career development, so that staff are confident and competent to deliver safe and effective care, in addition to adequate administration support.

11 Integrated workforce to support all aspects of the patient pathway

There is a need, and a drive, to increase integrated care[4] within sleep medicine. Dividing tasks by role and discipline can fragment care[125] and results in the patient meeting multiple professionals along their care journey, and staff spending increasing amounts of time conferring with each other to coordinate care with increasing costs.[126] Upskilling staff to be able to carry out a range of tasks along the patient pathway which can enable a more holistic and personalised approach to care.[125] The increasing move towards integrated care and the development of CDCs will generate more roles that cross traditional care boundaries. These roles can improve staff satisfaction, wellbeing, and retention and maximise variety of experience to facilitate greater integration of services and allow greater development opportunities.

12 Workforce work flexibly with better use of clinical time and physical space

The planned expansion of integrated care[1,4,127] requires changes in working patterns and practices. Staff could work within rotas to extend the working day or week to optimise capacity. Staff should be supported to work comprehensively and efficiently wherever they are physically located, for example within both community and specialist settings. This requires robust integrated IT infrastructures, supporting remote log-in regardless of physical location, to prevent delays in patient care. Appropriate equipment to perform remote virtual and telephone consultations is also required.[111]

9.0 Enablers: Provider considerations

Recommendations

1 Cost efficiency

There is often little evidence to demonstrate the most cost-effective options. For example, auto-titrating CPAP devices have historically been more expensive than their fixed pressure equivalents, but may provide other cost savings, for example in reduced numbers of follow up appointments to adjust pressure settings.[128] Medication costs are fluctuant and should not be the limiting factor for inclusion in formularies. Limited primary care prescriptions of certain medications, such as melatonin, result in increased routine prescribing by, and referrals to, specialist services, incurring increased cost.

2 Access to treatments

Access to treatments should be equitable and up-to-date to provide high quality care with limited unwarranted variation. Treatments appraised by NICE or recommended by organisations such as the Regional Medicines Optimisation Committee are not obliged to be funded or approved by local commissioning bodies or local formularies. The OSP working group would encourage sleep centres to work in partnership with primary care teams and commissioners to make access to expert review and treatments as responsive and local as possible.

3 Shared Care Agreements

Shared care agreements[80] ensure that the prescribing needs of the population are met, optimise use of available resources and minimise access issues to prescribed medications. When considering medications to be covered by shared care agreements, commissioners should take into account operational and resource requirements of primary and specialist care to ensure that patient care remains safe and effective.

4 Remuneration

Recent changes to funding, in that services have transferred to block contracts, has altered remuneration to services, stifled innovation and has not encouraged holistic or novel service design. There are opportunities at the next renewal of contracts, to harness learning from services with well-established coding systems to ensure that all patient contacts within newer pathway methods are acknowledged and reimbursed. *Please see Appendix Ia*. There is also an urgent need to increase the accuracy of activity level data, which is a longstanding issue within sleep medicine.[1] Without accurate data reflecting activity levels, services will find it difficult to demonstrate a clinical need for development and investment.

10.0 Outcome measures

To enable ongoing improvement and quality of care in the pathway, it is important to ensure that outcome measures are assessed. The purpose of the collection of any outcome data is to enable services to facilitate continual and integrated improvement, to ensure a sustained quality of service and to support ongoing service development to meet evolving patient and population needs. As services move away from block contracts, it is vital that accurate activity levels are measured to ensure that services are appropriately remunerated to ensure financial sustainability. With the ongoing global environmental challenges, and the Greener NHS programme,[129] it is also important to measure impact of services to facilitate environmental sustainability.

Recommendations	
1	**Use existing national service evaluation measures where possible**
Services should assess operational delivery of the sleep pathway in addition to patient and healthcare professional experience. Specific measures for certain NHSE initiatives, such as PIFU and SAG are required, in addition to existing national processes to capture patient experience and operational data. Therefore, the working group were keen to avoid adding burden to this process, and instead recommend usage of measures that are already being captured and are therefore deliverable now.	
2	**Develop local service evaluation measures where required**
Further local evaluation will be useful, particularly for ongoing local service development. When patient pathways are designed, they should include assessment points to ensure that responsibilities for each stage of the patient pathway are clearly recognised and measured.	

10.1 Patient related outcome measures

To monitor several of the aims of the OSP, there is a need to collect patient related outcome measures (PROMs).

Recommendations	
Patient related outcome measures	
1	Patient experience measures including quality of life measures
2	Service user demographic data, including protected characteristics and health inequalities data
3	Time to first appointment
4	Time from diagnosis to treatment provision
5	Wait list numbers
6	Did-Not-Attend rates
7	Compliance to therapy rates
8	Proportion of patient enrolled in PIFU pathway
Relevant national outcome measurements	
1	National GIRFT report
2	NHS e-RS open data dashboard
3	Referral to treatment waiting times data

4	NHSE PREMs and PROMs
5	Friends and Family test
Local outcome measurements	
1	Local GIRFT assessments
2	Local patient feedback including quality of life measures through questionnaires, focus groups
3	Regular audit of service user demographics and of protected characteristics

10.2 Staff related outcome measures

It is also important to collect staff experience information.

Recommendations	
Workforce related outcome measures	
1	Staff experience measures
2	Staff retention rates
3	Staff sickness rates
4	Staff development measures
5	Numbers of referrals to specialist services
6	Usage of advice and guidance
Relevant national outcome measurements	
1	National GIRFT report
2	Friends and family test
3	NHS Digital Workforce Statistics
4	Staff retention data
5	HEE workforce survey
6	Professional bodies workforce surveys eg. General Medical Council, ARTP
Local outcome measurements	
1	Local GIRFT assessments
2	Local staff feedback

10.3 Service delivery outcome measures

Service delivery outcomes should be monitored to ensure ongoing service quality and for improvement. Additionally, there are NICE targets relating to service delivery for some conditions, which should be assessed to ensure that services are delivering optimal care.

Recommendations	
Service delivery outcome measures	
1	Referral volume eg. number of SAG requests, number of new referrals, number of referrals with vigilance critical occupation, conversion rate SAG to new referrals, waiting time to first appointment
2	Diagnostic volume eg. number of sleep studies performed (DM01 or HRG Dz50Z), waiting time for investigation, backlog data
3	Patient volume eg. number of patients within the service
4	Treatment volume eg. numbers on CPAP therapy

5	Follow up eg. new:follow up ratio, % PIFU pathway
Relevant national outcome measurements	
1	NHS e-Referral Service (e-RS) open data dashboard - NHS Digital
2	Referral to Treatment Times for CPAP (CPAP RTT < than 6 weeks; <4 weeks for those in critical vigilance occupations) Referral to Treatment Waiting Times (RTT) - NHS Digital
3	Elective recovery outpatient collections
4	Model hospital metrics
5	Outpatient commissioning data set
6	National GIRFT reports
7	Service performance measures
8	Sleep medicine prescribing data from Medicines Policy Unit NHSE
Local outcome measures	
1	Local GIRFT assessments
2	Patient adherence and healthcare utilisation of patients on PIFU
Aspirational service outcome measurements	
1	Dashboard with continual tracking and measures to identify and flag potential breaches in wait time and functionality to generate a list of patients at risk of breach with summary clinical data. This would support service audit and enable all healthcare professionals, and the patient, to be aware of where the patient is within the pathway.
2	Novel methods to capture engagement of patients within PIFU, or traditional, pathways.
3	Shared information between providers related to cost of devices/medications

10.4 Patient Initiated Follow Up evaluation

The following recommendations are advised to evaluate implementation of PIFU within sleep services.

Recommendations	
Early evaluation eg. within 3 months of implementation	
1	Number and proportion (%) of patients moved onto a PIFU pathway each week
2	Total number and proportion (%) of patients on a PIFU pathway
3	Number and proportion (%) of patients who have initiated an appointment
4	Clinical experience and feedback
5	Administrative staff experience and feedback
6	Estimate future demand on administrative services eg. due to booking follow-up appointments
Longer term evaluation eg. within 12 months of implementation	
1	Patient experience and feedback - patient related outcomes, regular patient questionnaires with resource implications
2	Estimation of proportion of patients in the service who could potentially be placed on a PIFU pathway
3	Assessing potential impact of establishing those patients on future demand for services

4	Inclusivity and diversity data
National outcome measurements	
1	PIFU Completions
2	Episodes moved to PIFU
3	Episodes Discharged to PIFU
4	Episodes on Active PIFU Pathway
5	Appointments initiated by patient
6	PIFU DNAs

10.5 Specialist advice and guidance evaluation

The following recommendations are advised to evaluate implementation of SAG within sleep services.

Recommendations	
Recommended local outcome measures	
1	Numbers of eRS referrals, SAG requests
2	Numbers of referrals seen, numbers of SAG responses
3	Conversion of SAG requests to referral or appointments
4	Responded within 48 hours / 7 days
5	Average turnaround time (eRS only)
6	eRS Requests Rate/ 100,000
National outcome measures	
1	System Elective Recovery Outpatients Collection (EROC) data collection
2	SAG dashboard
Local outcome measures	
1	Regular internal qualitative review and audit of SAG responses by provider to ensure quality and consistency
2	Patient feedback
3	Review and reporting of high volume and / or repeated SAG requests with incomplete clinical information or relating to advice available from accessible and recognised national referral resources
4	User satisfaction (with outcomes) and experience (of process) – for both requesting and responding healthcare professionals

10.6 Sustainability measures

These measures are important to allow providers to strive towards delivering sustainable services.

Recommendations	
Sustainability related outcome measures	
1	Virtual:face to face consultation rates
2	CO_2 metrics - Greener NHS » Delivering a net zero NHS
3	Transport survey of staff and patients for travel modality to services

11.0 Future aspirations

The previous chapters describe short to medium term aspirations. There are several innovations and aspirations that the working group would hope to see within the longer-term transformational change of sleep medicine, which are described below. Ongoing horizon scanning to identify and harness advances and to gain from practices elsewhere within the NHS and quicker dissemination and processes to implement novel ideas would expedite innovation.

Independent sleep profile

To overcome many of the issues identified in this report, sleep requires an independent profile, separated from other specialities such as respiratory and neurology. Sleep can be neglected: OSA is within the respiratory training curriculum[130] and the respiratory GIRFT report,[1] but no mention is made of non-respiratory sleep conditions; sleep medicine is not included in the Neurology GIRFT report.[131] . Whilst we believe the multi-professional nature of sleep medicine is one of the specialty's strengths, we would like to see closer working and an enhanced profile for the speciality. Anticipated benefits include relief of operational challenges, for example through pooling referrals, reducing navigation issues and reduction of the identified recruitment and workforce challenges.

Enhanced screening for sleep pathologies

Given the volume of undiagnosed sleep conditions,[12] the significance for healthcare utilisation and the societal and financial implications, it would be desirable to pull patients considered high risk for sleep conditions into the pathway, or in those that have occupational considerations.

AI could provide opportunities to find undiagnosed patients eg. primary care records could be designed so that, if patients have multiple risk factors for sleep apnoea they could be digitally contacted to complete additional screening tools, such as the Epworth Sleepiness Score[54] and the STOP-BANG[55] questionnaire and supported into the pathway if appropriate.

Sustainability

Enhanced sustainability of sleep diagnostics – with the increased use of home, or disposable kits, there is a need to ensure that the sustainability and footprint of disposable kit be considered alongside the convenience. Small re-useable kits will facilitate this and avoiding disposable kits will reduce electrical waste.

Improved patient education

Educating patients enhances engagement in sleep condition management through shared decision making and improved patient empowerment. Educational programmes, such as the Desmond programme[132] for patients newly diagnosed with diabetes, could be helpful for common conditions such as OSA. There is also unmet need for educational programmes for patients living with rarer sleep conditions, such as narcolepsy.

Digital aspirations

1 Utilise artificial intelligence, for example to identify individuals with undiagnosed sleep conditions in the community, to identify patients within the service in need of support

2 Interoperability of monitoring and treatment equipment, for example patients with home blood pressure, CPAP and weight scales being able to load information directly into patient records

3	Greater functionality within the NHS app to reduce numbers of patient apps required, and to join-up care
4	Linked information across boundaries and opportunities for automated processes. For example, in patients of childbearing age using medications contraindicated in pregnancy, if they do not order repeat contraceptive medications with their primary care provider, there could be an automated processes to link with the patient to enquire whether their circumstances have changed, or those with intrauterine devices may benefit from reminder notifications when the product is reaching the end of its effective period
Research	
1	Increase clarity between criteria for choice of NIV and CPAP, and models of CPAP delivery in OSA and obesity hypoventilation
2	Optimisation of adherence to treatment
3	Develop tools to predict MAD response
4	Further trials in treatments for rarer sleep conditions such as idiopathic hypersomnolence

Appendices

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S	Case study: Liverpool, Computer guided consultation
T	EHIA – specialist advice and guidance
U	EHIA – patient Initiated Follow Up

Appendix A: Sleep services for non-healthcare professionals – an overview

What is sleep medicine?

Sleep medicine is a medical subspeciality which focusses on diagnosing and treating sleep disorders and other sleep-related concerns. There are many types of sleep conditions, which explains why several specialities are involved in managing sleep conditions. Specialities include neurology or respiratory medicine, ear nose and throat medicine or anaesthetics.

There are respiratory sleep conditions, which are conditions when the patient's breathing is affected overnight while they are sleeping. These diseases are usually managed by teams including respiratory consultants. The commonest respiratory sleep disorders are obstructive sleep apnoea/hypopnoea syndrome, central sleep apnoea/Cheyne-Stokes breathing and nocturnal hypoventilation.

There are many neurological sleep disorders. Examples of these conditions include narcolepsy, night terrors, parasomnias and sleep-related movement disorders, and these diseases are usually managed by teams including neurology consultants.

Why is it important to manage sleep conditions?

Sleep disorders are common and if left untreated can have significant long-term consequences such as increased risk of heart disease, stroke, type 2 diabetes, and obesity. These conditions themselves are associated with patient morbidity, in addition to healthcare resource use.

Sleep disorders also have public health considerations: patients are at increased risk of road traffic accidents, workplace accidents and anxiety and depression. There is also potential for substantial social consequences for families and relationships. Sleep disorders are also associated with reduced productivity and significant economic costs.[133]

Who works within sleep medicine services?

Sleep services are usually composed of multidisciplinary teams, who work together to diagnose, manage and treat patients with sleep conditions (see table below). Team members may include:

1. **Sleep physiologists** – these specialists conduct and often interpret a series of tests on patients with sleep disorders. They use a variety of highly specialised equipment and support patients who are using home sleep therapy equipment (e.g. CPAP and NIV). Sleep physiologists have specialised qualifications, with additional levels of qualifications and responsibility as the individual becomes more senior.
2. **Consultant clinical scientists** – these specialists may work alongside medical consultant colleagues and often lead sleep services. They undertake patient consultations, perform complex diagnostic testing and develop and implement management plans.
3. **Specialist nurses** – specialist nurses often support patients with home sleep therapy equipment and complex medications.
4. **Band 2-4 associates** – these members of the team support the running of the service by distributing equipment, downloading remote patient data, and running diagnostic tests.
5. **Psychologists** – some sleep services are supported by specialised psychologists.
6. **Pharmacists** – some sleep services are supported by specialised pharmacists.
7. **Consultant physicians and trainees –** doctors trained in many specialities including respiratory, neurology or ENT, with an interest in sleep medicine

Diagnostic testing in sleep medicine

Obtaining accurate sleep diagnoses is very important. Diagnoses are usually made using physiological measures during sleep. These measures also give an indication of disease severity.

There are different diagnostic techniques which vary based on the number and type of variables measured. A simple diagnostic test is overnight home oximetry, a two-channel sleep study recording oximetry and pulse rate that can be completed at home. Many centres use oximetry as part of the diagnostic work-up and some centres use a positive oximetry test, combined with a typical history of OSA as confirmation of a diagnosis of OSA.

Home respiratory polygraphy is the most widely used diagnostic test. This is a diagnostic system that obtains more than the two-channel oximetry study. Home respiratory polygraphy measures oxygen levels and pulse rate in addition to air flow, chest or abdomen effort. Polysomnography includes all aspects of respiratory polygraphy along with electrical monitoring of the brain and muscles to provide more information on sleep stages.[63]

Current practice is variable with some sleep centres offering oximetry as the first-line test and others offering home respiratory polygraphy. This can be due to clinical preference, but is usually due to what the CCG commissioned.

When developing the NICE OSAHS guidance, the committee reviewed extensive evidence of the role of the available diagnostic tests. Their conclusions were that both home and hospital respiratory polygraphy should be the first-line diagnostic test most likely to give an accurate result without the need for retesting. This test can aid in the diagnosis of other conditions such as central sleep apnoea and nocturnal hypoventilation and provides more comprehensive information regarding artefacts than oximetry alone. The use of oximetry alone, or oximetry followed by home respiratory polygraphy where initial oximetry is negative, is less cost effective but could be considered if there would be significant diagnostic delay due to limited access to respiratory polygraphy.[63]

The working group would advocate that services use home respiratory polygraphy as a first line assessment as it reduces the need for further investigations resulting in better cost effectiveness, reduced time to treatment and ultimately enables the patient to proceed through the pathway as efficiently as possible. We do acknowledge that analysis of home respiratory polygraphy requires staff of a higher banding (usually Band 5-6) than to set-up, upload and analyse oximetry alone (usually Band 3 staff), however despite this the working group are in favour of the benefits conferred by home respiratory polygraphy.

The NICE OSA committee agreed that further investigation with polysomnography, which is more accurate and more expensive than home respiratory polygraphy, should be an option to provide more detail for people with symptoms who have a negative home respiratory polygraphy or oximetry result but continue to have suggestive symptoms,[63] which the working group would agree with.

What is the difference between screening and diagnostic tests?

Screening tests are used to detect early disease or risk factors for disease in large numbers of apparently healthy individuals. Diagnostic tests are used to establish the presence, or absence, of disease as a basis for treatment decision in symptomatic, or screen positive individuals.

Appendix B: Sleep services for non-healthcare professionals - workforce

Healthcare professional	Role	Agenda for change grading
Support services	Support the running of the sleep service through managing patient contacts such as telephone support line, facilitating patient referrals and consultations including virtual clinics, distributing equipment and correspondence, managing bookings.	Band 2 – 3
Consultant clinical scientist	Senior team member providing highly specialised investigation interpretation and advice. Increasingly lead sleep services.	Band 8 – 9
Sleep physiologist	Specialists conducting and often interpreting sleep investigations, support patients using home therapy equipment.	Band 4 – 8
Associate physiologists	Support the running of the service by distributing equipment, downloading remote patient data, and running diagnostic tests.	Band 2 – 4
Sleep physician	Consultants from respiratory, neurology, anaesthesia, ear nose and throat surgery and psychiatry specialities managing more complex patients and contributing to multidisciplinary teams.	n/a
Specialist nurse	Specialists conducting and often interpreting sleep investigations, support patients using home therapy equipment.	Band 6 – 7
Specialist pharmacist	Provision of clinical advice, counselling of medication, treatment monitoring and optimisation via pharmacist-led prescribing clinics. Evolving roles of prescribing pharmacists working within sleep services to better manage more complex medication regimens.	Band 8
Psychologist	Some sleep services are supported by specialised psychologists.	Band 5 – 7
Dental healthcare professionals	Dental healthcare professionals provide mandibular advancement devices for patients with obstructive sleep apnoea.	n/a
Lifestyle support professionals	Access to healthcare professionals to advise patients on how to improve diet and exercise, for example dieticians, smoking cessation practitioners, alcohol support workers, sports scientists.	Various

Appendix C: Sleep workforce role and training

	Role expectations	Relevant qualifications or training programme
Band 2 Assistant practitioner / support services	Distributing diagnostic kits and correspondence Downloading device compliance data Managing patient contacts eg. telephone support line, facilitating patient referrals and consultations including virtual clinics, managing bookings	
Band 3 Assistant Practitioner, Healthcare Science Support Worker Higher Level	Perform capillary blood gas sampling Undertake basic sleep diagnostic set up and downloading (e.g. overnight oximetry, polygraphy and actigraphy) Undertake CPAP set up (indirectly supervised) Downloading device compliance data	ARTP Spirometry Practitioner Certificate (level III) ARTP Associate CPAP Certificate ARTP Overnight Pulse Oximetry Certificate Level 4 Healthcare Scientist Associate Apprenticeship programme ARTP Blood Gas Sampling Course ARTP/BSS/HEE short courses
Band 4 Associate Practitioner, Healthcare Scientist Assistant	Perform capillary blood gas sampling Undertake basic sleep diagnostic set up and downloading (e.g. overnight oximetry, polygraphy and actigraphy) Undertake CPAP set up (if holds ARTP associate CPAP certificate, indirectly supervised) Undertake basic CPAP reviews (decision making supported by Band 5+)	ARTP Overnight Pulse Oximetry Certificate ARTP Associate CPAP Certificate ARTP Associate Professional Qualification (Level I) ARTP Clinical Examination (Level II) AASM Accredited Sleep Technologist Education Program (A-STEP) – modules of Level 6 Healthcare Scientist Practitioner Apprenticeship Scheme ARTP/BSS/HEE short courses
Band 5 Clinical Respiratory Physiologist, Healthcare Scientist Practitioner	Undertake sleep diagnostic set up and downloading with basic interpretation (e.g. overnight oximetry, polygraphy and actigraphy) Undertake CPAP set up and reviews (independently) Polysomnography set up (no interpretation)	ARTP Practitioner Qualification (Level III) ARTP Overnight Oximetry and Polygraphy Practitioner Certificate ARTP Progression/Practitioner CPAP certificate AASM Accredited Sleep Technologist Education Program (A-STEP) Certified Polysomnographic Technologist Examination (CPSGT) European respiratory sleep certified training programme
Band 6 Specialist/Senior Respiratory Physiologist, Clinical Scientist, Respiratory Healthcare Scientist Specialist, Specialist Nurse	Undertake diagnostic analysis and interpretation including full polysomnography, multiple sleep latency test, actigraphy	ARTP Overnight Oximetry and Polygraphy Practitioner Certificate ARTP Progression/Practitioner CPAP Certificate

	Clinically review sleep and NIV therapy Arterial blood gas sampling	AASM Accredited Sleep Technologist Education Program (A-STEP) Registered Polysomnographic Technologist Examination (RPSGT) European Sleep Research Society Examination of Certification in Sleep Medicine for Sleep Technologists ARTP/BSS/HEE Postgraduate Certificate in Sleep Medicine European respiratory sleep certified training programme
Band 7 Advanced Respiratory Physiologist, Advance Healthcare Scientist, Researcher, Healthcare Scientist Team Manager, Sub-specialism Lead, Specialist Nurse	Undertake complex diagnostic analysis and interpretation Initiation and clinical review of sleep and NIV therapy Sub-specialism lead Triage referrals	MSc ARTP/BSS/HEE PG Certificate in Sleep Medicine Higher Specialist Scientist Training Programme European respiratory sleep certified training programme
Band 8 Clinical Services Manager, Healthcare Science Service Manager, Consultant Clinical Scientist, Advanced Clinical Practitioner, Senior Advanced Respiratory Physiologist	Triage referrals Undertake complex diagnostic analysis and interpretation Initiation and clinical review of sleep and NIV therapy Liaise with physicians at MDT meetings for complex/problem cases Follow up of patient Service lead with responsibilities for procurement of reliable equipment of a certified standard, business issues, liaising with DVLA, innovation, service development Functions as consultant clinical nurse or scientist	PhD Higher Specialist Scientist Training Programme and/or equivalence European respiratory sleep certified training programme
Specialist nurses **Band 6-7**	Initiation and clinical review of sleep and NIV therapy Sub-specialism lead Arterial blood gas sampling Undertake sleep diagnostic set up and downloading with basic interpretation (e.g. overnight oximetry, polygraphy and actigraphy)	PACR (physical assessment and clinical reasoning course) ARTP/BSS/HEE PG Certificate in Sleep Medicine European respiratory sleep certified training programme
Physicians	Complex diagnostic analysis and interpretation Initiation and clinical review of sleep and NIV therapy Clinical or service lead	ARTP/BSS/HEE PG Certificate in Sleep Medicine European respiratory sleep certified training programme
Specialist pharmacists	Provide medication counselling, treatment optimisation, management of prescriptions and monitoring of patients on pharmacological agents.	

Appendix D: Patient information leaflet

Mandibular Advancement Devices

You have been advised to use a mandibular advancement device (MAD) by your sleep professional. This leaflet contains information about MADs so that you can understand what this treatment is, and what to expect.

Who should use a mandibular advancement device?

A mandibular advancement device (MAD) is a medical device used to treat snoring and sleep apnoea. MADs are often used to treat mild to moderate obstructive sleep apnoea (OSA), but are less commonly used in severe OSA. Patients with severe OSA should ideally use a mask-based therapy called continuous positive airway pressure (CPAP), but a MAD could be used if an individual is not able to tolerate CPAP therapy (*NICE Guideline 202, 2021*).

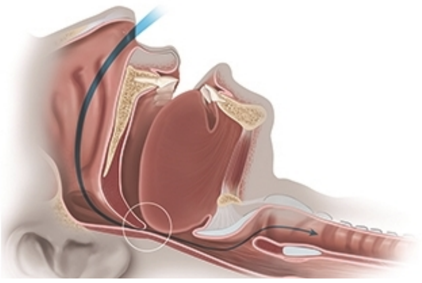
OSA is a sleep problem where you have pauses in your breathing, or have periods of shallow breathing, during sleep which occur more often than is normal. As well as disturbing your sleep, there are other negative health consequences of sleep apnoea, including increased risk of stroke, high blood pressure and heart problems.

What is a MAD?

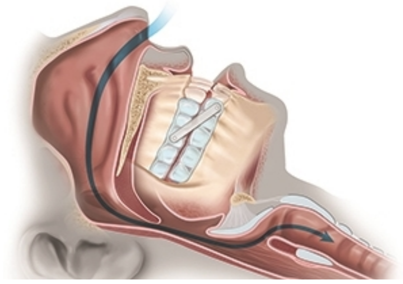
An MAD is a device that is worn in the mouth while you sleep. It is made up of two parts that fit securely over the upper and lower teeth. There are a range of MADs made by different manufacturing methods and of different materials which are all rigorously tested and are safe for you to wear.

How does an MAD work?

MADs helps to reduce, or eliminate, snoring and OSA events. The device holds the lower jaw forward, which moves the tongue forward, opening and stabilising the airway during sleep. By keeping the airway open during sleep, you experience more normal breathing. Therefore, you can ensure that you get enough oxygen into your body and get rid of the waste gas carbon dioxide. This reduces snoring and sleep apnoea.



During sleep there is restricted airway space



The MAD moves the jaw forwards increasing the airway space

How do I get an MAD?

There are different ways to get an MAD. MADs should ideally be provided by dentists trained in dental sleep medicine, who arrange for you to have a personalised device. There are some semi-customised devices that you can mould at home, like a sports gum shield.

How do I use my MAD?

You should aim to wear the MAD for as long as possible at night, ideally for all the hours you are asleep. Wearing a MAD is similar to wearing two sports guards attached together to hold your lower jaw forward. The MAD is significantly less bulky than sports mouth guards. It is more comfortable if you wet the MAD under cold water before putting it in your mouth.

How do I look after my MAD?

The most important aspect of treatment with an MAD that you wear in the mouth is keeping it clean and hygienic.

Every day you should wash your MAD with cold water and brush it with a toothbrush and soap but NOT toothpaste, as you would your teeth. Dry the MAD thoroughly and store it in an open container allowing it to be exposed to air during the day.

Every week you should use orthodontic cleaning tablets that refresh and disinfect the MAD. Soak the MAD for 20-30 minutes only. The tablets, (which should not contain chlorine as in denture cleaning tablets) can be bought online or in larger pharmacies. You also need to make sure that you look after your teeth, with regular dental check ups.

Is the MAD easy to use?

Your dental sleep specialist will aim to fit you with an MAD that is bespoke and comfortable to wear. Some patients can take longer to get accustomed to wearing an MAD but it gets easier as your quality of sleep improves. You may try and wear the MAD for short periods of time in the day while you are at home. This will make it easier to wear at night.

Short term side effects include experiencing an ache in the jaw, which is usually because of the muscles and ligaments around the jaw being stretched. You may also experience an ache in some of your teeth. Both feelings usually pass quickly. Gentle massage and exercises of the jaw are helpful. Hot or cold packs and simple painkillers can also be used.

If any of the above symptoms are severe or persistent, please stop wearing the MAD and contact the dental sleep department that provided your MAD.

What if I can't use my MAD?

You should speak to the dental sleep department for support in persevering with the treatment. Occasionally, patients find MADs too difficult to continue to use.

Who will check the MAD is working?

You will be given contact details to use if you experience any problems with the device. You may be asked to attend for review from time to time to make sure it works effectively and to look for any side effects.

When a MAD is well taken care of, it can be used at least 3-5 years, but you will eventually need a replacement.

If you have any problems, please contact dental sleep department for advice and an appointment.

More information:

NHS website OSA page: nhs.uk/conditions/sleep-apnoea/
British Society of Dental Sleep Medicine website: bsdsm.org.uk

Managing your Mandibular Advancement Device

This leaflet contains information about managing your MAD so that the therapy is most effective for you.

Wearing your MAD

The MAD needs to be worn for as long as possible at night, ideally for all the hours you are asleep. It takes everybody a different length of time to get used to wearing their MAD. This is because having a device in your mouth might feel unnatural at first.

If you are finding it hard to tolerate it for long periods of time in the night, you can try wearing it in the day for a while and then in the night while sleeping for as long as you can. You will get used to it once your quality of sleep improves.

Are there any difficulties and side effects when wearing an MAD?

Bespoke MADs should generally be comfortable and therefore easy to wear. Some people experience side effects which can include:

1. **Teeth discomfort** – this is due to the pressure on the teeth whilst the lower jaw is being pulled forward by the MAD. It should pass after a few days; if not the MAD might need adjustment. Simple painkillers, such as paracetamol, can help.

2. **Ache in the jaw** – this is because the muscles and ligaments around the jaw are being stretched and will pass with time. Hot and cold packs, massage and special exercises can help. Sometimes patients need physiotherapy or simple painkillers.

3. **Excessive saliva (hypersalivation)** – this is a normal reaction to having a 'foreign object' in your mouth and settles down after a few days. You could use a towel over your pillow.

4. **Dry mouth** – this could be due to the material the MAD is made of or suggest that you are continuing to mouth breath with the MAD. Speak to the dentist who fitted your MAD who might suggest taping your mouth with micropore tape or specific mouth sealing tape for breathing

5. **Bite change** – after using the MAD for some time, the lower jaw position can change due to muscles that help move the jaw may not be able to relax. This can be managed with jaw exercises, briefly chewing sugar-free gum and speaking to the dental sleep department.

6. **Broken device** – rarely the MAD can fracture causing it to become loose and be less effective. You must report this to the dental sleep department who will provide you with a new device.

If any of the above symptoms are severe or persistent, please stop wearing the MAD and contact the dental sleep department that provided your MAD.
Very occasionally, a patient may find it difficult to continue with the MAD and may have to discontinue treatment.

Looking after your MAD

The most important part of MAD treatment is keeping the device clean and hygienic.
Every morning, run it under cold or lukewarm water (never hot water). Use a toothbrush and brush it well inside and out as well as you would your teeth. You can occasionally use gentle hand soap with the toothbrush but if you do, rinse off the soap thoroughly. You should not use toothpaste as it is abrasive and can damage the surface of the MAD. Towel dry the cleaned MAD and store in an open container allowing it to air breath during the day.
Each week you should use cleaning tablets that refresh and disinfect the MAD. Soak the MAD for about 20-30 minutes only and never leave it to soak all day. Orthodontic cleaning tablets, can be bought online or from larger pharmacies.

Looking after your teeth

Dental check-ups – it is important to keep your mouth and teeth healthy. You should have regular dental check-ups to maintain healthy teeth and gums. If you get a new filling or a crown, please take your MAD with you and advise the dentist that you wear it when you sleep. Please do this before you have the treatment as the dentist can usually adapt the new filling or crown to fit within the MAD. Occasionally the MAD can be adjusted slightly but it is preferred that this is kept to a minimum.

Cleaning your teeth – you should carefully clean your teeth before putting the MAD in your mouth. Keeping a clean, healthy and moist mouth will mean that the MAD will stay effective and hygienic. It will also make sure that you do not get any gum inflammation or tooth decay. Wetting the MAD under running water prior to wearing it makes it much more comfortable to wear.

Follow up and review of the MAD

You will be given the contact details for the dental sleep service. You should contact the service if you any concerns or problems. You may be asked to attend for review of the MAD to ensure that it remains effective. MADs usually last 3-5 years after which time they will need replacement.

More information:

NHS website OSA page: nhs.uk/conditions/sleep-apnoea/
British Society of Dental Sleep Medicine website: bsdsm.org.uk

Continuous Positive Airways Pressure Therapy (CPAP)

You have been advised to use continuous positive airways pressure therapy (CPAP) by your sleep professional. This leaflet contains information about CPAP so that you can understand what this treatment is, and what to expect.

Who should use continuous positive airways pressure therapy?

Continuous positive airways pressure (CPAP) is a treatment used for sleep apnoea. CPAP is often used to treat moderate to severe obstructive sleep apnoea (OSA), but can also be used in mild OSA.

OSA is a sleep problem where you have pauses in your breathing, or have periods of shallow breathing, during sleep which occur more often than is normal. As well as disturbing your sleep, there are other negative health consequences of sleep apnoea, including increased risk of stroke, high blood pressure and heart problems.

What is CPAP?

CPAP is a therapy that helps breathing overnight by providing slightly pressurised air. To deliver this, a mask is worn over the nose and/or mouth and connected by tubing to a machine. This machine pumps air, quietly, holding the throat open.

How does CPAP work?

CPAP has been proven to reduce, or eliminate, OSA events. The pressurised air that the machine generates, helps keep the airway open during sleep. By keeping the airway open during sleep, you experience more normal breathing. Therefore, you can ensure that you get enough oxygen into your body and get rid of the waste gas carbon dioxide. This reduces snoring and sleep apnoea.

How do I get CPAP?

CPAP is provided and monitored by specialist sleep centres. You can be referred to your local sleep service by your General Practitioner (GP).

How do I use CPAP?

You should aim to use the CPAP therapy for as long as possible at night, ideally for all the hours you are asleep.

How do I look after my CPAP?

It is important to keep your CPAP mask clean and hygienic, therefore please clean your mask regularly.

Is CPAP easy to use?

It can take some time to get used to wearing CPAP. If you find it difficult to use, you could try wearing it during the daytime, for example when you are watching television, in order to get more used to the mask. If you develop any sores on your face or on the bridge of your nose, you should get in contact with the sleep service that provides your CPAP.

What if I can't use my CPAP?

You should speak to the sleep service for support in persevering with the treatment. Occasionally, patients find CPAP too difficult to continue to use.

Who will check the CPAP is working?

You will be given contact details to use if you experience any problems with the treatment. You may be asked to attend for review from time to time to make sure it works effectively and to look for any side effects.

CPAP devices usually require an annual service, and the mask will need replacing intermittently.

If you have any problems, please contact dental sleep department for advice and an appointment.

More information:

NHS website OSA page: nhs.uk/conditions/sleep-apnoea/

Appendix G: Patient Information Leaflet

Patient Initiated follow-up appointments (PIFU) for sleep disorders

This leaflet contains information about a type of follow up called patient initiated follow up (PIFU)

It has been traditional in the past for patients with sleep disorders to have regular face-to-face follow-up appointments with their clinician. The majority of patients with long-term conditions like sleep disorders, or following hospital treatment, do not necessarily need regular follow up appointments by the Hospital Team.

Patient Initiated Follow-Up (PIFU) has been introduced which works differently. Rather than having regular appointments, you can contact your team for support when you need it. This type of follow up has many names, including open-access follow up, telephone support line and unscheduled follow up.

What are the advantages of PIFU?

1. Reducing unnecessary visits to Hospital
2. Reducing your waiting time
3. Enabling the Clinical Teams to see patients in a timely manner
4. Supporting you quickly when you need it most
5. Providing you with replacement equipment or medications as quickly as possible

How does PIFU work?

Your Clinical Team will have a discussion with you to decide whether PIFU is the right pathway for you. Most patients will be suitable to be offered follow-up on a PIFU register, although there are some circumstances where it might not be appropriate, for example if you are a professional driver.

PIFU would start once you have been successfully started on treatment. Once started on a PIFU pathway, you can contact the team for support or to arrange a follow-up appointment, rather than receiving routine follow-up appointments.

How will I know when I need to contact the team for PIFU?

Your Clinical Team will advise you on the symptoms and scenarios you need to watch out for and when you should contact the service for support.

You may want to contact the service for a variety of reasons. This could include:

1. If you experience a change in your symptoms or your condition is worsening
2. If your treatment is becoming less effective
3. To inform us of equipment/ technology / prescription issues or a need for replacements
4. If you are experiencing side effects from your treatment, for example issues with your mask fit or medication side effects
5. Other advice, for example about travel or driving

Patients may experience occasional issues which might not require contact with the PIFU service, for example occasional side effects of medications or isolated incidents of raised AHI on the CPAP machine.
However, we would always encourage you to contact the service if you have any concerns in order for us to ensure safety of your treatment.

When not to use PIFU

If you require urgent medical advice you should contact your GP or NHS 111, or if you are really unwell, your local Emergency Department (A&E). For all other concerns, or if you are feeling unwell, your GP remains your first point of contact.

Contacting for PIFU support?

When contacting the service, please provide the following information:

Patient and contact details

- Your full name and date of birth
- Your hospital number and/or NHS number
- A telephone number so we can call you back during our opening hours

Reason for contact

Briefly explain your symptoms or situation and that you need some clinical advice or support.

Once you contact the team, your request for a PIFU appointment will be assessed by the clinical team and decide whether you need immediate clinical advice, or if you need an appointment, and which member of the team will be best able to address your needs.
If the team think you need an appointment, we will contact you to agree an appointment date and time. In most cases we will arrange an appointment for you within 10 working days. Sometimes it will be most appropriate to support you by having a remote consultation over the telephone or video link.
Sometimes your request may be for something to be sent to you, which we can dispatch directly to your house, or arrange for you to come to collect from the hospital.

Will you still be looking after me if I am on a PIFU pathway and don't contact you?

Yes. It is anticipated that you will remain on our patient registry and stay under the care of the clinic team on the PIFU pathway, for as long as you remain under the care of the sleep disorders team.
If you change your mind about being on the PIFU pathway, you can inform us and we will revert back to booking routine hospital appointments with you.

Where else can I get information from?

You can find more information about sleep disordered breathing on the trust website (provide link) or patient charities such as Hope2Sleep and SATA.
You can get this information in another format, such as braille, or language, by contacting the trust PALS service.

Appendix H: Patient Information Leaflet

Snoring & Sleep Apnoea

British Sleep Society
UK Multidisciplinary Sleep Professionals

⇒ ***Do you or your partner snore?***
⇒ ***Do you grind your teeth at night?***
⇒ ***Is it disrupting your sleep?***
⇒ ***Is your snoring leading to marital tension?***
⇒ ***Do you as a couple sleep in separate bedrooms?***
⇒ ***Have you noticed you or your partner stop breathing during sleep?***
⇒ ***Are you or your partner waking up tired or feeling un-refreshed?***
⇒ ***Do you wake up with jaw ache or pain in your face?***

Read this leaflet to understand how your dentist can help your snoring.

Snoring

Snoring is the sound made when the muscles of the upper airway relax more than normal during sleep. This allows the soft palate to flutter, resulting in the noise of snoring.
The noise can be loud and disturb your bed partner - 95% of snorers say that their snoring bothers their partner.

Obstructive sleep apnoea

Obstructive sleep apnoea (OSA) is when the airway muscles collapse completely leading to the stopping of breathing for 10 seconds or more during each episode.
This causes snoring and excessive daytime tiredness, and can lead to serious conditions:

- heart attacks
- depression
- high blood pressure
- mood swings
- strokes
- diabetes
- lack of concentration
- depression

4 in 10 men who snore …

and **2 in 10 women** who snore …

also suffer from OSA.

Could you have OSA?

High risk of OSA: if you answer yes to 5 or more questions
Intermediate risk of OSA: Yes 3 - 4 **|** **Low risk of OSA:** Yes 0 - 2

STOP		
Do you **SNORE** loudly? (louder than talking or loud enough to be heard through closed doors)?	Yes	No
Do you often feel **TIRED**, fatigued, or sleepy during daytime?	Yes	No
Has anyone **OBSERVED** you stop breathing during your sleep?	Yes	No
Do you have or are you being treated for high blood **PRESSURE**?	Yes	No
BANG		
BMI: more than 35kg/m^2?	Yes	No
AGE: over 50 years old?	Yes	No
NECK circumference: > 16 inches (40cm)?	Yes	No
GENDER: Male?	Yes	No

What next?

If you scored on the screening questions above, you are at risk of OSA. Your dentist trained in dental sleep medicine is able to offer a comprehensive assessment, starting with a snoring assessment, to best understand you and your concerns.

Any risk of underlying OSA will be highlighted during this assessment and an appropriate referral will be initiated to your GP or a private sleep service for further investigation.

Your dentist trained in dental sleep medicine can also offer treatment options and follow up for some cases.

Investigations

A sleep study is the only way to confirm a diagnosis of OSA, and is often performed at home or occasionally in hospital.

Treatments

OSA treatment options will include lifestyle changes and may include oral devices or mask-based therapy. Anti-snoring treatment options also include lifestyle change and oral devices.

⇒ Mandibular advancement devices

These devices are worn in the mouth to help with snoring and are increasingly being used for OSA. Research has shown that the most effective mandibular advancement devices are adjustable and bespoke and are obtained from a dentist trained in dental sleep medicine.

Find a dentist trained in dental sleep medicine:
bsdsm.org.uk/findadentist

Appendix I: Case Study: Sandwell and West Birmingham

Patient Initiated Follow Up in Sleep Medicine	
Organisation	Sandwell and West Birmingham Hospitals NHS Trust NHS Sandwell and West Birmingham NHS Trust
Synopsis	Sandwell and West Birmingham Hospitals (SWBH) has a comprehensive sleep service for 5,000 continuous positive airway pressure (CPAP) / non-invasive ventilation (NIV) users, which has been delivering patient initiated follow up (PIFU) for 14 years. For the 4,000 patients with obstructive sleep apnoea (OSA) on CPAP in the service, there is a standardised follow-up algorithm for the first 12 months, to ensure consistent compliance and symptom control. Following this, patients considered high risk (for occupational or clinical reasons) are offered annual review and most other patients PIFU. An office-hours telephone service exists for patients to contact for support. CPAP consumables are automatically dispatched annually. All patients have five-year reviews, regardless of usual follow up methodology, to facilitate machine replacement. Widespread PIFU enables focussing of resources towards clinical need. The service has evolved to maximise efficiency and utilise clinical expertise where needed. Most reviews are undertaken by physiologists/clinical scientists; doctors may see patients at time of initial referral and discuss complex patients weekly in MDT. Imminently, there are plans to develop the staffing model with the addition of Admin & Clerical staffing to support dispatching equipment and to take messages on the support line. All patient interactions, regardless of whether the patient is involved or not, attract a tariff, ensuring that the service is adequately reimbursed (A8a)
Keywords	Patient initiated follow up (PIFU) Sleep apnoea
Key contact	Name: Mike Lang, Head of Respiratory Physiology Email address: michael.lang@nhs.net
Content	
Background	SWBH comprises of three hospitals and several other sites providing comprehensive services to the 530,000 person population of North-West Birmingham and towns within Sandwell. Sandwell and West Birmingham CCG traditionally managed the local healthcare provision, however since April 2021 it is now part of the wider Healthy Futures Black Country and West Birmingham ICS system serving 1.4 million patients. Sleep services are run from City & Sandwell Hospitals and the service design has been organically grown and developed over several decades with the support of the operations teams.
The problem	The local population has significant deprivation and an above average prevalence of OSA (1). This means that there is a huge demand for sleep services. 14 years ago, increasing waitlists and patient cohort size led the service to recognise that there was a need for service delivery change. Managing the expanding patient cohort with traditional out-patient service methodology of regular face-to-face appointments was unsustainable and not best-use of the

	finite resource. Anecdotally patients also found the recurrent routine appointments constrictive. Therefore, there has been continued service development over the last 14 years, to create a more efficient and streamlined service. The service changes were supported by the Trust and CCG and facilitated by local operational teams.
The solution	The service delivery changes were achieved organically with slow change over many years, and a natural response to the demands on the service. Consequently, there is not a documented timeline for change or SOP. *Appointments* Initially, the service was run traditionally with face-to-face outpatient appointments booked at intervals. The service recognised that many of the appointments did not result in significant change in management, and that structuring the follow-up in such a way was not necessary for most patients. Therefore, a PIFU service began to evolve. This was enabled by the presence of a telephone support line for patients to call for assistance and to arrange appointments when required. There was recognition that not all patients would be suitable for PIFU therefore inclusion and exclusion criteria for PIFU, and for "traditional" follow up were devised. *Funding* Initially, there were standard treatment function codes for reimbursement of care. With the support of the local operation teams and approval from the CCG, local tariffs became established to ensure that every interaction was reimbursed. This is a continuous process with ongoing symbiosis between coding teams and clinical teams to ensure that any new type of interaction is awarded a tariff (appendix 1). *Workforce* The traditional workforce arrangement has evolved, and the service is predominantly physiologist-led. At the first appointment, patients may see a doctor or a consultant level physiologist (band 8). Following this, care is delivered by physiologists/clinical scientists (band 6-8) with a weekly multi-disciplinary team meeting where complex cases can be discussed with consultant sleep physicians. The department also has band 4 Associate Physiologists who free-up time for the physiologists to provide care. There is a plan to recruit administrative support to further ringfence the clinical team for clinical duties. *Technology* The department runs most appointments via phone and utilising remotely accessed data from the therapy device. There are some circumstances where patients would be required to come into the centre, for example when problems with therapy or equipment cannot be solved over the phone or the machine needs replacing. *Helpline* Patients have access to a telephone support line from Monday to Friday between 8.30am and 4.30pm. This is managed by the Associate Physiologists who take messages from patients and triage the requests to the relevant clinician. The clinical team aims to return the call of the patient within half a working day. There are emergency appointments available every day, therefore patients can be seen within 2 working days, although in practice this is usually only 1 working day.

Costs	The service has prioritised effective reimbursement tariffs to ensure that the work is compensated fairly (appendix 1). There has also been a drive to ensure that tasks are completed by those with appropriate skill levels. This manifests as a comprehensive Associate Physiologist support team, triaging and completing tasks not requiring clinical training. This facilitates the ring-fencing of clinical staff to complete tasks for which their specialist skills are required. There is minimal consultant physician involvement in routine care and instead patients are identified and discussed with consultant physicians at MDT.
Challenges	*Clinicians* 1. Increased administration load, for example with dispatching service packs, answering helpline – *resolved by expanding Associate Physiologist support to ring-fence clinicians and funded by ensuring that these tasks also attract tariff*. 2. Ensuring that patients with “high-risk” occupations are managed safely and in line with national guidance – *exclusion criteria for PIFU including professional drivers, high-risk occupations, those struggling with therapy and complex cases* 3. Lack of national guidelines – *no guidelines existed at the time of developing this service therefore all workarounds had to be novel.* 4. Keeping track of large numbers of patients is challenging, particularly if they are not automatically in follow-up – *this was overcome by development of an effective patient management system and careful diarising of patient care (for example with annual dispatching of consumables).* 5. Ensuring that patients on PIFU get consumables timely if they are not attending hospital for annual appointments – *experience demonstrated that patients needed replacement of equipment approximately 12 monthly therefore this process has now been automated and sent out to those patients that are on PIFU by Associate Physiologists. Patients on traditional follow-up will be given their replacement consumables at their in-person annual review.* 6. How to ensure that patients do not stop using therapy – *this challenge exists regardless of the follow-up methodology, five-year review provides a safety net.* *7.* Ensuring reimbursement for all services – *comprehensive tariff process with ongoing additions to ensure all care paid for. Collegiate approach with administration services facilitates this.* *Patients* *1.* Preference for routine appointments – *small numbers of patients prefer to have routine appointments, even if they do not have any of the exclusion criteria for PIFU; mediated by shared decision making about follow-up planning.* *2.* Being automatically sent equipment – *patients are notified by letter in advance that their equipment will be dispatched, ensuring that patients have choice to receive items at home, or collect from the hospital.*
Impact	*Benefits for patients include* 1. Bespoke care, as intensive as required, led by the patient

	2. Convenience of equipment automatically coming to the patients home rather than having to remember to order, and to attend to collect equipment 3. Shorter waiting times as more efficient service 4. Patient feedback consistently positive 5. Flexibility in decision for PIFU or traditional follow up *Benefits for the staff include* 1. Ability to focus on patients who require input 2. Career development opportunity for physiologists, novel roles developed *Benefits for Trust/Commissioner* 1. Comprehensive tariff structure 2. Efficient and cost-effective structure 3. Productive service *Benefits for the population* 1. Good access to sleep services in area of high prevalence of OSA 2. Ensure safety as close monitoring of those with high-risk occupations
Lessons	*1. Get the finances sorted* It is important to have the finances aligned and ensure that the service is properly renumerated, given that there will be additional administration work and that demand in all sleep service continues to grow annually. Payment-by-results is the preferred financing method, however there is now a move to block contracts that requires significant input from the sleep service to contracting/finance to ensure that forecast activity is as accurate as possible. Also need to build in allowance for equipment breakages within 12 months (consumables) and 5 years (CPAP/NIV machines). *2. Anticipate additional administration work* Anticipate that there will be a need for accurate patient management systems, and sufficient support staff to manage the service. *3. Introduce PIFU early* Introduce the concept of PIFU to patients early so they are aware that it is coming and engage them in shared decision making. Empower patients to be more self-sufficient and equip them with the knowledge to know when they need to call for help. *4. PIFU patients are self-selective* There are some patients where PIFU will not work, but the majority it will work for. We have approximately 80% of patients on PIFU. *5. Job-planning* A PIFU service runs differently to a traditional service therefore it is important that the job planning is right so that you have the right skill-mix in the team
Next steps, sustainability and scaling	Next steps will be to gain approval for Admin & Clerical staffing to further support the clinicians. We are also working to link the patient management system with the electronic notes system for further automation of patient diarisation.
Find out more	Please see appendices 9a and 9b for local tariff agreements and the patient journey diagram for pictorial representation of the service.

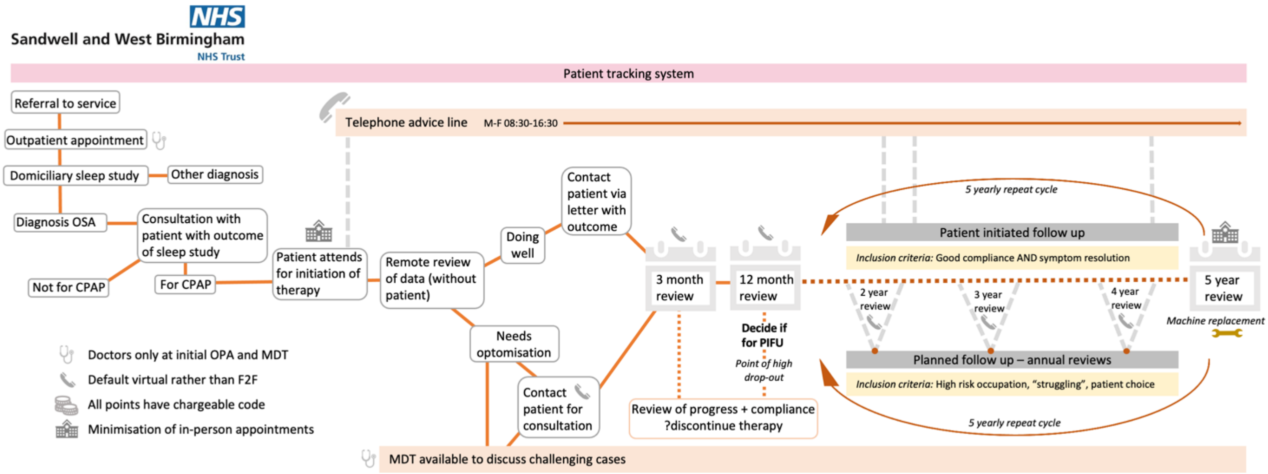
Appendix Ia: Tariff codes for CPAP services

NHS
Sandwell and West Birmingham
NHS Trust

1. Where multiple procedures occur at same time then highest tariff only is billed
2. Duplications, such as a phone call and then separate review on same day, rationalised to one tariff

Healthcare Resource Group Code	Diary Procedure	Description
CPAP_AD	CPAP Additional Consults	CPAP - Extra Consultation CPAP Non-Scheduled Appt/Breakage Loan of Humidifier for CPAP/NIV Patient Change Mask Size Patient Swap Mask Type Replacement of Faulty CPAP Machine Return of Loan Humidifier for CPAP/NIV Review of extended CPAP Trial Specialist Consultation Suspected Faulty CPAP Machine Trial Loan of Humidifier for CPAP/NIV - 2 weeks
	CPAP Virtual 1 month review	CPAP Virtual 1 month review
	CPAP Virtual 3 month review	CPAP Virtual 3 month review
	CPAP Virtual 6 month review	CPAP Virtual 6 month review
	CPAP virtual extra consultation	CPAP virtual extra consultation
CPAP_FA	Start Trial of CPAP Treatment	New CPAP Patients
	Replacement CPAP Machine & Review	CPAP Replacement
CPAP_FA_CX	Commence Complex CPAP	Complex CPAP
CPAP_FU_CX	Complex CPAP Replacement Machine & Review	Complex CPAP Review
CPAP_FU	CPAP - Patient Led Follow Up	CPAP Follow Ups
	CPAP Annual Follow Up/Review (Year 2 on-wards)	CPAP Follow Ups
	CPAP Virtual Review (Year 2 on-wards)	CPAP Follow Ups
CPAP_TEL	CPAP - Conversation Note	Telephone Contact (CPAP Helpline)
CPAP_CBT	Cognitive Behavioural Therapy (CBT)	CBT for CPAP-NIV

Appendix Ib: PIFU patient journey diagram



Appendix J: Case Study: Queen Elizabeth University Hospital, Glasgow

Digital integration of remote monitoring in sleep medicine	
Organisation	Queen Elizabeth University Hospital, NHS Greater Glasgow & Clyde
Synopsis	This case study describes successful use of a remote patient monitoring and asynchronous patient communication platform within clinical practice.
Key words	*Sleep medicine* *Remote monitoring* *Asynchronous communication* *Patient records*
Key contact	Name: Chris Carlin *christopher.carlin@ggc.scot.nhs.uk*
Content	
Background	NHS Scotland has an agenda to transform and improve digital infrastructure, alongside ensuring post-pandemic recovery. Aligned to this, Queen Elizabeth University Hospital (QEUH) ran a successful innovation project to enhance digital care for patients with COPD using NIV. Usual practice for understanding patient compliance is to manually download data from each patient device, and for it to be uploaded into the patient record via a PDF sheet. This manual process is very labour intensive for support services staff and makes longitudinal assessment of patient compliance challenging.
The problem	There was a need to improve the communication between the remote monitoring data that is collected, and in the patient record, to improve clinical user experience and ultimately patient care.
The solution	A patient and clinician patient management system was developed that integrates data from remote monitoring devices with patient interfaces. The platform enables clinicians to review patient cohorts on a platform to understand their compliance and quality of therapy delivered. This platform enables longer term review of data, and is more accessible and user-friendly than previous PDF data exports that were available. The platform also has function to provide asynchronous two-way communication with patients, to enable patients to be able to contact the service for support and to review their own data. This is beneficial for patient empowerment and provides an effective method of communication between provider and patient, particularly if services transition to patient initiated follow up pathways.
Costs	There were financial costs for the supplier and for QEUH to deliver the digital changes required. It is anticipated that digitalisation of processes would relieve healthcare professionals and support staff to utilise for other aspects of patient care, which could confer a cost saving.
Challenges	Digital challenges 1. Challenge of transfer of information between two platforms to facilitate to achieve seamless integration Engagement 2. Early adopters quick to get on board, enthusiastic and have positive feedback. 3. Challenge to disseminate those less interested in transformation, particularly if initial need for dual processing (e.g. digital platform and telephone support line)

	4. Pace of adoption of new ideas Digital Inequality 5. Patients who are experiencing digital poverty are at risk of health inequalities which need to be managed to ensure equity of access when implementing digital innovations
Impact	Patients 6. Positive patient feedback 7. Reduced need for patients to travel with automation of processes remotely Staff 8. Removing tasks that can be digitalised will free time for staff to utilise for other aspects of patient care, improving pressures on workforce 9. Opportunity for career development with regard to contribute to digital transformation work 10. Opportunity to develop partnerships with companies 11. Opportunity to harness more data for clinical research 12. Need to run parallel systems during period of scaling up – e.g. running telephone and digital platforms for patient contacts
Lessons	Importance of ensuring that there are sufficient devices for staff to be able to access digital information.
Next steps, sustainability, scaling	This case study has highlighted the disparity that exists within the digital infrastructure of the NHS. For example, Scotland has agreements with NIV/CPAP providers that enabled unlimited remote monitoring, compared to England where often contracts for remote monitoring expire after 12 months. Disparity also exists between the UK and countries of the continent with regards to access of patient data. The service is looking into feasibility of a fulfilment centre which would outsource certain parts of the patient pathway, for example the distribution of patient consumables. There are also considerations for whether artificial intelligence could be used to provide automated reports, or to flag patients whose therapy may be sub-therapeutic. The data could also have coding and logic applied, for example, to ensure that patients are using their therapy before automatically dispatching consumables. Including members of the support services team in the design of the interface is important to ensure that it is optimally functioning from a support as well as clinical perspective, in addition to ensuring that patient feedback and input is prioritised. There are hopes that the platform would be developed to ensure that patient reported outcome measures are automatically collated and reported.
Find out more	Appendix Ja: summary of project

Appendix Ja: Summary of project: stable early usage rates following remote-based CPAP initiation at an experienced centre

Stable early usage rates following remote-based CPAP initiation at an experienced centre

Alex Wood, Duncan Macfarlane, Maureen Manthe, Andrew Morley, Chris Carlin
Queen Elizabeth University Hospital, NHS Greater Glasgow & Clyde

Prior to the COVID-19 pandemic CPAP initiation in our unit was at a face-face appointment, with remote-monitoring and telephone-based follow up appointments. We had piloted NHS NearMe video appointments for CPAP initiation and mask-fit troubleshooting.

We had co-designed the LenusSleep app with patients and clinicians to improve asynchronous appointment management, including structured patient reported outcomes, kit and stock management.

COVID-19 pandemic prompted us to pivot our service to an asynchronous sleep diagnostic pathway with end-end remote-based CPAP initiation and management.

Calidicott guardian approved detailed service evaluation is in progress. Other units have reported deterioration in patient CPAP usage with remote-initiation. We therefore undertook a preliminary evaluation of compliance data in matched cohorts of patients who had face-face (n=50) or remote-based (n=97) CPAP initiation.

Referral - possible OSAS

Capture patient-reported outcome set

Collect-return home sleep study (somnotouch or apnealink)
Clinic review, PSG, postal apnealink options alternate options if remote-rural, complex features etc.

Asynchronous clinician review
Referral, EHR, PRO and sleep study data with standardised outcomes

Normal evaluation
Advice letter
3-month opt in option for sleep clinic rev

Mild symptoms & mild sleep disordered breathing
Advice letter

Indeterminate evaluation or possible other sleep medicine diagnosis
Advice letter
Further assessment
Sleep clinic and/or PSG

Likely OSAS
Advice letter
including CPAP information, video links, driving responsibilities
Sleep team contact
Fully remote CPAP setup?
Onboard AirView +/- LenusSleep
Issue CPAP
Courier kit from hospital to patient
CPAP setup appointment
Clinician-patient video call
Initial follow up
2 week remote-monitoring data review and telephone appointment
Additional follow-up
Regular reviews to address issues from initial follow up until CPAP optimised, or treatment trial concluded.

Face-face CPAP setup
Available by exception if remote-based setup not feasible, appropriate or successful

Possible cardiorespiratory failure
Ventilation clinic review
NIV or OSAS pathway +/- further evaluation as indicated

NHS GG&C YouTube channel
CPAP setup patient information videos

Sleep diagnostic and CPAP pathway
Link to pdf of NHS GGC process map

NHS NearMe
NHS Scotland video appt system

NHS GG&C resources for remote-monitoring of respiratory support therapy

Remote-monitoring office for data reviews & NHS NearMe video calls

Patient support YouTube channel

Patient and clinician information videos

CPAP usage following face-face or remote-based setup

Contrasting with other unit's reported experience, we noted similar CPAP compliance (>4 hours per night in >70% of nights) with fully remote-based initiation.

Selected screens from LenusSleep patient app

Patient reported outcomes at scheduled frequency, kit replenishment requests, asynchronous patient <> clinician messaging

Selected screens from LenusSleep clinician app

View patient reported outcomes and progress with remote-monitored CPAP initiation, schedule asynchronous appointments, allocate kit, review and fulfil kit replenishment requests, stock management

Appendix K: Case Study: Imperial College Hospitals NHT Trust, London

Rotational staff working	
Organisation	Imperial College Healthcare NHS Trust
Synopsis	Imperial College Healthcare NHS Trust's (ICHNT) airways team works cross site, and cross boundaries. This case study examines staff satisfaction and experience of a cross-site and cross-boundary role.
Key words	Respiratory, Integrated Care, Community Care, staff experience
Key contact	Liz Goodman Elizabeth.goodman1@nhs.net
Content	
Background	ICHNT has an integrated airways team that works across secondary and primary care. The multidisciplinary staff within the airways rotate between acute inpatient care and community outpatient care. The multi-professional team consists of respiratory nurses, respiratory physiotherapists, administration support and doctors. The team meets weekly in a hybrid virtual and face-to-face MDT meeting where clinical and non-clinical issues are discussed with the involvement of a consultant physician. Physiotherapy and nursing staff move between two teams: 1. Inpatient "AIR" team, who review patients on the ward and support with discharge planning 2. Outpatient / community team, who review and manage patients at home, support admission prevention and facilitate early and supported discharges. Band 7 staff rotate annually, and band 6 staff rotate 6 monthly. This service is a fully-NHS service with no aspect provided by a private provider. The rotational working pattern is now well established and well-liked by the majority of staff that work within it.
The problem	The service has experienced some challenges: 1. Adequate administration support Whilst the outpatient/community team has the support of an administration team, the inpatient team do not have dedicated administration support and rely on administration support linked to physicians within the service. 2. Adequate IT integration IT systems are streamlined, and access is either to the inpatient "Cerner" platform or primary care "SystmOne" for documentation. Healthcare professionals working within the teams have access to both systems, however staff outside of the team do not. This means that there is a challenge in accessing information stored in the different systems, but the airway team is able to join up the communications and ensure that information found on the community platform is shared with inpatient teams when required. 3. Preference for inpatient or community Some team members prefer to work in either the community or inpatient services, or may have a preference to have an area of expertise rather than rotating and gaining broader expertise. Some staff describe the potential for anxiety about changing roles, however given the weekly MDT and support structure within the service this is managed effectively. It is anticipated that staff would prefer one role over the other.

Impact	**Staff benefits** The team identify many benefits of this style of working: 1. Opportunity to experience variety at work The service structure enables staff to experience a huge variety – staff gain experience of inpatient and outpatient care, acute and chronic disease management, and there is a huge opportunity for independent working. The staff reflect that this prevents "stagnation" in the workforce. 2. Broad expertise This style of working allows staff to develop expertise in a wider range of areas and provides excellent career development opportunities. 3. Patient experience driving job satisfaction Patient experience fully integrated care with one team communicating seamlessly between their admission, discharge and ongoing community care. The ability to follow a patient's journey is rewarding and educational for those involved, in addition to supporting the patient benefits listed below. 4. Cross-cover The presence of two teams with the same skills and training means that there is ability to flex staffing, perhaps to cover sickness, or to accommodate winter pressures. It also provides benefits on a personal level, as it provides greater support in facilitating annual and study leave. 5. Understanding of the broader healthcare landscape Staff report that there is opportunity to gain greater understanding of the healthcare landscape, beyond secondary care. This involves understanding challenges, funding and operational considerations. **Patient benefits** There are multiple patient benefits that have been identified. This includes familiarity within the team, reassurance to the patient that there is communication about their care, and continuity in their care across the boundary of community to secondary care. Staff comment that patients report they feel more secure about their transfer of care into, or out of, hospital.
Lessons	**Enablers** The staff reflected that the following enable the service to be a success: 1. Cross-site working is the norm within the trust Most staff within ICHNT work cross-site. This overcomes any challenges about working in more than one place and therefore extending this to community too was not as significant a step, compared to a trust that may only operate from one site. Additionally, many professions, such as physiotherapists, routinely rotate as part of job-plans. 2. MDT The weekly MDT meeting is very important as it is an opportunity for collegiate working and support. This provides an anchor for teams, particularly community teams who may be working off-site for much of the week. The meeting also provides opportunity for oversight, and ensures that individual team members are not over-burdened. It is also a crucial conduit for information transfer between community and inpatient teams. 3. Communication

	The team has a WhatsApp group to discuss staffing or flag issues (without sharing patient-identifiable data) quickly to enable rapid response. 4. New starters New starters to the team are encouraged to shadow every part of the service to fully understand how each aspect joins-up. This is perceived as a priority and therefore new-starters are supported as comprehensively as possible to adapt to the role.
Find out more	Please see the Respiratory GIRFT report that also features the Imperial College Healthcare NHS Trust Integrated respiratory team.

Appendix L: Case Study: Guys and St Thomas' NHS Trust, London

Learning from establishing a novel PIFU sleep service	
Organisation	Guy's & St Thomas' NHS Trust
Synopsis	The GSTT sleep service has recently undertaken service re-design implementing a novel PIFU service for patients receiving continuous positive airways pressure (CPAP) therapy.
KEY WORDS	*Patient initiated follow up* *Sleep Medicine*
Key contact	Karen Bacon – CPAP Specialist Practitioner (Karen.A.Marshall@gstt.nhs.uk) Asia Woroszyl – CPAP Specialist Practitioner (Asia.Woroszyl@gstt.nhs.uk)
Content	
Background	The GSTT sleep service has been established for many years however over the last 10 years it has experienced significantly increasing patient numbers within the service leading to lengthening waiting times. The service has adapted over time, to try to counteract the expanding patient numbers, including with movement into a larger physical location.
The problem	There was a need to re-develop the sleep service to accommodate the expanding patient numbers and the increasing wait list. Planned service re-design was halted due to the pandemic, however as part of post-covid service recovery PIFU has an important role.
The solution	A novel PIFU service was designed and trialled in Spring 2022. The service was designed so that patients who are newly started on CPAP therapy would be offered PIFU, as would all patients currently within the service. Patients would be commenced on CPAP therapy through usual intensive 3 month supported follow up, before a further appointment at 12 months. Following this, patients would be scheduled for an appointment at 5 years, to coincide with when machine servicing might be required. Patients can contact the service any point via phone or email for support. Patients were divided into 4 cohorts: 1) Cohort 1 – overdue an appointment by >12 months, 2600 patients 2) Cohort 2 – established CPAP patient needing machine replacement, 272 patients 3) Cohort 3 – due appointment in 2022, seen in 2021, 3590 patients 4) Cohort 4 – new patient set up on CPAP in 2022, 1250 patients The service decided to start the trial in cohorts 1 and 2. This was to ensure that the trial started with manageable patient numbers, and with patients who were overdue review on the current pathway or due to be seen within the service imminently. Cohort 2 was the smallest cohort, who were already established on CPAP therapy, and may have been with the service for many years. Patients are provided with a patient leaflet, in addition to a letter to both the patient and GP explaining the service. Patients enter into a PIFU pathway using shared decision making. The service is explained to patients that the novel method allows patients to be seen when they need support and to ensure that those who need to be seen the most can be seen timely. There were certain patient groups, for example occupational drivers, who were excluded from PIFU at this time. Patients who were having lots of issues with therapy were also excluded from recruitment, until their

	condition is under good control. Patients with complex management needs, requiring further review were also excluded from PIFU.
Costs	The sleep service remains on block contract currently following the pandemic. When contracts are reviewed, the service aims to ensure that each patient contact would have financial support. It is anticipated that the service will generate similar income with PIFU compared to previous care models.
Challenges	1. Difference in opinion Deciding on the patient pathway was challenging as there was conflicting opinion between the clinicians involved in the service design. The plans were also changed following peer review. Due to the change in plans, it was decided that during the pilot phase and until the final care pathway had been decided, senior staff would commence PIFU rather than all staff, in order to ensure that the process is robust before more junior members of the team start recruiting patient to PIFU. 2. Staffing During the pilot phase there were staffing challenges including sickness and change of roles. This meant that implementing the PIFU pilot was delayed as there were very few members of staff skilled to recruit to PIFU. 3. Delays in finalising patient literature There were unexpected delays in the processes around generating the patient literature. 20 patients were consulted on the patient literature before the final version was published. 4. Administration processes The processes to change clinic codes and to change the appointment structure took time, but once changed, there was not the patient recruitment to PIFU at the same rate. This led to a need for work-arounds. 5. Co-ordinated working It was important for management, administration and clinical teams to work together to coordinate works so that all parties knew what was happening. 6. Change mindset Staff had to be firm in implementing PIFU and stopping the previous model of annual review. 7. Patient flow As the service wanted to ensure that all patients are seen at the 5th birthday of the device, this meant that there would have to be a reliable process step in the pathway to calculate when the 5th birthday would be for each device and ensure that there is an appointment booked.
Impact	**Patients** 50% of patients offered PIFU enrolled. From experience of the patient cohort, those that declined PIFU were patients with overall poor experience of NHS. For example, if they had been lost in the system before, they may not wish to be put onto a PIFU pathway. Patients in cohort 2 had typically been managed by the service for many years and had the experience of the service when it was very small, when they saw the same staff member. Honing down that PIFU means that there is always someone available, ensured that the messaging was positive. The initial feedback is that none of the patients who enrolled on PIFU feel that they are getting less service than they previously were provided. **Staff**

	Staff have reported positive feedback within the staff involved in delivering PIFU. Staff have been struggling with the exponential growth in clinic numbers for several years, but before the pandemic, commissioning structures meant that it was difficult to implement novel methods such as PIFU. Following the pandemic, there has been an urgent need to revolutionise outpatient delivery, enabling PIFU to be implemented. **Waiting lists** The project has long-term goals of trying to
Lessons	1. Start with manageable patient numbers and patient types By splitting the patients into cohorts it became more manageable to start implementing PIFU in smaller numbers, and in groups which were most easy to begin with, for example patients being newly started on CPAP therapy, or those overdue annual review. 2. Anticipate lead times The group were delayed by time taken to peer review patient and GP letters and patient information leaflets. 3. Ensure all parties are aware of timescale The PIFU project is a long-term outpatient management plan rather than a quick win. It is important that all parties involved in the delivery of PIFU are aware of the longer-term benefits for the service, rather than expecting an immediate change in waitlist, for example. 4. Shared decision making It is very important that patients are involved in a shared decision making, and they understand the rationale for PIFU. Patients should be informed that they are each being prioritised when they require support, and that PIFU is not giving them a disservice. Those that decline PIFU at the first offer, will be re-offered PIFU at the next consultation. Careful wording should be used. 5. How to manage patients who decline therapy The service is considering how to design a system that is robust enough to manage patients who are not compliant with therapy. Currently these patients are not offered PIFU, but in time, it is hoped that there will be an ability whereby those that have been supported to the maximum capacity, but continue to decline therapy, could contact the service in the future if required. 6. Call capacity There is a need to ensure that the service has adequate capacity within the workforce to manage the telephone and email contacts from patients enrolled on PIFU. This needs to be accommodated within job plans given the high volume that the service received in contact to these methods. There are plans to develop a triage tool to ensure that patient contacts reach the right team member timely.
Next steps, sustainability, scaling	GSTT is part of a larger partnership containing other organisations, e.g. The Royal Brompton Hospital and Kings College Hospital. This provides opportunity for economy of scale and to share practice across the whole partnership. There may also be opportunity to explore widening PIFU to patient cohorts who are currently excluded from PIFU.

	It is too early to understand whether PIFU impacts adherence, however the working group is hoping to study this in time. As above, a triage tool is in development.
Find out more	Karen Bacon *Karen.A.Marshall@gstt.nhs.uk;* Asia Woroszyl *Asia.Woroszyl@gstt.nhs.uk*

Appendix M: Case Study: Great Western Hospital, Swindon

Drop in services for patient follow up in sleep medicine	
Organisation	Great Western Hospitals NHS Foundation Trust
Synopsis	Great Western Hospitals NHS Foundation Trust (GWH) has a comprehensive sleep service for 6,000 patients with obstructive sleep apnoea (OSA) and movement disorders. Most of these patients receive continuous positive airway pressure (CPAP) and approximately 170 patients use non-invasive ventilation (NIV). The service is provided by 1.6 FTE specialist nurses, 0.4 FTE respiratory consultant and 0.6 FTE administrative support. Patient are tracked on a patient tracking log provided by Phillips (the main supplier of CPAP machines to this service). For the last 7-8 years, most patients using CPAP are on an “SOS”, or PIFU, programme where once they are established on therapy, they then contact the service for support when they required; rather than having any routine follow up scheduled. Some patients are excluded from this, including those on NIV, those with high-risk occupations such as HGV drivers, and those at risk of health inequality or who may struggle to contact the service. Patients may also choose to have regular follow up. An office-hours telephone service exists for patients to contact for support and leave voicemails. The telephone line is answered by the specialist nursing team, who prioritise clinical urgency and respond to requests within 1 week. Prior to the pandemic, a weekly drop-in service existed for patient to attend without appointment for advice, or equipment. This was well-liked by patients and clinicians; and funded as part of the block-contract the service is on. This still exists in a more limited capacity post-covid, with pre-booking to collect equipment only. GWH also provides community engagement through yearly engagement events where patients and members of the local community are invited to learn more about OSA and CPAP, meet the team, and learn about equipment. This is funded by the department, and there is some contribution from medical suppliers.
Key words	Patient initiated follow up (PIFU); drop in service
Key contact	Name: Samantha Backway, Sleep Specialist Nurse Email address: s.backway @nhs.net
Content	
Background	GWH provides healthcare services for the population of Swindon and the surrounding area. The sleep service is currently managing over 6,000 patients and commences approximately 500 patients on CPAP each year. Sleep services are run from Saturn ward, the respiratory ward, where the sleep team has an office to work from and store equipment. The ward side room where inpatient sleep studies and outpatient reviews were traditionally performed, has been absorbed into inpatient capacity during the ongoing pandemic. Consequently, the service does not have a dedicated outpatient area currently.

The need	There is significant local demand for sleep services. The patient cohort increases by approximately 500 patients per year, and there are currently over 6,000 patients in the service. Due to increasing patient waitlists and patient cohort size, the team recognised that there was a need for service delivery change. Managing the expanding patient cohort with traditional out-patient service methodology of regular face-to-face appointments was unsustainable and not best-use of the finite resource. Therefore, the service adapted to a PIFU model, termed locally "SOS" service. Patients were attending the hospital for support erratically which was disrupting the rest of the service. Therefore, a decision was made to offer a drop-in service.
The solution	The service delivery changes were gradually implemented and were a natural response to the demands on the service. Consequently, there is not a documented timeline for change or SOP. *Appointments* Initially, the service was run traditionally with face-to-face outpatient appointments booked at intervals. The service was overwhelmed with long waits between appointments. Therefore, a PIFU service began to evolve, and patients were encouraged to either telephone the support line, email the service, or attend the weekly Wednesday drop-in service. Both the telephone and drop-in services are run by the specialist nurses. There are additional appointments on Wednesday afternoons for complex issues, both with the speciality nurses (2 slots) and with the respiratory consultant (4 slots). *Funding* The sleep service is funded by block contract currently. Each of the drop-in and telephone appointments are coded as an outpatient consultation. There is an ongoing process to review the block-contract arrangement. *Workforce* The service is run by specialist nurses, with limited administration support. There are no clinical scientists or physiologists within the team. A patient will be referred to the sleep service. They will undergo a sleep study, which is facilitated by the specialist nursing team, and interpreted by the respiratory consultant. Complicated patients are reviewed by the respiratory consultant; most patients with sleep studies confirming OSA will go straight to nurse-initiated CPAP therapy. The service is supported by a weekly volunteer who helps patients navigate the drop-in service and ensures that patients are seen in order of attendance. *Patient education* There is an annual patient engagement event where patients within the service, and members of the local community are invited to meet the team and learn about OSA and CPAP therapies. This model has been replicated at other sites within the region, e.g., Yeovil. The event helps to increase awareness of OSA leads to increased referrals into the service. There is also a website with information for patients: https://www.gwh.nhs.uk/wards-and-services/sleep-service/ *Traditional follow up* Options for traditional follow up exist for patients in high-risk professions, those that have professional DVLA licencing requirements

	and any patients at risk of health inequalities. Any patient can also opt-in for routine follow up, ensuring patient choice.
Costs	The service has a block contract; all patient contacts are coded for. The patient engagement events are funded by department and by the medical equipment representatives.
Challenges	*Clinicians* 3. Ensuring that patients with “high-risk” occupations are managed safely and in line with national guidance – *patients with high-risk occupations, at risk of health inequalities, those struggling with therapy and complex cases are maintained on traditional follow up* 4. Keeping track of large numbers of patients is challenging, particularly if they are not automatically in follow-up – *this was overcome by utilising the medical equipment companies’ patient log to ensure all patients are registered within the service* 5. Ensuring that patients on PIFU get consumables timely if they are not attending hospital for annual appointments – *patients contact the service or attend the drop-in day for equipment* 6. How to ensure that patients do not stop using therapy – *this challenge exists regardless of the follow-up methodology* 7. Physical space – *ensuring that there is enough space for the drop in patients to wait and be seen* 8. Workforce – *high patient:clinician ratios; little capacity within system to accommodate annual leave or staff absences* *Patients* 9. Preference for routine appointments – *small numbers of patients prefer to have routine appointments which is honoured*
Impact	*Benefits for patients include* 10. Bespoke care, as intensive as required, led by the patient 11. Shorter waiting times as more efficient service 12. Patient feedback generally positive 13. Flexibility in decision for PIFU or traditional follow up 14. Security + reassurance provided by weekly drop-in *Benefits for the staff include* 15. Ability to focus on patients who require input *Benefits for the population* 16. Good access to sleep services in area of high prevalence of OSA 17. Ensure safety as close monitoring of those with high-risk occupations
Lessons	*Anticipate additional administration work* PIFU service require accurate patient management systems and proactive administration which takes time.
Next steps, sustainability and scaling	Next steps will be to increase staffing, as currently staff are working at the limit of capacity. Transitioning to new suppliers of medical equipment will also require transition to new patient management systems.
Find out more	Please see GWH sleep services patient website: https://www.gwh.nhs.uk/wards-and-services/sleep-service/

Appendix N: Case Study: Royal Brompton Hospital, London

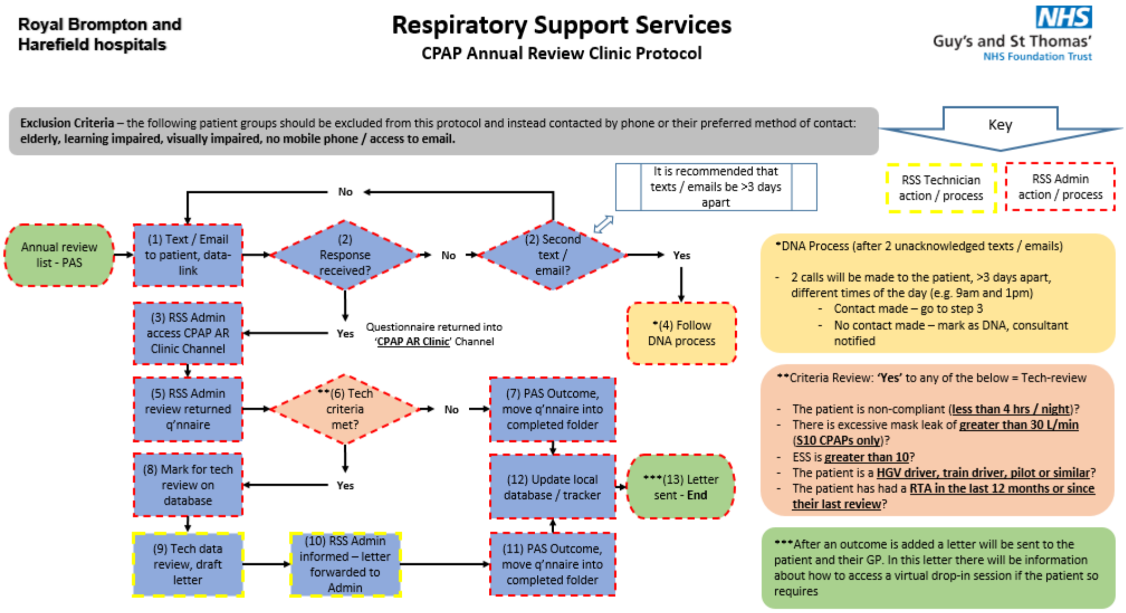
Remote Drop-in Sleep Clinic	
Case study title	Remote Drop-in Sleep Clinic
Organisation	Royal Brompton Hospital
Synopsis	Sleep and Ventilation department at Royal Brompton Hospital (RBH) cares for 2500 patients with a ventilator and 5500 patients on CPAP. To support the Sleep and Ventilation Medical team, an additional department was created: Respiratory Support Services. Respiratory Support Services is Physiologist-led and looks after all patients receiving home ventilation and CPAP therapy, supporting the physician team. Therapy compliance is one of the main challenges for patients on CPAP therapy. Over the years, the department have investigated various ways of engaging patient with therapy and to empower patients to be in control of their own therapy. RBH patients have access to Physiologist Support from Monday to Friday 08:30 until 19:00 via phone and they also have access to support via email. There is one email just for spares – RSS administration lead -, where patients can contact for the supply of spare parts for their own device. If there are any problems with therapy (mask leak, excessive pressure, difficulty tolerating therapy etc), the patient can contact an email supervised by RSS Physiologists. One of the key developments for patients using CPAP therapy, has been the implementation of remote monitoring. This technology has given patients the power of being in control of their own therapy, by having their machine connected to a phone app (MyAir) that lets the patient know when therapy is not optimal and when additional help might be required. At RBH, all new patients to CPAP therapy also receive a link for a weekly virtual clinic, staffed by a sleep and ventilation consultant and a physiologist. This clinic does not require a booking or appointment time and patient can just "drop in" as needed. They can then discuss any technical issues with the physiologist, who can call upon the consultant physician to review the patient, as needed. This review is patient-initiated and runs alongside the physiologist-led CPAP follow up service, which has fixed review intervals. This clinic is still under evaluation, therefore tariff and patient activity tracking is still being developed.
Key words	Patient initiated follow up (PIFU), drop in clinic
Key contact	Name: Vitor Roldao (Sleep Lead) + Nisa Pinto (Chief Sleep Physiologist) Email address: V.Roldao@rbht.nhs.uk; N.Pinto@rbht.nhs.uk
Content	
Background	Royal Brompton & Harefield NHS Foundation Trust is a partnership of two specialist heart and lung hospitals, Royal Brompton Hospital in Chelsea, London, and Harefield Hospital near Uxbridge. Royal Brompton Hospital is under the CCG for North West London but since 1st of February 2021, Royal Brompton & Harefield NHS Foundation Trust merged with Guy's and St Thomas' NHS Foundation Trust and is now a clinical group within that Trust. The RBH Sleep and Ventilation department cares for 2500 patients with a ventilator and 5500 patients on CPAP. It performs complex diagnostics

	and has a comprehensive team comprised of doctors, specialist nurses, clinical physiologists and administration services.
The problem	Until 2016 CPAP compliance was recorded by patients returning their SD card and completing a separate Epworth Sleepiness Scale (ESS) via post. The SD card was then downloaded and added to patient clinical notes; the physiologist then reviewed and reported the results. The main issue with this system, was the fact that SD return was dependent on patients wanting to return it. There was no system in place to control or monitor, if all the patients set up on CPAP were returning SD card and compliant with therapy. Over the years, several audits were conducted with the aim to improve patient compliance and patient access to follow up. The audit performed in 2015, lead to redesigning of the OSA patient care pathway to incorporate a remote monitoring system. Additionally, there was development of more supportive tools for the patients, and improved access to consumables, telephone, and email support. Annual follow up reviews pre-covid involved a Medical Lead Annual Review Clinic, where patients requiring medical input due to other comorbidities and complex management on top of CPAP therapy can attend. There was also a Physiotherapist, Hospital Practitioner and CNS Lead Annual Review Clinic, where patients diagnosed with OSA and no other comorbidities that require medical input. Since covid, there has been an increasing need to transform and adapt the way we could follow up patients in the community. There is a medical team led Annual Review Clinic, aiming to follow up patients requiring medical input due to other comorbidities and complex management on top of CPAP therapy. There was also a Physiologist Lead Annual Review created where a link is sent to the patient to complete an ESS form and to enable download of CPAP compliance data if using old device. This was particularly necessary due to a large backlog of annual reviews, confounded by reduced numbers of sleep physiologists. To help overcome this, a new protocol was instated where the respiratory sleep services administration team triaged the patients. Those patients that were compliant with CPAP (> 4 hours per night) and did not have mask leak (< 30 L/min) and did not have symptoms (ESS < 10) were automatically sent a letter to the GP communicating the patient compliance. Those that did not fulfil these criteria were passed on for Physiologist review.
The solution	Once a patient is diagnosed with Obstructive Sleep Apnoea (OSA), they are offered a 90 day trial of CPAP therapy, supervised by physiologists. During this time, the physiologist will try to address any problems with therapy, offer interventions and face-to- face appointment with patient, if required. Because of covid, video appointments are also offered to patients. During these 90 days, if patient still non-compliant or not tolerating therapy, patient is referred to the medical team. The 90 days trial comprises of the following pathway: 1. Patient contacted within the first 2 weeks (phone call and letter sent to patient and GP).

	2. If patient struggling at 4 weeks, physiologist to contact patient but if doing well compliance downloaded to EPR but no contact required. 3. At 90 days a decision is made if patient to continue CPAP therapy 4. If patient compliant, letter sent to patient and GP to communicate that patient successfully completed 90 days trial and we will review patient at 12 months. 5. Every patient, that successfully completes a 90 day trial is then reviewed every 12 months by Medical Lead Annual Review Clinic or Physiologist Lead Annual Review. When the patient is set up face to face or via video call, they are given a link to connect to Wednesday Drop-in Clinic. This was created to reassure patients that despite the covid pandemic and limited face-to-face appointments available, there is a channel where they can benefit from a joint review from medical team and a physiologist as required. Patient can join this meeting between 14:00 – 17:00. When patient logs in via a link they are admitted into Physiology area. Most commonly, they see the physiologist first and then if medical input is required, patient is transferred on to the consultant. In the eventuality of patient not having a smart phone/ computer or not feeling very comfortable with technology, patients are advised to contact the physiologist team. The request is then triaged and determined whether the patient needs to see the consultant and whether an OPD face-to- face appointment is required.
Costs	There is not a tariff in place or clinical code associated with Drop-in Clinic. Any activity will need to be extracted from Attend Anywhere. There is work in progress to develop a clinical code and tariff in order to track and be reimbursed for this activity.
Challenges	Clinicians point of view: 1. Patient feedback is positive because they have a consultant available to see within a specific time frame 2. So far, the number of patients attending the clinic is not excessive and medical team able to manage the influx of patients 3. The clinic is job-planned into the consultant timetable 4. Physiologists report as a very good platform to troubleshoot and help patients in achieve good therapy control Patient feedback: 1. Ability to be seen by consultant without having to make an appointment 2. Ability to see a physiologist without having to wait for a reply to email or spending time on the phone 3. Patients feels in control of their own therapy 4. Waiting timings is variable – anecdotally the wait is usually up to 15 minutes
Impact	There is not enough information yet to comment on the efficiency and productivity of this clinic. A new code is being developed to track the clinic work. Patients will be tracked on spreadsheets by clinicians and administration support. Outpatients Administration team are taking

	ownership of this clinic and will report patient attendance to this service and waiting times.
Lessons	Organically grown services such as the drop-in service can be developed without the accompanying coding and tracking processes, as discovered when writing this case-study.
Next steps, sustainability and scaling	An audit will be conducted to assess patient feedback, number of patients attending this service and issues reported by staff and patients. There will be ongoing discussions of the numbers of patients attending and the staffing requirements to facilitate the service.
Further information	Appendix Na: Respiratory support services – physiologist led annual reviews

Appendix Na: Respiratory support services – physiologist led annual reviews



Royal Brompton and
Harefield hospitals

Respiratory Support Services
CPAP Annual Review Clinic Protocol

Guy's and St Thomas'
NHS Foundation Trust

Exclusion Criteria – the following patient groups should be excluded from this protocol and instead contacted by phone or their preferred method of contact: **elderly, learning impaired, visually impaired, no mobile phone / access to email.**

It is recommended that texts / emails be >3 days apart

*DNA Process (after 2 unacknowledged texts / emails)

- 2 calls will be made to the patient, >3 days apart, different times of the day (e.g. 9am and 1pm)
  - Contact made – go to step 3
  - No contact made – mark as DNA, consultant notified

Criteria Review: **'Yes' to any of the below = Tech-review

- The patient is non-compliant (**less than 4 hrs / night**)?
- There is excessive mask leak of **greater than 30 L/min (S10 CPAPs only)**?
- ESS is **greater than 10**?
- The patient is a **HGV driver, train driver, pilot or similar**?
- The patient has had a **RTA in the last 12 months or since their last review**?

***After an outcome is added a letter will be sent to the patient and their GP. In this letter there will be information about how to access a virtual drop-in session if the patient so requires

Appendix O: Case Study: Papworth Hospital, Cambridge

Community Outreach and GP Oximetry sleep service	
Organisation	Royal Papworth Hospital
Synopsis	The Respiratory Support and Sleep Centre (RSSC) starts 1500 patients on CPAP p.a. Over 13,000 CPAP users are supported in the community. The number increases by 9% a year. The RSSC is committed to long term follow up of CPAP users. In order to manage growing demand and to provide more local access to patients across a large area we developed community based models of care. These include a network of 7 Outreach clinics and 13 'hub' G.P. surgeries through which we have been offering diagnostic studies. New Outreach patients (mostly suspected OSA) are assessed by senior Drs. Follow-up is by Dr or CPAP practitioner. Oximeters distributed at outreach venues by couriers in the week before clinics. Oximetry is inexpensive and robust with acceptable levels of sensitivity and specificity to act as a screening test. The patients took them home and returned with them on the day of clinic for data download. We repeat oximetry or escalate to more complex diagnostics as required. The G.P. practices held a stock of one or two oximeters which go to and from the patients' homes and are returned to the practice for download. Covid obliged us to adapt this service – see below.
Key contact	Name: Tim Quinnell Email address: tim.quinnell@nhs.net
Content	
Background	1. See synopsis 2. Initially involved new (suspected) and review (treated) OSA patients *3.* The lead organisation managed this, sourcing venues from local organisations.
The problem	Our referral base covered a large area including many rural communities. Patients living further away had to travel far for appointments, sometimes sequential days for home sleep studies. Others living even further afield had to be admitted or would stay in a B&B near RPH to undertake sleep studies before attending clinic. Our CPAP follow up population was growing and facilities at RPH were reaching capacity.
The solution	1. Conceived, developed and implemented at business unit level with higher managerial support. 2. Referral patterns and locations of more distant concentrations of follow-up patients were considered when identifying areas to cover and sourcing venues. Venues (e.g. rooms in community hospitals) were secured through contracting with local organisations. 3. Candidate Hub GPs were approached. Those who would be engaged were provided with oximeters, IT etc. and training given. 4. Patients were identified from those referred to the RPH sleep service and matched to Outreach or RPH clinic by postcode and clinical details (complex cases came to RPH).

	5. Hub GPs and neighbouring practices had direct access to ‘GP oximetry’. The data were transferred to Papworth for interpretation along with completed sleep questionnaires. Next steps: discharged with advice to GP; sleep clinic appt e.g. to discuss CPAP; escalation to more complex diagnostic. 6. The clinical team adjusted their working patterns to include outreach clinics and over time the team expanded. 7. Staff received travel assistance – pool cars/fuel reimbursement 8. Couriers delivered oximeters and were trained to hand them out to patients with simple instructions. Couriers also transported hardware on clinic days (CPAP kit, IT incl. for study download, patient notes etc.). Their duties evolved to reflect process changes at RPH.
Costs	Venue hire and courier costs. Travel for staff. IT for study download and later connectivity with RPH. Oximeters and in-house IT solution for GP oximetry
Challenges	*Clinicians:* Adjusting working patterns to be offsite once or twice a month. Occasionally having to manage unexpectedly complex outreach cases with limited resources. Shorter effective working day due to length of commute. Whole day clinics. Specific venue limitations (e.g. aged facilities/parking/venue access). Some staff needed co-worker present – lone working policy. Hub engagement, reliability and testing thresholds varied. *Patients:* Locating venues. Specific venue limitations (e.g. parking, access).
Impact	*Patients:* Benefits of reduced travel/time commitments and fewer overnight stays. Fairer geographical access to sleep apnoea service. In 2016-17 around 18% of RPH oximetry studies were carried out through outreach clinics. 11% were via GP hubs. Increased and more local access improved waiting times for new patients and strengthened follow-up. *Staff:* Advent of electronic medical records facilitated pre-Covid development of remote working for RPH. Transition to fully remote teleclinics (incl. WFH) during Covid required less adaptation. *Unintended consequences:* Unrelated imposition of centralised appointments booking system, combined with new PAS system and loss of key RSSC admin staff at time of hospital move in 2019, exposed system vulnerabilities and waiting list backlog developed, subsequently exacerbated by Covid. Matching of patients to venues started failing and travel for both couriers and patients developed inefficiencies confirmed by big data analysis. Covid led to all outpatient services being suspended. It hasn’t yet been possible to reopen outreach venues due to infection control challenges. Outreach clinics continue to be run as teleconsults for now. This has catalysed the development of a postal oximetry service which has shown promise at pilot stage and is being extended. Big data analysis of travel distances to RPH and community venues yielded unexpected information

	related to social deprivation that provided further impetus for development of postal service to support ongoing teleclinics, while considering further research and educational programmes. Our service's established outreach programme made it vulnerable to being squeezed out of lead organisation facilities when available clinic capacity shrunk with move to new hospital site.
Lessons	Reliable, robust and responsive bookings process essential. Staff engagement key to success and sustainability. They needed to accept and embrace new challenges of travel and navigating limitations of local venues. Quality of outreach team must be equal to that of parent organisation. Importance of rotation, CPD, mentorship etc. Reliable and high level IT functionality vital. When this performed poorly or occasionally failed, outreach clinics became dysfunctional and unpleasant for patients and staff. Venue selection needs to be rigorous. As minimum aim for facilities and access to be on par with parent organisation, even if clinical toolkit is streamlined, or there will be a risk of patients feeling neglected. Our experience is that patients appreciated RPH coming to them, but not at expense of quality of care/experience. They often prefer to travel further (eg to lead organisation) if their local experience is poor (facilities/logistics/clinical care) and when they perceive better care is available at lead organisation. Having access to full range of sleep diagnostics at lead organisation was essential to the success of community programme. ***What is the single most important one line of advice which you can give to others starting a similar project?*** Keep things simple at first and build in strong links with parent organisation. OSA well suited to this care model.
Next steps, sustainability and scaling	Outreach was sustained for several years. Capacity became more challenging as CPAP follow-up population grew. Remote, partly patient initiated web based solutions being sought for stable long term patients. Postal oximetry service being developed. Reduction in follow-up sleep studies with greater reliance on machine downloads. We have continued to restrict CPAP implementation to lead organisation but this may be subject to review in future.

Appendix P: Case Study: Royal Free Hospital, London

Sleep Pathway at Royal Free Hospitals	
Organisation	Royal Free London NHS Foundation Trust
Synopsis	The Royal Free hospitals developed an integrated community-based pathway for the diagnosis of OSA. This comprised of a monthly clinic run from within a local general practice supported by a 'virtual multidisciplinary team' run by the hospital specialist team. The service led to quicker diagnosis and management of OSA and had very positive patient feedback. This work has been published and the link to the full paper is below.
Key words	Integrated care Sleep medicine Sleep pathway
Key contact	Name: Dr Swapna Mandal Email address: swapnamandal@nhs.net
Content	
Background	The Royal Free London NHS Foundation Trust (RFLNFT) comprises of three sites: The Royal Free, Banet and Chase Farm hospitals. The service has a relatively new sleep service, ran by one consultant, and several physiologists (3.0 WTE band 7, 0.37 WTE band 8 and 1.5WTE band 4). There is limited administration support. The service manages 3000 patients on CPAP and almost 400 on ventilation. There is also a twice weekly MDT.
The problem	The specialist sleep and ventilation service at RFLNFT receives in the region of 1500 referrals annually for suspected OSA and also provides care for patients across the spectrum of sleep disordered breathing. The service was becoming overwhelmed with referrals and consequently there were lengthening wait for both diagnostics and treatment starts.
The solution	Within one of the catchment boroughs, Camden, primary care worked in collaborative groups based on their geographical location. A 'hub and spoke model' was used to establish a monthly community outreach OSA clinic within a centrally located 'hub' GP practice. This clinic received referrals for patients with suspected OSA directly from other neighbourhood GP practices (the 'spokes'). This clinic was staffed by a sleep and ventilation clinical fellow and consisted of a half-day session with capacity to review eight patients. To refer a patient, GPs based at any of the other 'spoke' practices within the neighbourhood were required to complete an electronic referral proforma which collected basic patient data as well as a pre-test probability score (STOP-BANG) and an assessment of somnolence (Epworth Sleepiness Scale). This form was embedded within the practice electronic healthcare portal and once completed, was sent via a dedicated confidential NHS mail account to the sleep and ventilation team. Referrals were screened by the sleep and ventilation clinical fellow and those with a STOP-BANG ≥3 were accepted and subsequently allocated to an appropriate clinic appointment at the hub practice. Patients with impaired mobility (who would normally require hospital-provided transport to attend appointments) and those who required externally

	provided translation services were excluded from this pathway and instead booked into a regular hospital appointment. At the outreach clinic, patient had a brief consultation before being issued with equipment for a home sleep study. Patients were assessed for somnolence and non-respiratory sleep disorders using a questionnaire. Once the devices and questionnaires had been returned to the hub practice, they were reviewed within a virtual MDT meeting run by the specialist sleep and ventilation team based at RLHNFT. The final diagnosis, suggested management and follow-up arrangements, were then communicated directly to the patient and their registered GP. Those patients requiring treatment or further review were automatically scheduled to attend a secondary care clinic. Of all of the sleep studies performed, 31% were diagnosed with moderate or severe OSA or a hypoventilation syndrome. 24% had mild OSA and those with a significant symptom burden had further follow up in secondary care. 43% had a sleep study that demonstrated snoring or partial airflow compromise or was normal. These patients were discharged to ongoing GP care.
Costs	From referral to diagnosis made, the community OSA pathway incurred an average estimated overall cost per patient of £442.31 representing a significant cost-saving when compared with £732.81 for the hospital-based pathway.
Challenges	The service was ceased due to pressures related to the covid pandemic.
Impact	1. Reduced time from referral to diagnosis – the hospital pathway involves on average 2 clinic appointments and a >32 week wait, compared to 6 weeks in the community pathway 2. Community clinic DNA rate reduced compared to hospital DNA rate (23% v 33%) 3. Significantly higher patient satisfaction community v hospital pathway 4. GP preference for community-based diagnostic approach due to convenient, responsiveness, enhanced relationship between secondary care and primary care providers 5. Improved confidence in, and awareness of, sleep medicine within primary care
Lessons	6. A community based approach can result in significant reductions in waiting times, is favoured by patients and clinicians, and has the potential to achieve considerable cost-savings 7. Additional time resource will be required initially when setting up services such as these 8. The community outreach pathway was instituted within a borough with pre-existing strong collaborative working practices between constituent GPs. This method of working might have contributed to the successful outcomes of this pathway and might not have been observed to the same extent if the pathway was introduced in an alternative borough. 9. The team enjoyed the opportunity to work within and alongside primary care as well as secondary care
Next steps, sustainability and scaling	10. Hope to re-start the service once post-covid recovery established 11. Extend reach of the clinic beyond general practice such that referral to the pathway can be made by allied HCPs working

	within relevant community settings such as weight management services, dietetic and therapy department 12. Hub clinics to be run by an experienced band 7 HCP with adequate training in the provision of sleep medicine care and diagnostics, rather than clinical fellow
More information	Nikesh Devani, Tom Aslan, Fiona Leske, Stephanie K Mansell, Sarah Morgan, Swapna Mandal - Integrated diagnostic pathway for patients referred with suspected OSA: a model for collaboration across the primary–secondary care interface: BMJ Open Respiratory Research 2020;7:e000743. Appendix Pa: GP referral form

Appendix Pa: GP Referral to Adult Sleep Clinic Royal Free London NHS Trust

Patient Information:

Surname		**NHS Number**	
First Name		**MRN (if available)**	
D.O.B	Click here to enter a date.	**Date of referral**	Click here to enter a date.
Address			

Screening questions: ***(please answer yes or no to the following questions)***

Does the patient snore loudly?	Choose an item.	
Does the patient feel tired or sleepy during the day?	Choose an item.	
Has anyone observed the patient stop breathing during their sleep?	Choose an item.	
Is the patient being treated for hypertension?	Choose an item.	
BMI >35kg/m^2?	Choose an item.	**Actual BMI:**
Age >50 years old?	Choose an item.	
Neck circumference> 16 inches (40cm)?	Choose an item.	
Male Gender?	Choose an item.	

Epworth Sleepiness Score:

How likely is the patient likely to doze off or fall asleep in the following situations, in comparison to feeling just tired?

Use the following scale to choose the most appropriate number for each situation:

0 = would never doze

1 = slight chance of dozing

2 = moderate chance of dozing

3 = high chance of dozing

Situation	**Chance of dozing (0=low, 3=high)**
Sitting and reading	Choose an item.
Watching TV	Choose an item.
Sitting still in a public place (e.g. theatre, cinema or a meeting	Choose an item.
As a passenger in a car for an hour without a break	Choose an item.
Lying down to rest in the afternoon when the circumstances allow	Choose an item.
Sitting and talking to someone	Choose an item.
Sitting quietly after lunch without having drunk alcohol	Choose an item.
In a car or bus while stopped for a few minutes in traffic	Choose an item.
TOTAL	

Is the patient currently being investigated or treated for any of the following conditions? ***(please answer yes or no)***

Ischaemic heart disease?	Choose an item.
Diabetes mellitus?	Choose an item.
Atrial fibrillation?	Choose an item.
Hypothyroidism?	Choose an item.
Cerebrovascular disease?	Choose an item.
Is the patient an occupational driver?	Choose an item.

Please attach a list of medication and current co-morbidities. Thank you

Appendix Q: Case Study: Royal Hospital, Salford

Referral and triage pathways	
Organisation	Salford Care Organisation, Northern Care Alliance NHS Foundation Trust
Synopsis	Salford Care Organisation has a busy sleep service which has adapted to manage the patient volume through a variety of means.
Key words	*Referrals, Triage*
Key contact	Name: Dr Vicky Cooper, principle clinical scientist Email address: Vicky.cooper@nca.nhs.uk
Content	
Background	Salford has a busy sleep service, performing approximately 1400 sleep studies per year. Less than 40% of referrals are from primary care, with bariatric surgery (11%), other pre-op assessments (12%) and neurology (15%) taking up the majority share of referrals. The service is delivered as an MDT approach with 2 respiratory consultants, who contribute to the service as part of busy job plans, a neurologist and two neuropsychiatrists. There has been a recent increase in non-medical staffing with the development of an acute NIV outreach service. The staff now consists of 1 clinical scientist, 1 highly specialist physiologist, 2 respiratory nurse specialists, 1 specialist physiotherapist, 1 assistant practitioner, 1 clinical support worker (CSW) and full-time secretary. There is a regular MDT with the respiratory consultants to discuss patients. There are weekly mini MDT meetings for junior staff to discuss patients with senior staff. The service completes 20-30 sleep studies per week. There is capacity to start 11 patients per week on CPAP. Consultant access is limited and associated with significant waits. There are currently 2000 patients on various modes of CPAP with approximately 25 on ASV.
The problem	The adaptations to the service have happened over time due to the rising patient numbers, new technology and the pandemic.
The solution	**Referral** To manage the large numbers of referral coming into the service, a referral proforma was introduced to enable more effective triage. The referral proforma contains both free text and medication. The primary care triage is performed by the lead consultant. She will request a home sleep study for the majority of patients. This will be with or without limb leads dependent on whether there is a history suggestive of restless legs/ periodic limb movement disorder. **OSA pathway** When investigating for OSA the patient undergoes a sleep study which is then reported by the clinical scientist, highly specialist physiologist or specialist nurse who will triage the patient at this point. If the result is positive, then the patient will go on to have a telephone assessment clinic appointment with the same level of staff who report the studies (band 7 and 8A). This clinic is currently a sticking point in the pathway, although much less so than consultant appointments. If the sleep study is negative, mild or complex, the patient will have an appointment with the consultant (GP referrals). Negative studies from secondary care referrals will be returned to the referrer. A results letter is sent to the GP informing them if the patient is to be reviewed in clinic and/or giving advice where CPAP is felt not appropriate but there is some sleep disordered breathing and

	also advising to re-refer if there are more significant symptoms. This triage is enabled by the use of a questionnaire completed at the time of the sleep study and the referral proforma which helps exclude non-respiratory sleep conditions; and identify those who are excessively sleepy compared to the sleep study result who need to see the sleep consultant. For patients that do not tolerate CPAP, where appropriate, patients are referred onto Manchester Royal for consideration of MAD. There is currently work under way for an additional service with the dental hospital. During the pandemic many CPAP were set up via a video link. However, there is a move back to increase more face-to-face set-ups due to issues with patient engagement on remote calls e.g. taking the call when in the supermarket, car or in bed and with network / video issues. Follow-up of CPAP trial patients has been done by telephone clinic with remote data since this was available in 2015. Prior to the pandemic there was also a weekly drop-in clinic for problem solving that could not be done by phone. The drop-in clinic has been suspended since the pandemic but patients can be seen face to face on and ad-hoc basis where problems cannot be solved remotely. All CPAP patients are reviewed annually. Since the pandemic this has been via telephone with either remote data from modems or with patients sending in their memory cards which are then returned by post along with new masks, filters etc. Once the Philips replacement program commences there are plans to reintroduce face to face annual reviews with a blended approach moving forward. More complex patients will be seen face to face annually, whereas more routine patients will alternate between a telephone review one year and face to face the next. **Non respiratory sleep** Whilst the respiratory consultants do manage some patients with non-respiratory disorders such as narcolepsy and PLMD, the majority of non-respiratory disorders are managed by a neurologist and 2 neuro psychiatrists. Prior to the pandemic, once a month all of these consultants would have clinics on the same day in the same location so that they could call on each other's expertise where needed. The clinical scientist, physiologist and specialist nurse would also be in clinic doing annual reviews at this time and were available for help and guidance to the consultants. However, these clinics are now being done via telephone and therefore where other expert help is needed this requires referral onwards outside of the clinic time. **Patient initiated follow up** All patients are routinely followed up on an annual basis but in between these reviews patients can initiate their own follow-up (PIFU). Prior to the pandemic, patients had access to a weekly drop-in clinic. This enabled troubleshooting of machine issues and clinical review. This has changed to a telephone service during the pandemic. There are plans to reinstate the clinic but with a different approach where patients will need to call and book. The clinic they are booked to will depend on the nature of their issue – mask fitting problems will be seen by the support worker, whereas clinical problems will be dealt with by clinical staff. The patients can access the team via email and telephone as well as the drop- in clinic. A band 2 CSW supports this service by sending out consumables and

	triaging calls to the service. She will also collect and deliver equipment when required. **Patient Experience** Patients are given information on accessing the service by leaflets provided with their new patient set-up. There are also reminders on all clinic letters. This includes telephone and email contact details. Some patients experience language barriers, therefore an interpreter line is used frequently. The service currently has one patient that uses sign language and therefore where issues cannot be sorted via email a sign language interpreter is used and the patient is seen face to face. Institutionalised patients, such as those in hospital for mental health, can face challenges in being contacted remotely. Patients have provided feedback – 90% of patients feel that they have sufficient support with PIFU and annual review.
Costs	Pre-covid the service ran on payment by results and due to efficient coding services linked to electronic patient records was financially satisfactory. This has now been changed to block contract which has resulted in income reduction with no change in patient care.
Challenges	As above, some patients struggle to engage in the service, such as those with mental health conditions who are institutionalised; or those with language barriers. A transition to remote working resulted in huge increases in administration. Appointment of a band 2 clinical support worker and a band 4 assistant practitioner has ensured that more senior physiologists are freed up to be able to perform more complex tasks.
Impact	As above, 90% patient satisfaction with the service.
Lessons	A move to virtual clinics and remote healthcare resulted in an increased need for administration support.
Next steps, sustainability and scaling	1. Re-introduction of face-to-face clinics, as the pandemic allows 2. New PIFU pre-triaged “drop-in” clinic 3. Increase capacity of the assessment clinic

Appendix R: Case Study: Newcastle Neurological Sleep Service

Patient Initiated Follow Up in Sleep Disorders	
Organisation	Newcastle Upon Tyne Hospitals NHS Foundation Trust
Synopsis	Newcastle Upon Type Hospitals NHS Foundation Trust (NUTH) treats patients within Newcastle and the North East. Within the neurology department, there are multiple examples of patient initiated follow up (PIFU) used to manage patients with sleep conditions. These examples have been developed locally in response to wait-list lengths and a need for more personalised care.
Key words	Patient Initiated Follow Up (PIFU) Neurology
Key contact	Name: Dr Kirstie Anderson Email address: kirstieanderson@nhs.net
Content	
Background	The neurology-led sleep service at NUTHFT consists of 2 consultant neurology physicians, trainee (registrar level) physicians, prescribing pharmacists, specialist nurses and sleep technicians. Within the neurology service, there are many conditions where patients are commenced on medications that are prescribed by secondary care. Historically this would have led to multiple routine outpatient appointments. Recognising the demand on the service for these routine appointments, the service adapted to offer “opt-in” follow up; a form of PIFU.
The problem	The sleep medicine department at NUTHFT was struggling with large patient numbers and delays scheduling follow-up appointments. There was a need to remove routine follow up appointments that were not clinically required.
The solution	Within the neurology department, there are multiple examples of PIFU. **Narcolepsy** Stimulants can be prescribed for narcolepsy but are contraindicated during pregnancy. Women of child-bearing age must stop the medication as soon as they intend to conceive. Patients follow-up is therefore paused at this point whilst they conceive, carry and deliver the baby. Once they are postnatally wishing to be re-started on medication, they are advised to contact the service. The service then offered advice for re-starting to the general practitioner. The patient is then booked into an appointments 4 weeks after recommencing the medication for review. The patients can contact the service directly for support at any stage, for example with employment issues. **Insomnia** Patents have an initial appointment and are then referred for 6 weeks therapy for treatment of insomnia. Most patients are discharged following this therapy however all patients are provided contact details for the service and can book back in if they have a relapse in the future without having to go via the GP again. **REM sleep behaviour disorder** Patients on treatment for REM sleep behaviour disorder remain on annual review. However, between these appointments, if they have

	any issues or deterioration in symptoms such as memory or movement issues, they can initiate an appointment, enabling personalised care. **Parasomnia** Patients with parasomnias often experience erratic symptoms. Therefore, following diagnosis, patients are encouraged to get home videos of any symptoms. Patients then email the video to the service which is reviewed at any stage without an appointment.
Costs	Financially, the reduction in unnecessary routine appointments results in cost saving. There is no change to the structure or number of support staff required to deliver the service.
Challenges	**Avoiding health inequalities** It is a priority for the service to avoid exacerbating health inequalities. This includes patients such as those experiencing digital exclusion, those who are vulnerable for example those with severe and enduring mental health problems, or those who are avoidant of healthcare. To overcome this challenge, the service has comprehensive patient databases to ensure that all patients within the service are logged. The service then has an annual "sweep" of the patient lists to look for any patients that make have stopped engaging with the service. **Urgent appointment requirements** The service must be able to accommodate urgent patient appointments, for example those who unexpectedly fall pregnant and therefore need to be seen urgently to manage medication changes.
Impact	**Population health outcomes** Benefits on a patient population health level are that there is more capacity created within the system, so that patients can access sleep services more quickly. **Health inequalities** There is a risk that there could be exacerbation of health inequalities therefore the service has a comprehensive patient database and an annual "sweep" to ensure that there are no patients being excluded from the service, which mitigates the risks to health inequalities. **Patient safety** Patient safety is maintained through the safety nets previously described. Anecdotally, the process of putting the responsibility of patients has had a positive impact on patient safety – for example, patients on teratogenic medications are advised that they should speak with the service to arrange coming off the medication before becoming pregnant. The patients are repetitively reminded of this, which has flagged the importance of this to patients and led to greater patient awareness and empowerment. The "sweep" ensures that patients with legal requirements to the DVLA are adherent. **Pharmacy** Interval data on patients who were dispensed sleep medications is provided to the treating team. This enables a further safety net to ensure that patients are being managed safely. High workload also led to the diversification of the workforce by appointing prescribing pharmacists to the team to help manage patients established on therapy.

	Patient experience Patient benefits include personalised care, and the ability to see support when required, rather than attending unnecessary routine appointments. **Clinician experience** Clinicians find the flexibility in management helpful, particularly for sporadic conditions such as parasomnias.
Lessons	**Administration** Maintaining a stable level of administrative support is key to facilitating the service to run in such a way. **Patient database** It is essential to have a complete log of patients and that it is possible to log and document accurately the commencement of therapies. **Pharmacy data** Pharmacy reporting data can be very helpful and robust way to monitor the service. Pharmacy data already exists therefore this should not require much time to export and use. **National guidance** Lack of national guidance has led to development of SOPs which is essential with expanding staffing numbers.
Next steps, sustainability, and scaling	**Prescribing** Many medications in sleep services are off-licence. There is growing resistance within primary care to initiate medications that are off-licence. Locally, there are ongoing negotiations and plans to streamline this and improve patient experience. Currently, the service initiates a trial of off-licence medications for patients, alongside lifestyle advice. The patient is advised to contact the service if the medication if effective. If the patient contacts the service, then shared decision making processes occur and the patient's GP is requested to reinitiate the medication. This reduces the number of requests to GPs, prioritising those who find the treatment effective; and GPs are not left to determine whether the medication should be continued or not. **Patient empowerment** Monitoring for the development of hypertension in patients on stimulant medications is required. There are no guidelines guiding how this should be performed; but there are well established hypertension guidelines. Therefore, the service is beginning to trial self-monitoring of blood pressure amongst patients on stimulants. Patients are prompted to get their own blood pressure monitor and then contact the service should their blood pressure become raised. The service is hoping to expand this to more patients.

Appendix S: Case Study: Liverpool Sleep Service

Implementation of a Computer Guided Consultation (intelligent clinical decision support system software) in the Liverpool Sleep Service: the creation of a digital ecosystem to transform patient pathways	
Organisation	Liverpool Sleep and Ventilation Centre, Liverpool University Foundation Hospital Trust
Synopsis	The Liverpool Sleep Centre provides secondary/tertiary level care for a range of sleep disorders. An increasing volume of referrals and the impact of Covid threatened to overwhelm the service resulting in increasing clinical risk and decreased patient satisfaction. We describe how the use of technology addressed these challenges through the implementation of Computer Guided Consultation system i.e. clinical decision support software (CDSS). The CDSS is a digital ecosystem comprising multiple intelligent consultations encompassing the entire sleep pathway including assessment and diagnosis, CPAP set up, monitoring on CPAP and issuing consumables thus acting as an end to end system solution and an Electronic Patient Record. The CDSS also features a "clinical dashboard" allowing the service to track activity, monitor RTT performance and identify high risk patients e.g. sleepy drivers, hypoventilation in real time. The implementation of an intelligent Computer Guided Consultation system has resulted in pathway transformation enabling scarce Consultant resource to be channelled to where it is most required and enhancing service capacity, efficiency and patient safety. Adopting the system results in multi-level health economic benefits and facilitates greater service oversight.
Key words	*Pathway, risk management, outpatients*
Key contact	Name: Sonya Craig Email address: sonya.craig@liverpoolft.nhs.uk
Content	
Background	Liverpool Sleep Centre provides secondary and tertiary care for Liverpool and a large part of the North West. We are the second busiest centre in terms of Sleep studies and referrals (GIRFT data) and have the largest cohort of Narcolepsy patients in the North West. Liverpool has the top two most deprived areas in the UK and a huge demand for Respiratory and non- Respiratory sleep services due to the combination of obesity, social deprivation and mental health problems. Prior to COVID our service was in crisis due to long wait times and referrals increasing from 1400 per year in 2012 to over 5000 per year in 2019. Since 2015, a group of the Sleep consultants have partnered with a company, Lunghealth to develop a clinical decision support system for Sleep medicine. This company had already developed a similar product for Asthma and COPD which is used in primary care to allow NICE guidance to be followed when patients are reviewed by primary care nurses. Our original thought was to develop this for primary care to allow Sleep diagnostics to take place in primary care.

	We have validated the product against expert clinicians and confirmed that it performs at least as well as a Sleep physician even when the reviewer has no Sleep experience.
The problem	The main concern in our service was safety of our patients who were awaiting review and the inability to prioritise patients except by consultant review. We also had no single database as information was spread over a number of systems leading to inefficiencies and no way of monitoring performance or auditing our service. Previously, all referrals to the sleep service were vetted, underwent a sleep study and the results of which together with the information contained in the referral letter were reviewed by a Consultant in a Virtual clinic with treatment decisions made in such clinics. In order to meet this demand, the service required 5 Consultant Virtual clinics consisting of 20 patients each. Since March 1st to June 2021 following CDSS implementation, 325 patients with suspected OSA were assessed by paramedical staff using the CDSS. Only 15% of these patients subsequently required a Consultant review either in a Virtual or a Face to Face manner (translating into just 0.5 clinics weekly). The clinical dashboard is used to highlight difficult cases for a weekly MDT and to filter patients with hypoventilation into more intense follow up clinics. The CDSS generates automated clinical letters for each review thus greatly reducing secretarial time/costs for the service as no typing is required.
The solution	Due to long waits in the diagnostic service in the North West a number of inexperienced services had been started which had led to instances of hypoventilation being missed and poor quality care. Whilst we knew we could give better care it was clear that we would either require many more staff (and there were a number of vacancies that we were struggling to fill) or we had to change the way we delivered our pathway. At this point one of our consultants was helping develop a CDSS in Asthma and COPD for use in primary care which was very successful. The consultants and company Lunghealth were primarily interested in ensuring safe, consistent and guideline driven Asthma care within primary care. This model is now used in a number of PCNs and is very successful. From 2015- 2019 we developed the algorithms for Sleep and initial testing was carried out to validate that the software worked when used by a Sleep physician compared to normal care. We then compared its performance compared to an expert when used by a nonspecialist. The software was concordant with the final diagnosis in 95% and 93% in the two cohorts respectively and where there was doubt prompted clinical review. No cases of OSAS were overlooked. (Chakrabarti et al ERJ Open Research 2020 6:00362-2019; DOI 10.1183/23120541.0032-2019) In 2018-19 we used a test programme for patients presenting to our service when doing home studies to ensure that any software glitches could be ironed out prior to full launch. This was ready by end of 2019 but procurement was delayed due to the onset of COVID. Due to COVID the need for a digital solution was even more urgent so the CDSS was procured by Aintree (LUHFT) in Jan 2021 and installed at the beginning of March 2021. We have regular meetings with the software engineer and clinical coordinator and all staff were trained in its use prior to the start date.

Costs	The cost of hosting and software engineer is £80,000. No additional staff are required and there are savings in terms of consultant and secretarial time. The initial consultation alongside giving out diagnostic equipment (e.g. Apnoea link or Watchpat) takes 15-20 minutes and is currently face to face. This could be carried out remotely prior to the diagnostic test pick up and could easily be carried out by practice nurses prior to referral to secondary care.
Challenges	*1. The clinician's point of view* The development of the software has been long and time consuming. All work on the software by the clinicians has been unpaid and performed out of hours. It has taken many months to convince our hospital that investing in alternative pathways rather than paying for waiting list initiative clinics is a good idea. However, having a searchable database, a clinical dashboard with overview of patients and a specialist Sleep EPR is already paying dividends. Our staff are better educated as they are learning how to take a proper sleep history and the data and information that we have on our patients is very valuable for research and audit. We have already shown that insomnia is extremely prevalent in our population despite the fact that we don't have a formal insomnia service. We are able to pick out sleepy drivers or those patients with RLS or hypoventilation and can track how the service is performing each week. 2. Patient's point of view We aim to carry a patient experience survey of the software but prior to COVID we engaged with a patient representative and presented it to her as she was frustrated by the old pathway and lack of information. She is very positive about it and informal feedback from our patients is very positive as they have a very structured interview which is educational and explains to the patient why they may have their symptoms even before diagnosis. All patients are asked to consent to us holding their data on the Aintree server and its anonymised use for research. We can email patients directly with their full sleep study and report if they wish and we hope to give patients their own hand held notes (similar to maternity services) to improve patient education and empowerment. Patients generally like answering the questions and we have not had any refuse so far.
Impact	We have been able to reduce the number of virtual review clinics at the start of our pathway (post diagnostic test) by 85%. This is approximately 4 PA per week of consultant time. In addition consultants will only review patients with complex sleep problems or hypoventilation and most patients will be reviewed by physiologists and not require further review if there are no alerts from the software or physiology team. Safety has improved as we have greater visibility of our patients and we can track them through the pathway. We can download the whole database into excel or SPSS and audit our performance as well as checking for demographics and any trends. We have already reported that the most deprived areas tend to have poorest compliance for CPAP so this group could be highlighted for more intensive review to reduce health inequalities in our system. Our staff like using the software and have told me that they feel they are getting training in Sleep medicine as they can now take a very detailed Sleep history and the software helps alert them to abnormalities. We have had a number of medical students through the service who have also used it very

	effectively. We feel that primary care would be able to use this software very rapidly with initial training and would soon feel confident using this. The software has improved efficiencies in CPAP set up as the programme acts as a EPR enabling the CPAP practioners to rapidly start the CPAP pick up with built in drop down menus. We are improving CPAP set up rates by 40-50%. We have discovered high rates of insomnia in our patients which is interesting as these patients can be rejected by “Respiratory” Sleep centres. The vast majority had OSA as a cause of maintenance insomnia showing that it is important to investigate so called primary insomnia and exclude common sleep disorders first. We have reported the first 350 patients but are now upto over 700 so we can continue to review our patient cohort and inform referrers/CCGs. We have noted the educational value of the software for patients and staff members and we regularly have medical student, clinical scientists and respiratory nurses training on the software. This ensures consistency across the department and high levels of satisfaction in our students and junior staff.
Lessons	Perseverance is key to this type of project as lots of testing of algorithms is required as well as validation. In addition, finance has been the big stumbling block but showing the improved throughput for CPAP set up and improved patient safety should persuade CCGs that this is more cost effective than paying for WLI clinics. I would suggest speaking to commissioners, primary care providers and procurement team and explain the rationale behind the pathway change and get as many people on board as possible.
Next steps, sustainability and scaling	We would hope to move the first part of our pathway into primary care. This would allow patients to be seen closer to home and reduce trips to hospital. The software remotely connects to the hospital server so oversight could be provided by the Sleep centre for any queries and patients could either be set up with CPAP at hospital or in larger primary care centres. We are hoping to set up a referral hub for this type of work and have approached a PCN but this has been delayed by COVID. As the CDSS translates all the questions into a database in the background it will be possible to use this for research. We would hope that if other hospitals or primary care networks were interested in using this then we would be able to have a UK Sleep database to enable much larger epidemiological work. Part of this could be funded by pharma perhaps who wish to recruit patients for clinical trials.
Find out more	Chakrabarti B, Lewis-Burke N, Pearson M et al. Implementation of a computer-guided consultation in the assessment of suspected obstructive sleep apnoea syndrome. ERJ Open Research, 2020 6(3):00362-2019.

Appendix T: Equalities and health inequalities assessment, specialist advice and guidance

Summary of the proposal and its benefits

Specialist Advice and Guidance (SAG) services are a key part of the National Elective Care Recovery and Transformation Programme's work. SAG provides primary care with continued access to specialist clinical advice, enabling a patient's care to be managed in the most appropriate setting, strengthening shared decision making and avoiding unnecessary outpatient activity. SAG is non-face-to-face activity delivered by consultant-led services which could be contact digitally or by telephone at the time of the patient review or at another time. Specialty clinicians may be consulted for advice on a treatment plan, the appropriateness of a referral, identifying the most appropriate service to send a patient into or to seek clarification of a patients test results.
As part of the NHS long term plan to redesign outpatient services and reduce face-to-face appointments, a priority is to utilise SAG services to improve the interface between primary and secondary care, manage elective patients in the most appropriate setting, and reduce unnecessary referrals into secondary care. NHSEI has developed a national approach identified to support the reduction of health inequalities at both national and system level. The approach defines a target population cohort – the 'Core20PLUS' – and identifies '5' focus clinical areas requiring accelerated improvement. Within sleep medicine, obesity and case finding of hypertension are particularly relevant, therefore all interactions with patients should serve as an opportunity to address these issues.

How specialist advice and guidance could impact health inequalities

Overall, it is anticipated that SAG could have a positive impact on patients in all equality groups as it reduces the need for routine secondary care consultations when they are not required. It could also reduce inequalities by promoting personalised care and supporting self-management. For those that have anticipated negative impact, mitigating actions should be taken. For example, those at high risk of digital exclusion or those with frequent change of should be supported with alternative communication methods.
However, there should be inclusion and exclusion criteria, in additions to guidelines, developed for SAG to ensure that appropriate patients are discussed. Some groups may not be appropriate, or be too high risk, for specialist advice and guidance. Clinicians should receive adequate training and support to facilitate SAG and there should be adequate administration support to facilitate the service. All patient literature should be patient-appropriate, not require a high reading age, and be available in other accessible formats. All patients should be informed of the outcome of the SAG discussion.
Feedback on the service should be obtained to ensure that it is working for patients and clinicians. The service should be audited to ensure that patients from all groups are being considered for SAG.

Summary recommendations from this EHIA

The high-level recommendations from this EHIA are outlined below:

Before implementation

1. Ensure all clinicians are trained and supported in the use of shared decision making
2. Run local clinician engagement sessions for all staff involved in specialist Advice and Guidance and give them the opportunity to feed back on the proposed processes and potential risks
3. Develop local guidelines for where specialist Advice and Guidance will be used, including inclusion and exclusion criteria for which patients specialist Advice and Guidance may be suitable for and how to use it
4. Ensure specialist Advice and Guidance can be used in conjunction with timed appointments or usual referrals if appropriate for patients

First three months of implementation

5. Ensure patient information on specialist Advice and Guidance process and symptoms to look out for do not require a high reading age, and are available in easy read format, large print, braille, and other languages
6. Ensure patient information is written in a gender-neutral format and include diverse images of patients and staff

7. Consider including a non-discrimination policy in patient information

3-12 months of implementation

8. Continued local engagement with primary care staff on specialist Advice and Guidance to understand how it is working for them, and to highlight any shared learning opportunities. Audit of use of specialist Advice and Guidance would be helpful to ensure that the interventions are effective, and to ensure that information remains useful for primary care staff. Feedback from primary care teams is very important.
9. Consider producing local information for patients and primary care in other formats e.g., videos with subtitles

Local situation

Whilst this EHIA has attempted to assess nationally the possible risks and challenges of specialist advice and guidance in sleep medicine, local assessments would also be required. This would include:

1. Considering the local population demographics and groups within the catchment area e.g., older population, people of particular ethnic groups, deprived groups etc.
2. Working with the Joint Strategic Needs Assessments (JSNA) document
3. An outline of demographics of patients who use the local outpatient services
4. Any known other local health inequalities which you intend to address

Potential impact of SAG on health inequalities for protected characteristic groups

Protected characteristic groups	Summary explanation of the main potential positive or adverse impact of your proposal	Main recommendation to reduce any key identified adverse impact or to increase the identified positive impact
Age: older people; early years; children and young people.	Benefits to older patients with multiple long-term conditions would include a reduced number of unnecessary routine appointments, and quicker access to secondary care advice. However, these patients may also experience difficulties in accessing digital systems. Middle-aged and younger patients may find the reduced requirements to attend secondary care appointments fits in better with a working-lifestyle. Some younger patients are typically more difficult to engage in care and there is a risk that a less paternalistic approach fails to engage these patients as effectively; however, there may also be a benefit for this group from less demanding follow up which may suit busy lifestyles. Paediatric patients (aged under 18) are not within the remit of this document.	Guidelines will be developed to which patients SAG is suitable for or not, and the action to take for those whom SAG is unsuitable. Ensure adequate capacity within primary care for patients to be re-reviewed timely, if they are not going to be seen in secondary care. Support patients with poor digital literacy to access information in appropriate sources, and enable alternative methods of communication, such as postal.
Disability: physical, sensory and learning impairment; mental health condition; long-term conditions; dementia	For patients with physical disability, there may be a benefit to them of not having to physically attend hospital unless clinically necessary. This will reduce time taken out of their lives to attend appointments, reducing associated travel or parking costs and therefore help reduce the inequalities that these groups face. For patients with learning disabilities, sensory disabilities or mental health conditions including dementia there is a risk that they might not be considered for SAG. Patients with long-term conditions may have benefits of more flexible management approaches with less requirement for secondary care. Patients with severe and enduring mental health conditions, such as schizophrenia, are at greater risk of digital exclusion and reduced engagement with healthcare services. As per Core20 Plus5 patients should be actively supported with weight loss, smoking cessation and screened for hypertension.	Guidelines will be developed for SAG and for action to take for those for whom SAG is not suitable. There should be ongoing support and training for clinicians to support SAG delivery.
Gender Reassignment and/or people who identify as Transgender	Individuals in this group who are concerned about experiencing stigma may be less likely to initiate a consultation.	These individuals should be supported to engage with healthcare services. Any patient information should be non-discriminatory and include diversity in images.

Protected characteristic groups	**Summary explanation of the main potential positive or adverse impact of your proposal**	**Main recommendation to reduce any key identified adverse impact or to increase the identified positive impact**
Marriage & Civil Partnership: people married or in a civil partnership	The proposed changes are unlikely to impact any patients if they are living with a partner.	Neutral impact expected on people who are married or in a civil partnership.
Pregnancy and Maternity: women before and after childbirth and who are breastfeeding	Patients who are pregnant, post-partum or have young children have large numbers of healthcare appointments, therefore there is a benefit to them of not having to attend unnecessary appointments at secondary care and to have more flexible options for healthcare. This will reduce healthcare inequality.	Ensure adequate capacity within primary care for patients to be re-reviewed timely if they are not going to be seen in secondary care; and for outcomes from SAG to be shared with patients.
Race and ethnicity	Differing cultures may affect health beliefs which may impact patient attitude towards SAG. These patients may also experience language barriers.	These patients should be supported to engage with healthcare services. Any patient information should include diversity in images. Patients should be supported to overcome language barriers.
Religion and beliefs: people with different religions/faiths or beliefs, or none.	Diversity in religious and related health-beliefs may mean that some patients are less likely to initiate an appointment in a timely manner.	Producing culturally relevant educational literature will help patients improve self-management of their condition and to ensure they are empowered to engage with healthcare services.
Sex: men; women	Men are less likely to initiate a follow-up appointment (Thompson et al., *BMC Fam Prac,* 2016) when required so could be adversely impacted.	Ensure adequate capacity within primary care for patients to be re-reviewed timely if they are not going to be seen in secondary care; and for outcomes from SAG to be shared with patients.
Sexual orientation: Lesbian; Gay; Bisexual; Heterosexual.	Individuals who are concerned about experiencing stigma based on their sexual orientation may be less likely to initiate a follow-up appointment when required.	Ensure adequate capacity within primary care for patients to be re-reviewed timely if they are not going to be seen in secondary care; and for outcomes from SAG to be shared with patients.

Potential impact of SAG on health inequalities for other groups of the population

Other vulnerable groups who face health inequalities	**Summary explanation of the main potential positive or adverse impact of your proposal**	**Main recommendation from your proposal to reduce any key identified adverse impact or to increase the identified positive impact**
Looked after children and young people	There may be a challenge in managing patients who are looked after or have frequent change of address. The flexibility in SAG may benefit this group. There may be a need for a more paternalistic approach, which would be provided in the more traditional programme.	The risks identified could be mitigated by engaging key workers in any medical correspondence. The potential availability of email contact addresses, rather than relying on patient postal addresses may help navigate frequent change of address.

Other vulnerable groups who face health inequalities	Summary explanation of the main potential positive or adverse impact of your proposal	Main recommendation from your proposal to reduce any key identified adverse impact or to increase the identified positive impact
	Paediatric patients (aged under 18) are not within the remit of this document.	
Children with safeguarding issues	Paediatric patients (aged under 18) are not within the remit of this document.	
Carers of patients: unpaid, family members	For patients who have care requirements and possibly multiple long-term health conditions, there may be convenience in rationalizing appointments. It may also have an adverse impact as it means even greater responsibility for the carer to watch out for the patient's symptoms, potentially creating stress for the carers and affecting their own health and wellbeing. Benefits would include potentially reduced numbers of appointments to need to take the patient to, with an associated reduction in financial and time cost.	Patients and their carers or relatives should be empowered to manage their condition and be aware of the options to seek help when required. Carers should be signposted to carer support services as required.
Homeless people: people on the street; staying temporarily with friends/family; in hostels or B&Bs.	Patients who are homeless will have the challenge of reduced access to communication methods and lack of permanent address for communications to be dispatched to. However, reducing the number of professionals that a patient needs to see will reduce the impact of this.	It may be helpful to offer email correspondence rather than postal communication for those who have frequent change of address. If patients have a key worker, with patient consent, correspondence could be copied to the key worker to provide another route to ensure information reaches the patient.
People involved in the criminal justice system: offenders in prison/on probation, ex-offenders.	Travel to hospital could be particularly disruptive for patients in this group, therefore an expected reduction in appointments may benefit these patients. Ex-offenders may be more nervous about going to hospital, experiencing stigma, or wishing to avoid contact with services. In such cases, these individuals may be less likely to initiate a follow-up appointment when it is required, leading to delays in clinical advice or treatment. Remote monitoring devices, such as CPAP devices used to manage obstructive sleep apnoea hypopnoea syndrome, must be set-up to ensure that they have tamper-proof systems in place that prevent access to the SD cards, and /or cellular modems, as per cyber-security requirements of the criminal justice system. Services should support enabling this to ensure that these patients do not experience monitoring and adherence difficulties.	For patients involved in the criminal justice system, the option of remote consultations when clinically appropriate will reduce the need to travel to hospital and may encourage patients to initiate their appointments. Prisons and other facilities within the criminal justice system should be supported to facilitate remote consultations. Care for patients in the criminal justice system who get moved location should be joined up to prevent gaps in provision. Healthcare professionals employed within the prison service should be empowered and educated to support management of patients with sleep conditions.

Other vulnerable groups who face health inequalities	Summary explanation of the main potential positive or adverse impact of your proposal	Main recommendation from your proposal to reduce any key identified adverse impact or to increase the identified positive impact
People with addictions and/or substance misuse issues	If patients are concerned about facing stigma or wish to avoid services because of addiction issues, then SAG may reduce health inequalities as it enables secondary care advice within primary care.	It may be helpful to offer email correspondence rather than postal communication for those who have frequent change of address. If patients have a key worker, with patient consent, correspondence could be copied to the key worker to provide another route to ensure information reaches the patient.
People or families on a low income	Patients with limited financial resources may have reduction in health inequalities with a reduction in attendance at secondary care. As per Core20 Plus5 these patients are at particular risk of obesity and smoking and should be supported to manage these conditions. Patients should be screened for hypertension.	Ensure adequate capacity within primary care for patients to be re-reviewed timely if they are not going to be seen in secondary care; and for outcomes from SAG to be shared with patients.
People with poor literacy, health literacy or patient activation (knowledge, skills, and confidence to manage their health)	Patients with poor digital literacy or health literacy may find it difficult to understand the concept of SAG.	Include these patients in personalised care approaches with appropriate education to enable shared decision making, and literature that is accessible.
People with little or no proficiency in English language	Patients with poor English language skills may find it difficult to understand the concept of SAG.	Include these patients in personalised care approaches with appropriate education to enable shared decision making, and literature that is accessible.
People facing digital exclusion - those without digital equipment and reliable connectivity or have little knowledge of the use of or prefer not to use technology	Patients at risk of digital exclusion should have access to alternative methods to receive feedback from the SAG outcome.	We acknowledge there may be a negative impact for patients experiencing digital exclusion. Mitigating actions could include engaging these patients in personalised care approaches with appropriate education to enable shared decision making, and literature that is accessible.
People living in remote, rural and island locations	Patients who live in remote areas may benefit from a reduction in necessary attendances at secondary care which would come with significant time and financial cost. SAG may provide an option for increased access to subspecialities in remote areas, provided these patients have access to suitable communication systems.	Ensure adequate capacity within primary care for patients to be re-reviewed timely if they are not going to be seen in secondary care; and for outcomes from SAG to be shared with patients.
Refugees, asylum seekers or those experiencing modern slavery	Patients who are experiencing modern slavery, are refugee or asylum seekers may benefit from a reduction in attendances at hospital appointments due to the resource needed to attend. There could be a negative impact in a reduction in attendances reduces the	These patients may be experiencing frequent change of address, therefore alternative methods to postal communications, such as email, should be offered.

Other vulnerable groups who face health inequalities	Summary explanation of the main potential positive or adverse impact of your proposal	Main recommendation from your proposal to reduce any key identified adverse impact or to increase the identified positive impact
	opportunity to recognise signs of abuse, such as those experiencing modern slavery.	If these patients have key workers, with patient consent, they could be copied into healthcare correspondence.
Gypsies, Romany Travellers	This group may benefit from reduced requirement to attend secondary care. Conversely if they are less likely to attend follow up from the GP then they may not benefit from SAG advice.	There should be engagement with the community to ensure that challenges faced by them are addressed when developing SAG pathways. If these patients are experiencing frequent change of address, then alternative methods to postal communications, such as email, should be offered.
Serving and ex-military personnel	This group could be reluctant to seek help when required so may be negatively impacted. They will also have the challenge of frequent change of address impacting their ability to have communications and resources dispatched to their home. Reducing the number of healthcare staff that a patient needs to see should improve this.	Include these patients in personalised care approaches with appropriate education to enable shared decision making.
People living in deprived areas	Patients who live in deprived areas may experience digital exclusion.	Patients should be asked their preferred means of communication and information shared as a non-digital copy.
People facing social isolation	This group could be reluctant to seek help when required so may be negatively impacted.	Include these patients in personalised care approaches with appropriate education to enable shared decision making.
Patients diagnosed with rare disorders	Some sleep conditions are rare and may have lengthy time until patients reach diagnosis.	SAG pathways should be designed to avoid delay in diagnosis of rare conditions. Adequate capacity within primary care should exist to ensure patients could be re-reviewed timely if they are not going to be seen in secondary care; and for outcomes from SAG to be shared with patients.

Engagement and consultation

Name of engagement and consultative activities undertaken	Summary note of the engagement or consultative activity undertaken	Month/Year
Task and finish groups	Discussion of EHIA document within task and finish groups consisting of patient representatives and clinicians.	Autumn 2021 to Spring 2022
Patient focus group	Patient focus group to further discuss EHIA in specialist advice and guidance	December 2021

NHSEI health inequalities workgroup	Attendance at wider reference group and review of document	February 2022

Sources

Evidence Type	Key sources of available evidence
Published evidence	NHS Long Term Plan: objectives including reducing outpatient appointments by a third by 2023-24. Universal Personalised Care – Implementing the Comprehensive Model
Consultation and involvement findings	Engagement with broad range of multidisciplinary team members via task and finish groups Engagement with patients within task and finish groups and patient focus group
Research	Anderson K, Warren N, Duddy M et al. Delivering an advice and guidance service in neurology. Pract Neurol. 2022;0:1-4. Craig S et all. Index of multiple deprivation paper. (In press, full citation pending). Thompson A, Anisimowicz Y, Miedema B et al. The influence of gender and other patient characteristics on health care-seeking behaviour: a QUALICOPC study. BMC Fam Pract. 2016:17;38.
Participant or expert knowledge For example, expertise within the team or expertise drawn on external to your team	Engagement with broad range of multidisciplinary team members via task and finish groups Engagement with patients within task and finish groups and patient focus group

Appendix U: Equalities and health inequalities assessment, patient initiated follow up

Summary of the proposal and its benefits

Patient initiated follow-up (PIFU) has been highlighted as a priority by NHSEI. Within the outpatient transformation programme there are NHS targets for increasing proportions of patient-initiated follow-up (PIFU) over the coming years. For respiratory medicine, sleep has been identified as an area to adopt this methodology. Therefore, a work stream has been established to create guidance for implementing PIFU within sleep medicine. PIFU describes when a patient (or their carer) can initiate their follow-up appointments as and when required, for example when symptoms or circumstances change. Patients experience personalised care as they are seen when they need it the most, for example when they are concerned that their symptoms are returning. This empowers patients to take control and reduces unnecessary appointments. Care is adapted to a patient's individual needs and preferences which means better outcomes and reduced anxiety. It also results in a reduced demand on services, improving waiting times, which would consequently benefit all patients on a service caseload (Taneja et al., *Intern Med J*, 2014; Thompson et al., *BMC Fam Pract*, 2016). It also leads to reduced travel to non-essential appointments, further benefitting the local population.

NHSEI has developed a national approach identified to support the reduction of health inequalities at both national and system level. The approach defines a target population cohort – the 'Core20PLUS' – and identifies '5' focus clinical areas requiring accelerated improvement. Within sleep medicine, obesity and case finding of hypertension are particularly relevant, therefore all interactions with patients should serve as an opportunity to address these issues.

How PIFU could impact health inequalities

While PIFU can benefit many patients in all demographic groups, it is not going to be right for every patient. For it to work, the patient (or carer) needs to know when and how to initiate an appointment and be confident in doing so. Patients need to be provided with, and fully understand, information on their condition and reasons to contact the service and be provided with health and wellbeing information and support to enable self-management.

When PIFU is offered to patients for whom it is appropriate, it is likely to have a positive impact on patients in all equality groups as it reduces the need for routine outpatient attendances when the patient doesn't need them. However, if PIFU is implemented using a "one size fits all" model, there is a risk that this could exacerbate health inequalities, by only benefiting groups in the population who are already at a position of relative advantage. Conversely, it can also help reduce inequalities by promoting personalised care and supported self-management. This document outlines how we can ensure that:

1. As many people as possible in England are able to access a PIFU pathway, when clinically appropriate;
2. Actions are taken to address reasons why patients may not be likely to initiate their appointment when required, preventing them from receiving timely care to address the issue;
3. We achieve consistently high outcomes for all people in the population; and
4. PIFU is used to reduce existing inequalities and prevent new inequalities from arising.

Patients should be managed in line with the 'Core20PLUS' NHSEI approach to health inequalities.

Summary recommendations from this EHIA

The high-level recommendations from this EHIA are outlined below.

Before implementation

5. Ensure safety nets identified as part of this assessment are in place; e.g., interval contact with patient for machine replacement
6. Ensure all clinicians are trained and supported in the use of shared decision making
7. Run local clinician engagement sessions for all staff involved in PIFU (both clinical and administrative) and give them the opportunity to feed back on the proposed processes and potential risks
8. Develop local guidelines for where PIFU will be used, including inclusion and exclusion criteria for which patients PIFU may be suitable for and how to use it.
9. Ensure PIFU can be used in conjunction with timed appointments if appropriate for patients
10. Ensure processes support use of PIFU alongside remote consultations where clinically appropriate

First three months of implementation

11. Carry out local patient engagement
12. Ensure alternative contact options are available for patients who cannot use a phone line

13. Ensure patient information on PIFU process and symptoms to look out for do not require a high reading age, and are available in easy read format, large print and other languages
14. Ensure patient information is written in a gender-neutral format and include diverse images of patients and staff
15. Consider including a non-discrimination policy in patient information
16. Ensure information about PIFU is copied to patients' GPs.

3-12 months of implementation

17. Continued local engagement with patients on a PIFU pathway to understand how it is working for them
18. Continued audit of the service for patients and staff providing the service
19. Consider producing local information for patients in other formats e.g. videos
20. Consider offering phone lines free of charge with increased opening hours
21. Consider monitoring demographic information about patients initiating follow-ups to ensure that patients from all groups are initiating follow-up appointments
22. Build in options to capture patients' preferred means of communication and provide information in a way that suits them
23. Consider offering local targeted education programmes to specific groups to improve symptom recognition and self-management

Local situation

Whilst this EHIA has attempted to assess nationally the possible risks and challenges of PIFU in sleep medicine, local assessments would also be required. This would include:

24. Considering the local population demographics and groups within the catchment area e.g., older population, people of particular ethnic groups, deprived groups etc
25. Working with the Joint Strategic Needs Assessments (JSNA) document
26. An outline of demographics of patients who use the local outpatient services
27. Any known other local health inequalities which you intend to address

Potential impact of PIFU on health inequalities for protected characteristic groups

Protected characteristic groups	Summary explanation of the main potential positive or adverse impact of your proposal	Main recommendation to reduce any key identified adverse impact or to increase the identified positive impact
Age: older people; early years; children and young people.	Patients of older age could have poorer digital literacy or prefer a more traditional follow-up structure. Conversely, the benefits are that those older patients with multiple long-term conditions will benefit from a reduced number of unnecessary routine appointments. Middle-aged and younger patients may find the less rigid follow-up structure fits in better with a working-lifestyle. Some younger patients are typically more difficult to engage in care and there is a risk that a less paternalistic approach fails to engage these patients as effectively; however, there may also be a benefit for this group from less rigid follow-up which may suit busy lifestyles.	Guidelines will be developed to which patients PIFU is suitable or not, and the action to take for those whom PIFU is unsuitable. Poor digital literacy is mitigated by options for face-to-face (F2F) or telephone calls. There is also the option to decline PIFU and remain on a traditional follow-up programme. Patients who are at risk of not being engaged would be triaged to traditional follow-up, or if they were on PIFU there will be an interval machine replacement which could also provide a safety-net. There is also the presence of remote monitoring which will enable remote review of compliance. PIFU has the option to share responsibility for initiating an appointment with a carer or guardian if the patient cannot do this themselves.

Protected characteristic groups	Summary explanation of the main potential positive or adverse impact of your proposal	Main recommendation to reduce any key identified adverse impact or to increase the identified positive impact
	Paediatric patients, defined as under 18 years old, are not within the remit of this document.	
Disability: physical, sensory and learning impairment; mental health condition; long-term conditions	For patients with physical disabilities, there may be a benefit to them of not having to physically attend hospital unless clinically necessary. This will reduce time taken out of their lives to attend appointments, reducing associated travel or parking costs and therefore help reduce the inequalities that these groups face. For patients with sensory disability, there is a risk of reduced engagement with virtual or phone appointments compared to F2F due to sensory impairments. For example, those with hearing impairments may find it difficult to book their follow-up on a phoneline if there are no alternatives. Patients with a disability such as a visual impairment may be adversely impacted without information resources that meets their needs. For patients with learning disabilities or mental health conditions there is a risk that they might not be considered for PIFU, or engage adequately with PIFU, unless it is adapted to work for them, or they are sufficiently supported. Patients with long-term conditions may have benefits of more flexible management and the ability to get appointments when clinically required. As per Core20 Plus5 patients should be actively supported with weight loss, smoking cessation and screened for hypertension.	Guidelines will be developed for PIFU and for action to take for those for whom PIFU is not suitable; and PIFU could include a timed appointment as a safety-net and for required machine maintenance. There should be ongoing support and training for clinicians to support patients with PIFU and to enable shared decision making. The service for booking appointments should be accessible through different means, for example via phone, text, and email to ensure that those with impairments such as hearing impairments, are able to access the service. Patient information should be provided in alternative formats. Patients should be provided with information about PIFU and their condition in a way that they can understand it, and so that the information materials are suited to their needs. The needs of carers will need to be considered.
Gender Reassignment and/or people who identify as Transgender	Individuals in this group who are concerned about experiencing stigma may be less likely to initiate a follow-up appointment when required.	Ensure all patient information is non-discriminatory and includes diversity in images.
Marriage & Civil Partnership: people married or in a civil partnership	The proposed changes are unlikely to impact any patients if they are living with a partner.	Neutral impact expected on people who are married or in a civil partnership.
Pregnancy and Maternity: women before and after childbirth and who are breastfeeding	Patients who are pregnant, post-partum or have young children have large numbers of healthcare appointments, therefore there is a benefit to them of not having to attend routine appointments and to be able to flex the	Patients who use CPAP are classed as high-risk pregnancies. Therefore, we would advise that patients should inform the service should they become pregnant or be considering conception.

Protected characteristic groups	Summary explanation of the main potential positive or adverse impact of your proposal	Main recommendation to reduce any key identified adverse impact or to increase the identified positive impact
	appointments as required. This will reduce healthcare inequality.	
Race and ethnicity	Differing cultures may affect health beliefs which may impact patient attitude towards PIFU. There also possible issues with English as a second language, which non-traditional follow-up modalities may exacerbate or relieve. There is a potential challenge of travelling or migrant groups having reduced access to communication and lack of permanent address for equipment to be dispatched to. Some ethnic groups may find mask-fit more challenging. This has been reduced with more modern masks. Mask fit can be affected by the presence of facial hair. In some circumstances, patients with facial hair are advised to remove the facial hair to improve mask fit. Some patients have facial hair for religious reasons therefore it may not be appropriate to ask these patients to remove their facial hair. Some ethnic groups and races may have less proficiency in English. Some cultures may need adjustments when using PIFU, e.g. in some cultures, women may not initiate or attend appointments without their husband or a male family member; or may prefer alternative medicine first rather than initiating a PIFU appointment.	The risks identified are mitigated by the presence of the traditional follow-up programme, in addition to a variety of consultation styles (F2F, phone, virtual), the presence of an open-access phone line. Culturally relevant targeted education programmes to improve management of condition and symptom management should be developed with a wide diversity of images with the patient information.
Religion and beliefs: people with different religions/faiths or beliefs, or none.	Diversity in religious and related health-beliefs may extend to attitudes towards PIFU which may mean that some patients are less likely to initiate an appointment in a timely manner.	Producing culturally relevant educational literature will help patients improve self-management of their condition and to ensure they are empowered to engage with PIFU. Patients who do not align with PIFU should have the option of having traditional follow-up.
Sex: men; women	Men are less likely to initiate a follow-up appointment (Thompson et al., *BMC Fam Prac,* 2016) when required so could be adversely impacted.	Flexible methods and opening hours for the PIFU service to be contacted will ensure the service is as accessible as possible. Demographic data will be measured to ensure that similar proportions of men and women are accessing follow-ups. Including images of men in information leaflets and writing in a gender-neutral format.

Protected characteristic groups	Summary explanation of the main potential positive or adverse impact of your proposal	Main recommendation to reduce any key identified adverse impact or to increase the identified positive impact
Sexual orientation: Lesbian; Gay; Bisexual; Heterosexual.	Individuals who are concerned about experiencing stigma based on their sexual orientation may be less likely to initiate a follow-up appointment when required.	Ensure all patient information is non-discriminatory in context and includes diversity of images. Include a non-discrimination policy on the information leaflet provided to patients.

Potential impact of PIFU on health inequalities for other groups of the population

Other vulnerable groups who face health inequalities	Summary explanation of the main potential positive or adverse impact of your proposal	Main recommendation from your proposal to reduce any key identified adverse impact or to increase the identified positive impact
Looked after children and young people	There may be a challenge in managing patients who are looked after or have frequent change of address. The flexibility in PIFU may benefit this group. There may be a need for a more paternalistic approach, which would be provided in the more traditional programme. Paediatric patients, defined as under 18 years old, are not within the remit of this document.	The risks identified are mitigated by the presence of the traditional follow-up programme, in addition to a variety of consultation styles (F2F, phone, virtual), the presence of an open-access phone and the potential availability of email contact addresses, rather than relying on patient postal addresses. Carers and guardians should be provided with adequate training to know when to contact the service for review.
Children with safeguarding issues	Paediatric patients, defined as under 18 years old, are not within the remit of this document.	
Carers of patients: unpaid, family members	For patients who have care requirements and possibly multiple long-term health conditions, there may be convenience in rationalizing appointments. It may also have an adverse impact as it means even greater responsibility for the carer to watch out for the patient's symptoms and initiate the follow-up appointment when required, potentially creating stress for the carers and affecting their own health and wellbeing. This could be a positive impact as the carer is empowered and it increases the carers' knowledge, skills, and confidence to manage the patients' health and care.	Patients and their carers or relatives should be empowered to manage their condition and be aware of the options to seek help when required. To mitigate the negative impact of additional carer responsibility, carers must have the support, knowledge and skills to manage their caring responsibilities effectively without adversely affecting their own health and wellbeing. Carers should be signposted to carer support services as required.
Homeless people: people on the street; staying temporarily with friends/family; in hostels or B&Bs.	Patients who are homeless will have the challenge of reduced access to communication methods and lack of permanent address for equipment or communications to be dispatched to. Patients who are homeless may have reduced ability to engage with CPAP therapy due to lack of electricity.	The risks identified are mitigated by the presence of the traditional follow-up programme, in addition to a variety of consultation styles (F2F, phone, virtual), the presence of an open-access phone and the service having an email address would be very useful for patients with

Other vulnerable groups who face health inequalities	Summary explanation of the main potential positive or adverse impact of your proposal	Main recommendation from your proposal to reduce any key identified adverse impact or to increase the identified positive impact
	There is a challenge in dispatching equipment to patients without a reliable postal address therefore we would require these patients to attend the hospital to collect equipment. Some people in these groups may be less likely to initiate an appointment if they are nervous about spending time in a hospital setting or facing stigma.	frequently changing postal addresses.
People involved in the criminal justice system: offenders in prison/on probation, ex-offenders.	For patients involved in the criminal justice system, there is a challenge of access to communication methods and lack of permanent address for equipment to be dispatched to. Travel to hospital could be particularly disruptive for patients in this group, and for prison services accompanying these patients, therefore an expected reduction in appointments may benefit these patients and the prison staff. PIFU could increase health inequalities for offenders in prison who may face restrictions about when they can travel to hospital which may make them less likely to initiate an appointment. Ex-offenders may be more nervous about going to hospital, experiencing stigma, or wishing to avoid contact with services. In such cases, these individuals may be less likely to initiate a follow-up appointment when it is required, leading to delays in clinical advice or treatment. Conversely, patients might enjoy attending hospital and prefer routine appointments to PIFU or remote appointments. There is a recognized challenge in getting home diagnostic kits into prison. Offenders on probation may have to tell their probation officer where they are going and may be less likely to initiate an appointment.	For patients involved in the criminal justice system, the option of remote consultations when clinically appropriate will reduce the need to travel to hospital and may encourage patients to initiate their appointments. All correspondence should be copied to the patient's GP.
People with addictions and/or substance misuse issues	If patients are concerned about facing stigma or wish to avoid services because of addiction issues, then PIFU may increase health inequalities as it could generate a barrier to initiating a follow-up appointment which could lead to delays in clinical advice or treatment. Patients with substance misuse issues who stay intoxicated for long periods may not be able to initiate appointments timely.	Exclusion criteria should be developed for PIFU, and PIFU should include a timed follow-up contact from the service, e.g. when machine replacement required. All documentation should be copied to the patients GP.

Other vulnerable groups who face health inequalities	Summary explanation of the main potential positive or adverse impact of your proposal	Main recommendation from your proposal to reduce any key identified adverse impact or to increase the identified positive impact
People or families on a low income	Patients with limited financial resources may struggle with a lack of digital or communication resource making PIFU more challenging. Patients with low income may struggle to pay for the electricity associated with CPAP therapy. As per Core20 Plus5 these patients are at particular risk of obesity and smoking and should be supported to manage these conditions. Patients should be screened for hypertension.	Patients should have choice in whether they enrol with PIFU or remain on standard management. Patients should be asked their preferred means of communication and information shared as a non-digital copy.
People with poor literacy, health literacy or patient activation (knowledge, skills and confidence to manage their health)	Patients with poor digital literacy or health literacy may find it more difficult to initiate, or understand how to initiate, their own follow-up appointments and result in increased health-inequalities.	Include these patients in personalised care approaches with appropriate education to enable shared decision making, and literature that is accessible.
People with little or no proficiency in English language	PIFU may exacerbate inequalities for people who do not speak English proficiently as they may find it difficult to understand how and when to initiate a follow-up appointment, or they may struggle to initiate an appointment if this is done by telephone. There is also a greater risk of misunderstanding and frustration of both sides of conversations.	Making information leaflets available in the most common languages spoken in the local area and offered in other languages and accessible formats.
People facing digital exclusion - those without digital equipment and reliable connectivity or have little knowledge of the use of or prefer not to use technology	Some patients, with low digital skills and/or little access to digital equipment such as smartphones or wireless connectivity may find it difficult to initiate an appointment.	Ensuring appointment booking options such as availability of phone lines. Patients should be asked their preferred means of communication and information shared as hard copy via non-digital means (such as through the post) as appropriate.
People living in remote, rural and island locations	PIFU is likely to benefit those in geographically isolated locations, as they will have fewer attendances to hospital, which may be particularly difficult to travel to for this group. However, some patients may be more reluctant to initiate an appointment if they think they will have to travel a long way. These areas may also experience greater digital exclusion.	Patients should be asked their preferred means of communication and information shared as a non-digital copy.
Refugees, asylum seekers or those experiencing modern slavery	Some patients in this group may have underlying and undiagnosed mental health issues (such as PTSD) which can affect their ability to self-manage and initiate an appointment when required.	There needs to be clear guidelines with a list of patients for whom PIFU is not suitable, such as those with safeguarding issues, which are followed consistently.

Other vulnerable groups who face health inequalities	**Summary explanation of the main potential positive or adverse impact of your proposal**	**Main recommendation from your proposal to reduce any key identified adverse impact or to increase the identified positive impact**
	Some patients may be nervous about 'figures of authority' or being charged for treatment (e.g., if they are not familiar with eligibility criteria) which may make them less likely to initiate an appointment when required. Some refugees and asylum seekers might move between localities as housing becomes available – this may mean they may not have easy access to initiate their appointment when required, or they may miss important correspondence if sent to an out-of-date address. People who are experiencing modern slavery may not have the independence or freedom to initiate or attend an appointment when needed.	Patients should be asked preferred means of communication and information shared as hard copy via non-digital means (such as through the post) as appropriate. Patient should be connected with local charities and social prescribing link workers and care coordinators in primary care. Free phone lines would make for easy access to making an appointment.
Gypsies, Romany Travellers	This group may be more reluctant to initiate an appointment if they anticipate discrimination and lack of cultural awareness. PIFU could increase health inequalities for people without a fixed address to receive letters or communications, as they may miss important information on how and when to initiate an appointment.	Engaging with the community to ensure that challenges faced by them are addressed when developing PIFU pathways, such as their access to services, community development and empowerment campaigns.
Ex-military personnel	This group could be reluctant to seek help when required so may be negatively impacted.	Include these patients in personalised care approaches with appropriate education to enable shared decision making. Provide opt-out options for PIFU.
People living in deprived areas	Patients who live in deprived areas may experience digital exclusion.	Patients should be asked their preferred means of communication and information shared as a non-digital copy.
People facing social isolation	It may increase health inequalities for people who live alone and/or who are socially isolated as they may not have anyone to remind them to look out for symptoms of concern.	Include these patients in personalised care approaches with appropriate education to enable shared decision making. These patients who struggle to engage in therapy should be excluded from PIFU.
Other groups experiencing health inequalities (please describe)	There are some groups of patients that are less likely to engage in therapy, with no obvious similarities. Patients with sleep conditions who have high risk occupations, such as pilot, HGV drivers, should be managed more proactively.	These patients who struggle to engage in therapy should be excluded from PIFU. Patients with high-risk occupations should be excluded from PIFU.

Engagement and consultation

Name of engagement and consultative activities undertaken	Summary note of the engagement or consultative activity undertaken	Month/Year
Task and finish groups	Discussion of EHIA document within task and finish groups consisting of patient representatives and clinicians.	Autumn 2021 to Spring 2022
Patient focus group	Planning a patient focus group to further discuss this	December 2021
NHSEI health inequalities workgroup	Attendance at wider reference group and review of document	February 2022

Sources

Evidence Type	Key sources of available evidence
Published evidence	NHS Long Term Plan objective of reducing outpatient appointments by a third by 2023-24. PIFU national guidance (Section 4 in Implementing phase 3 of the NHS response to the COVID-19 pandemic Guidance) Universal Personalised Care – Implementing the Comprehensive Model
Consultation and involvement findings	Engagement with broad range of members from multidisciplinary team via task and finish groups. Engagement with patients within task and finish groups and patient focus group.
Research	Bech B, Lykkegaard J, Lundbak T et al. Patient initiated follow up as reorganised support for increased patient involvement – focus group discussions among patients with inflammatory arthritis. BMC Rheumatol. 2020;4:44. Taneja A, Su'a B, Hill A. Efficacy of patient-initiated follow-up clinics in secondary care: a systematic review. Intern Med J. 2014 Dec;44(12a):1156-60. Thompson, A.E., Anisimowicz, Y., Miedema, B. et al. The influence of gender and other patient characteristics on health care-seeking behaviour: a QUALICOPC study. BMC Fam Pract. 2016;17:38. Whear R, Thomson-Coon J, Rogers M et al. Patient initiated appointment systems for adults with chronic conditions in secondary care. Cochrane Database Syst Rev. 2020;4(4). Whear R, Abdul-Rahman A, Boddy K et al. The clinical effectiveness of patient initiated clinics for patients with chronic or revurrent conditions managed in secondary care: a systematic review. PLoS One. 2013;8(10). Whear R, Abdul-Rahman A, Thomson-Coon J et al. Patient initiated clinics for patients with chronic or recurrent conditions managed in secondary care: a systematic review of patient reported outcomes and patient reported outcome and patient and clinician satisfaction. BMC Health Serv Res. 2013;13:501.
Participant or expert knowledge For example, expertise within the team or expertise drawn on external to your team	Engagement with broad range of members from multidisciplinary team via task and finish groups. Engagement with patients within task and finish groups and patient focus group.

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