THE DARK SELF

Susan Aldworth
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The Dark Self project was funded by Guy’s & St Thomas’ Charity (GSTTC) to investigate the different treatment journeys from primary to secondary care of patients with sleep disorders. The aim was to take an innovative arts-based approach to researching and exploring issues related to sleep and to the diagnosis and management of sleep disorders in the local area, and in doing so to build and develop new relationships between primary care and the Sleep Disorders Centre (SDC) at Guy’s Hospital.

Interviews were conducted with patients within both primary and secondary care – at the SDC and participating local General Practices – with the aim of capturing and understanding the experiences of patients undergoing treatment in both settings, and highlighting possible areas for improvement.

**RECOMMENDATIONS**

〜 SDC to expand accessible web-based and printed learning resources about sleep disorders for patients and for primary and secondary care.

〜 SDC to continue developing and highlighting the use of smartphone self-help apps for the management of insomnia, the commonest sleep complaint, such as Sleepio (for CBT) and Headspace (for mindfulness, a tool already being formally researched).

〜 SDC to set up patient groups for the commoner conditions such as sleep apnoea, restless legs and narcolepsy.

〜 SDC to facilitate a cradle-to-grave sleep service together with the Paediatric Sleep Centre, for a smoother transition for narcoleptic patients in particular.

〜 SDC to use outreach projects to build greater knowledge within primary care about sleep and sleep disorders, their management and treatment.
RECOMMENDATIONS

~ SDC to improve communication with local General Practices to make a reality of ‘taking the hospital to the patient’. This might include offering lectures and seminars to those practices and their patients, and using Skype sessions between GPs and consultants more freely.

~ SDC to provide current thoughts to GPs about the use of hypnotics for sleep disorders.

~ Address problem of drugs prescribed by SDC but not funded within primary care.

FOREWORD: THE ARTIST AS RESEARCHER

Willis Newson has been a leader in the field of arts and health consultancy for over ten years. It is committed to furthering knowledge and understanding of the role and effectiveness of arts practices for healthcare providers.

When Susan Aldworth initially came to us in 2014, it was to ask for support and advice on conducting research within a healthcare context in an ethical and robust manner. We worked together on the complex process of applying for formal Ethical Approval, drafted topic guides together, and discussed questions of research design and methodology. It has been evident throughout that she is deeply committed to completing this study with the most appropriate tools and a strong framework to guide her enquiry. Interviews, for example, have been conducted with attention to questions of informed consent, and recorded, transcribed and analysed with care. This is despite the fact that this was never meant to be a formal evaluation of a service or an academic study.

And if the project had stopped there it could have been characterized as an interesting exploration of the experience and journeys of patients with sleep disorders in local primary care and within the Sleep Disorders Centre. However, what is also interesting is what it reveals about the role of the artist researcher. A researcher has responsibilities, both in doing justice to her subject including being objective and avoiding bias, and in protecting and giving a voice through the research to people who participate in it. When the researcher is an artist and if, as seems to have been the case in this study, interviewees talk more readily and openly to an artist, the ethical context in which the interview is delivered becomes even more important. The Dark Self project has been effective in providing a medium in which voices can be heard.

**SUZY** It is something that I feel very sad about… I don’t think I have told that to anybody before.
Tonym: Thank you for listening. Because I can tell you that I don’t talk to many people about it. And when you asked me if I wanted to come and talk about it, I was very conscious of the fact that I would like someone to actually, to actually hear my story.

It has sought to make visible, and audible, experience that is described as ‘invisible’ by participants in the research.

Susan: It is interesting to me that you are interested in something like this. My sleep disorder] is sort of invisible.

In addition, because the researcher is an artist, and one of the intentions of the research is to inform art practice, questions of objectivity and subjectivity become complicated. Artworks that are created as a result of the research have the potential both to change the artist’s own conceptions of reality, and to affect the conceptions of others experiencing them in unexpected ways. Aldworth will be creating artworks during the second phase of this project, but her research and this artist’s book also possess dual identities as artwork. All of which poses fascinating questions about the nature of such research, the role of the artist in it, and of art practice responding to it.

Dr Karen Gray
Research and Evaluation Manager, Willis Newson
The human brain. Three pounds or so of fatty tissue, boxed inside the inky darkness of the skull. It needs its sleep.

In the past sleep was often described as a negative or deathlike state with little to offer in our understanding of what it is to be human – only in the middle of the twentieth century did sleep medicine become a medical specialty. Today we understand sleep as a positive state essential for both mental and physical health. Our brains are as active in deep sleep as they are when we are awake. In REM sleep our bodies are paralyzed to stop us acting out our dreams. We need the right amount of each for a good night’s sleep: the phrase says it all. Sleep accounts for approximately one third of human experience – for most of us. For those who suffer from a sleep disorder, however, things are very different.

Sleep deprivation is a multi-faceted issue, sometimes difficult to diagnose and an underlying predicator of a given number of other serious illnesses. Recent studies by scientists working across Oxford, Cambridge and Harvard have linked cancer, obesity and heart disease to lack of sleep, as the amount of sleep a person has affects the daily rhythm of their body clock and fluctuations and interruptions to sleep patterns over long periods of time can have a detrimental impact.

The purpose of the Dark Self project was to explore how sleep disorders are managed both in the Sleep Disorders Centre and in primary care by engaging directly with local GPs and their patients, and recording their experiences. That there are issues to be addressed is reflected in the number of patients whose sleep disorders remain untreated in primary care, and the numbers referred to the SDC. Accordingly, the research involved local GPs and patients participating in the process of capturing sleep disturbance. Recording patient narratives about their sleep disorders and their patient journeys was central to the overall purpose of the project.
But why employ an artist and not a medical researcher? The short answer is that sometimes we see, hear or get told things that the professionals don’t. An artist in a medical setting is uniquely placed to provide a ‘non-medical ear’ for patients which, evidence from past arts and health projects suggests, can encourage them to talk more openly about their medical conditions. Given the deeply subjective nature of sleep and sleep disorders, this artist-led approach can unlock evidence about the true prevalence of sleep disorders in the local population, and the impact of bad sleep on their health. Accordingly, this project captures, investigates and compares patients’ experiences in primary care and in the Sleep Centre. These narratives have been collated and analysed throughout the research process, and the outcomes evaluated and discussed by the SDC and participating GPs.

This report marks the completion of the first stage of the Dark Self project. It is by design a hybrid: part artwork, part research paper. It presents the findings of the research in the form of an artist’s book. The recommendations for action are set out clearly, but they emerge from the spoken words of the patients. Each of them has more than one journey.

The study of sleep disorders helps us understand the significance of sleep for us all. As an artist I wanted to find out everything I could about sleep – why we do it, how we measure it, how we treat it and how we experience it. I sat in on sleep clinics; my brain waves were measured while sleeping; I read philosophies of sleep; and above all, I interviewed, listened to and documented the testimonies of over ninety people with sleep disorders.

The initial aim of the interviews was to understand patients’ journeys from the point at which their sleep problem was first identified, through treatment, either in primary care, or through referral to secondary care at the SDC. The findings are in the section of the report called ‘The Treatment Pathway’. It provides a local ‘snapshot’ of these patients and their treatment. It offers a perspective from the patients’ point of view on how sleep disorders are managed, on the impact of problems with diagnosis, and on the effect of disorders on individual health. It describes details of the route to specialist care and gives an indication of what are seen as effective treatments. ‘The Treatment Pathway’ involves what might be called the external patient journey: process, diagnosis, treatment. However, the patients themselves were concerned with more than the simple logistics of the treatment pathway. They had their own inner journeys to contend with. In their interviews and testimony they spoke openly of the personal, subjective and practical realities of living with a sleep disorder. I want to respect and capture their experience in this report. So in presenting the individual journeys and narratives of my interviewees, it has been important to let them speak for themselves by using as many of their own words as possible. Their quotations inform both ‘The Treatment Pathway’ and the section called ‘The Patient Experience’, which focuses on what we might call the internal journey.

A NOTE ON METHODS
The methodology for this study was developed with the help of Dr Karen Gray of Willis Newson and Professor Adrian Williams of the SDC.

Professor Williams and his team identified specific issues to investigate, which provided a clinical as well as an artistic voice and ensured that the arts were responding directly to need. In consultation with both Professor Williams and Willis Newson a number of key questions were developed to ask patients and GPs during interviews.

It was decided that semi-structured interviews with patients and contributing GPs would be the most appropriate method of collecting data in order to explore
the texture of individual patient experience and reveal other material pertinent to the management and treatment (or non-treatment) of sleep disorders. Topic guides were developed in collaboration with Professor Williams.¹

A patient consent form was developed with Willis Newson to ensure that the research work was ethically sound, and that the process of participants giving their consent was effectively managed in order to ensure that ‘informed consent’ was obtained.

INTERVIEWS

Twelve patients with sleep disorders were interviewed for this study. All the patients took part voluntarily, and they represented a range of genders, ages, backgrounds and types of condition.

Of the twelve, eight were patients who had been referred to the SDC. Four further interviewees volunteered via their local General Practice in the Lambeth and Southwark area. Dr David Wickstead of the Corner Surgery and Dr Rajiv Mitra of the Lambeth Walk Practice supported the project and invited all their patients receiving treatment for sleep disorders to participate. Four patients from the Corner Surgery responded positively.

The two participating GPs were also interviewed. In addition, I sat in on 78 clinical consultations at the SDC, and kept detailed notes of these sessions.

All interviews were recorded and analysed with the help of Dr Gray for repeated themes using a grounded approach to analysis, similar to that described by Braun and Clarke (2006).²

ETHICS

Ethical approval for the project was sought and given by the NHS Health Research Authority, NRES Committee, London Bridge, in March 2015. My attendance at clinical consultations was made possible by the patients who kindly agreed to my involvement, and by Guy’s and St Thomas’ NHS Foundation Trust’s award to me of an honorary (non-medical) temporary contract. All interviewees gave consent for their participation and I have used pseudonyms when quoting them. Patient confidentiality has been maintained at all times.

LIMITATIONS

This is a non-academic study, involving a small sample of participants. It is not intended to produce generalizable results.

The process of obtaining ethical approval to interview patients was time-consuming and delayed the start of the project, meaning that I was able to conduct fewer interviews than had been planned. It also proved difficult to recruit to the study GPs and patients in primary care. GPs who responded negatively cited time pressures as a reason for not participating. No patients volunteered from one of the GP practices, and only four from the other. I was more successful in recruiting participants after their clinical consultations at the SDC, but this meant that the majority of those interviewed were already in secondary care.

Although relatively few people came forward, it was a surprise that nearly half of all interviewees had a diagnosis of narcolepsy, a sleep disorder that carries some social stigma and profoundly affects lifestyle. This is a relatively rare condition and they wanted to talk in depth about their experience. This was a limitation with positive and interesting consequences for the reflections and discussion prompted by the research.

ACKNOWLEDGEMENTS

The research was greatly facilitated by my appointment as artist in residence at the SDC by its director, Professor Adrian Williams. The insights I have gained into sleep and sleep disorders from both a clinical and personal perspective provide a rich resource. In the second phase
of the project I hope to explore this further in a series of artworks for the SDC and local GP practices.

I am grateful to GSTTC for funding the project, and to Nikki Crane, Karen Taylor, Gabrielle Allen and Viv Reiss for their help and support. To Professor Adrian Williams I owe an enormous debt, for my appointment at the SDC, for his generosity as mentor and for introducing me to his patients. Dr David Wickstead of the Corner Surgery in Denmark Hill and Dr Rajiv Mitra of the Lambeth Walk Practice were energetic and helpful throughout, introducing me to their practices and their patients. Dr Karen Gray of Willis Newson was a constant source of support and advice. Finally, I am indebted to all the patients who agreed to talk. This would have been nothing without them.

Susan Aldworth

¹ These are included in the Appendix.
There are three categories of sleep disorder:

**INSOMNIA**

Difficulty getting to sleep or staying asleep for long enough to feel refreshed the next morning.

*Sleeping tablets didn’t seem to help. Nothing can keep me asleep. I just want to have an honest night’s sleep. I just want to feel human.*

**HYPERSOMNIA**

Excessive sleep or sleepiness that interferes with everyday life. It can be caused by narcolepsy, sleep apnoea or restless legs.

*I have no real life. I am scared to go out. I feel my narcolepsy and cataplexy has ruined my life. I am in constant fear of collapse. I wake up about seven times in the night. It is very debilitating. I can’t be left alone, I can’t bathe alone and I can’t go out alone.*

**PARASOMNIA**

Abnormal or unusual behaviour during sleep.

*I slap my partner in my sleep. I have pulled the telly off the cabinet. I have scratched the ceiling. I see things that aren’t meant to be there. I see patterns to solve – I see mushrooms popping around.*

While every patient’s disorder will fall into these categories, there are many variations within each. Patients at the SDC vividly described their experience of restless legs, sleep paralysis, sleep shouting, sleep groaning and other behaviours, and it is clear that the individual experience of
bad sleep poses particular, often life-affecting, dilemmas. How will a young mother who sleepwalks safely manage her new baby on her own? Or what if going to sleep itself is terrifying?

By taking my sleeping pills, I go to sleep in a calm state which takes away my fear of sleep as death. Now the pills are being cut back, my fear of death is coming back.

For a sufferer from sleep eating, the problems are very different:

I haven’t had a proper night’s sleep for six or seven years. I wake up after a couple of hours sleep starving and have to eat a substantial amount of carbs to get back to sleep. I am awake when this is happening – or half asleep. My hunger pangs are so strong that they stop me sleeping. My weight fluctuates between 11 stone and 13½ stone. I try to control it by having no food in the house. But I wake up and circle the kitchen looking for food. Sometimes I have to go out to an all-night shop to buy something to eat. I wake up. It feels like 20 mins after going to sleep. This is my first hunger and I have a meal. This happens over and over – and after four night meals then I get to sleep. I wake up at about 8.30 or 9 – I have five hours’ sleep max. Luckily I work from home.

Sleep disorders may fall into categories, but they are complex, idiosyncratic and very human. Their breadth and nature makes treatment dependent on a patient’s being carefully listened to both in primary and secondary care. At the beginning of every consultation, Professor Williams asked his patients to tell their sleep story prior to his examination and diagnosis. This research report reinforces the significance of these sleep stories in sleep medicine.

AHMED is a young asylum seeker suffering from depression and insomnia.

ANNE was born in 1981, and has narcolepsy and cataplexy. She is married with a young child.

FRED is forty. He suffers from dizziness and is being tested for sleep apnoea at the SDC.

GINA was born in 1991 and has been diagnosed with sleep paralysis.

IVY is in her late sixties and suffers from insomnia.

JOHN is twenty. A student from South Africa, he was diagnosed with narcolepsy in 2013.

LOWE is in his seventies and has insomnia.

ROBERT was born in 1997 and has narcolepsy and cataplexy. His mother also suffers from narcolepsy; she recognised his symptoms when he was seven.

ROSE is in her forties. She has mild sleep apnoea.
SUZY is in her forties. She was diagnosed with narcolepsy and cataplexy in 1996.

TONY was born in 1994. He is studying at university and has recently been diagnosed with narcolepsy with cataplexy.

Unattributed patient quotations come from notes taken with patient permission during clinical consultations at the SDC.
Every patient’s experience is individual, but clusters of themes emerged from the interviews. For this section, the themes identified were: beginnings; diagnosis; journey in primary care; struggle and persistence; fear and relief; treatment in primary care; journey into secondary care; moving from a children’s service to an adult service; medication; and acceptance.

BEGINNINGS
Sleep is something we all do every day and feeling tired is part of normal human experience. For some people though, a feeling of tiredness will move from being ‘normal’ to being something so troubling that it needs medical attention. This is the point at which these patient journeys begin – and it sometimes took a while to recognise that there was a real problem to address.

**SUZY**
I just assumed that I was sleepy or not concentrating. I’d just done a postgraduate degree – I thought, it’s just that I haven’t studied for a long time, sitting here all day listening to things, I am finding it really, really difficult. But I didn’t equate it with anything apart from thinking gosh, this is awful!

**TONY**
I know in my Upper Sixth, I remember very vividly in my maths classes I used to fall asleep every time in the afternoon and the morning. I would come up with a method to fall asleep without the teacher seeing me, by putting my hand on my head and sort of covering my eyes. Once or twice the teacher did actually have to prompt me to wake up, so I assume it did start around then.

**ANNE**
I used to run three or four times a week and I noticed that in one of my arms I had
periods of lost sensation; and also, which I now know is cataplexy, the muscles would relax to the point that if I was holding a glass I would randomly drop it. I was at the time sleepy during the day, but to be honest I’ve always been someone who loved a good eight hours’ sleep... Initially I thought I was burning the candle at both ends, and just needed to have a bit more rest in the evening.

Because tiredness can seem a normal part of daily experience, and because some sleep problems are only evident when the patient is unconscious, it can take another person to see that something’s wrong.

ROBERT I didn’t really realise it, my mum did. At the time, I just thought it was natural... Like, when I was doing activity, I would nod off or go to sleep. But teachers and other people would think it was because I had stayed up overnight. But the majority of the time I hadn’t, and that is when my mum noticed that there was something wrong.

JOHN It was one of my teachers who noticed that I was falling asleep, and not paying attention in class. And she contacted my parents to find out if they knew what was happening. And that’s when we started to look into it... I kind of ignored it really. Between all of us we’d got used to it, we thought it was a character or personality trait, but the teacher thought we should look into it a little deeper.

ROSE It’s more my partner noticing when I am asleep that there are times when it sounds like I am either stopping breathing momentarily or sounds like I am choking.

Even acknowledging that something’s amiss doesn’t always help, however. Patients don’t naturally recognise that they might have the symptoms of a sleep disorder.

GINA It was something that I had been getting ever since I was a teenager really. I just thought it was a strange type of dream. I never really thought that it was something with a name.

SUZY What I experienced first was what I now know was part of my cataplexy, which was loss of muscle in the face because something was very funny. So when laughing it feels like you are paralysed. And I didn't know what was wrong at all. It was very frightening.

ANNE I always had really vivid dreams and I thought that was normal. I also used to get sleep paralysis, and I thought that was normal as well. Just before dropping off, I used to feel that I could hear voices and stuff in the room, which is part of the narcolepsy. And that would sometimes be quite frightening. You think – can I hear voices? Is there someone there? Is the house haunted?

Tony’s misunderstanding delayed a diagnosis of cataplexy for several years. He’d just finished his A-levels when he sought treatment for the hallucinations he’d been suffering:

TONY The first time I went to see [a consultant in a Sleep Clinic out of London], they weren’t able to give any sort of conclusive diagnosis because when I actually had...
the interview with the clinician, he asked me questions like ‘Do you have sleep paralysis?’ and I didn’t understand what it was. I think I asked him ‘What is that?’, and he said it was when you can’t move when you wake up. I didn’t realise that the timescale might be only thirty seconds. I thought he meant someone would be lying there for half an hour, so I thought ‘No, I don’t have that’.

And Suzy might just have gone on thinking she was tired if it hadn’t been for her other symptoms:

**SUZY** I don’t think I would have had [my sleep disorder] diagnosed if it wasn’t for the cataplexy. I think I would have thought that I was a bit crap.

**DIAGNOSIS**

Many patients spoke of the time it took to be diagnosed. This was particularly the case for those with narcolepsy and cataplexy.

**ANNE** I was 29, which is quite late to be diagnosed... I went to the doctors because I was concerned about this feeling in my arm. I didn’t know what that was. It took about a year and a half for them to diagnose me – I was diagnosed in March 2012.

Matters were sometimes also complicated by misdiagnosis, and some patients clearly felt that their own insights and feelings should have been better respected.

**ROBERT’S MUM** They need to be more aware of [narcolepsy]. What happens with children is they just want to put it down to weight, or their diet or lack of exercise or that I am allowing them to sit up all night watching TV, or playing [computer] games. And I am telling them this is not how it is, that this is what happens. It is only because he passed out in school twice, and an ambulance was called, that is when the GP actually sat up, and was like ‘Oh, ok, we will send him to Guy’s to be tested for a sleep clinic.’

**ANNE** They tried to suggest that I might be depressed, and tried to prescribe anti-depressants to me. I am someone who takes medication if I have to, but it is not a one tablet fits all and I think it’s a bit too easy. Luckily for me, whenever they did suggest that, I said ‘No! That’s not the answer’... I wasn’t scared about bothering them.

**JOURNEY IN PRIMARY CARE**

Patients had different experiences of their journey in primary care, from first seeing a GP to receiving treatment in primary care or being referred on to a specialist. For some, simply getting an appointment was hurdle in itself.

**ANNE** You know how hard it is to get an appointment these days, you do just think, ‘Can I be bothered?’

**ROSE** Trying to get GP appointments is always an issue.

Two patients had their sleep problem quickly identified and a speedy referral made to specialist care.

**SUZY** My GP was really incredible. I was really lucky with her – extremely lucky.
could you please make a referral so it can be investigated. I didn’t seem to hit a problem.

Things were not improved by what some perceived to be a lack of knowledge about sleep disorders within primary care.

ANNE It was frustrating because when you don’t know what’s wrong with you, and you know that something is not right, you are going to people who you think should be supportive and listen to you. I felt it was a bit of a battle to get the right level of test to diagnose my condition. And even following my diagnosis what frustrates me is the lack of knowledge within the NHS about it.

GINA It wasn’t a particularly rewarding experience, going to the GP surgery and realising that you knew more about it than they did because of the five minutes research on Google that I had done. But when I went back the next time, they took me more seriously because they had gone away and researched it... Then they started thinking about referring me to a Sleep Centre.

FEAR AND RELIEF

Many of the patients described their fears about what might be wrong with them before they were diagnosed.

SUZY I didn’t know what was wrong at all. It was very frightening. I went to my GP and she said, ‘Come on now, worst case scenario. What’s your fears? Let’s get them all out.’ And I said, ‘I think I’ve got a brain tumour.’ And she said,
that it might be something just intrinsic to me, my attention span had gone down or something, or alternatively it was something medical but it wasn’t something that was currently understood... That was something I couldn’t face ‘cos I knew that then I would have to continue going on the same way as I had been. So in a way I was kind of pleased when I was diagnosed.

TONY These were things I hadn’t even talked to my parents about or anyone else. I suppose it’s the stigma that’s associated with mental health. I thought at the time I was going mad.

Patients described their relief at finally getting a diagnosis:

JOHN We had spent quite a lot of time on the diagnosis of upper airways resistance. We’d tried various things, everything short of surgery – which was not something I particularly wanted. It was kind of a relief because there was at least a different diagnosis, that maybe we could find the medication for – which actually has helped.

ROSE It is nice to know that it is at the lower end of the spectrum. It takes away concerns. I’m very relieved that I won’t have to wear a mask at night – I had visions of the cat attacking me! Trying to get it off my face. Also it is a relief to know – the fact that it is more common is normalising.

TONY It was odd. I found myself actually hoping to be diagnosed with it. It seems crazy – why would you want to be diagnosed with something like this? I found myself really, really hoping it was narcolepsy because the alternative, that it might be something just intrinsic to me, my attention span had gone down or something, or alternatively it was something medical but it wasn’t something that was currently understood... That was something I couldn’t face ‘cos I knew that then I would have to continue going on the same way as I had been. So in a way I was kind of pleased when I was diagnosed.

TREATMENT IN PRIMARY CARE

Of the patients interviewed, three who were being treated by their GPs for sleep disorders also had other medical conditions or problems. Ivy has cancer, Lowe is diabetic, and Ahmed, who suffers from chronic insomnia, has depression:

AHMED They say it is depression, and they have been giving me anti-depression tablets... I have tried exercise. I am tired. I am in the bed. Still I cannot sleep. I cannot relax in bed. Is there any medicine to help me for sleeping? How can I improve my sleep?

Ivy, who has been offered a range of treatments for her sleep disorder, prefers to be treated in primary care with sleeping tablets.

IVY I have been to a sleep clinic. They gave me a few tricks. It was just a clinic up at the Maudesley. It was different ways of trying to relax. Sometimes, it used to work, but it doesn’t really work that much anymore. It seems my brain just keeps going. The doctors are great. They give me the tablets.
JOURNEY INTO SECONDARY CARE

The interviewees had mixed experiences of the journey into secondary care. Once referred to the SDC, some had a lengthy wait for their first appointment, but after this point progress was usually smoother.

ANNE It took quite a while for my GP to eventually refer me to a neurologist, and I went to a neurologist and had the same sort of conversations. He referred me to have some brain scans, and then I had the sleep study at St Thomas’. Which was the final point when they actually recognised that was what my symptoms were.

GINA Immediately at the end of that session, a doctor came in and told me having read all my charts and suggested that according to my sleep patterns, I did not have narcolepsy.

Patients praised the understanding, consistency and standards of care at the SDC.

ANNE The specialism is here. The reality is my GP doesn’t know about the condition, and there’s no willingness for them to learn anything about it, and at my local hospital no-one knows about it. My neurologist knows of it, but not about it necessarily. You haven’t got anyone to speak to [outside the SDC].

SUZY All the different doctors, under Dr Williams, I have seen over the years have been fantastic... The whole unit has always been fantastic.

For some, communications were identified as an irritation –

ANNE It was the sleep clinic [which diagnosed my narcolepsy]. And so, that’s quite frustrating as my neurologist keeps sending me out random appointments and I have to go and tell him about everything that St Thomas’ has done. Like, come on guys...

– while others found it hard simply to get through to their consultant or the clinic.

FRED Phoning is very difficult to get through to the clinic. Getting hold of someone is difficult.
MOVING FROM A CHILDREN’S SERVICE TO AN ADULT SERVICE

For Robert, who had been diagnosed as a child, it was a difficult transition from children’s services at St Thomas’ to the adult service at the SDC when he was 16. His mother described the problems they experienced. She suggested that consistency, a more gradual move and better communication between the two services would have made the transition easier:

ROBERT’S MUM

I found the transition from him leaving the children’s sleep clinic to the adult’s one, not good, to be honest. As soon as he turned 16, he was moved straight over to this one. He had been so used to [his previous doctor]. He had a rapport with him, and he had done meetings with other children his age. They’d done group sessions where he got to meet other kids. They got to talk about their situation, and how they were...

But it’s like there’s a gap... because you have turned 16 you are no longer a child, you are with the adults. But they are still children, they’re still young adults. So I think the doctors should work alongside them until they reach 18, and then transition them over to the adult section. Otherwise it is too much – you’re there one moment, and then you are over to this side, and then you don’t feel like you have the same support that you had and you have to explain again.

Since these interviews took place a joint clinic has been established to deal with the transition between the two services.
GINA  It took them quite a long time to actually send the information to my GP about prescribing the melatonin, but [the GP] said because of the cost of it versus the effectiveness of the drug, they had decided that they wouldn’t prescribe it in that area... It hasn’t been the best journey. I’ve now been discharged back to my GP. If they choose not to prescribe the drug, then that’s kind of it.

Ivy and Lowe are on sleeping tablets prescribed by their GPs for insomnia – a long-term solution they seem perfectly content with.

IVY  I do rely on the medication. If it was taken away from me I would struggle because at least I know, Friday or Saturday, I take the Zoga one, which I know will knock me out after a busy week. And about Tuesday I think about the Diazepam, and that will give me a good night’s sleep to get me through the rest of the week.

LOWE  My night sleep is not very good which is why I take sleeping tablets. I am happy with them. Sometimes I take a half instead of a full one.

For two patients, however, getting medication from their GPs was problematic: their local Primary Care Trusts (PCT) would not fund the drugs they’d been prescribed by the SDC. The patients found this difficult, disappointing and baffling.

SUZY  Camden PCT decided about five years ago that Ritalin could no longer be prescribed by GPs, so it has to be prescribed by a consultant. It’s a budget thing – not my GP’s decision. I think it’s awful. How can Camden be allowed not to let GPs prescribe the correct medication? Someone has to pay for it! It is not what we hoped from a NHS service.

THE TREATMENT PATHWAY

TONY  It is something that I have just got used to. It was not knowing before that was a big part of the problem. Not actually knowing why I felt the way I did. And now that I do know, I feel empowered to start to get my life actually back on track.

SUZY  Most of the time it makes me cross. It is so boring I can’t be bothered to talk about it or explain, and I can’t explain it as it is very difficult still after all this time. And there are periods when it does make me very upset.

JOHN  I think it [narcolepsy] did have an impact on me until we sorted it out with the treatment. The biggest thing for me is that it only affects me when I forget to take the Modafinil.

ROBERT  Basically yeah, it is just who I am.
I recognise that I will always feel tired. I get up every day and I feel tired and it will just be in varying different degrees. I have made the conscious decision that I can either succumb to that and spend my life drifting in and out of a nap at home, or I can think I don’t want to waste my time away sleeping... Life is not fair, this is the card you have been dealt. Just crack on with it. Because you still want to have a happy life.

Fred has had to make many adjustments because of his sleep disorder.

Fred has had to make many adjustments because of his sleep disorder.

I have had a lot of life-style changes. I can’t drive that much. Physically I used to be quite active, and I haven’t been able to be so active recently. I have had to cut down loads of things. I’ve had to change what I can eat. You can’t drink. There are loads of things you can’t have. I used to be a caffeine addict. I haven’t had caffeine for over a year.

Gina, however, is not resigned to her condition or its treatment. She worries that she might have been prescribed a drug before her disorder was properly understood, and holds out hope for a diagnosis that will change everything.

I do wonder if the melatonin is the best route to go down. Doctors tend to do this thing when they just prescribe something, and I wonder if, because it has been happening for such a long time, there could be some other underlying reason which should be investigated. It would be great to crack it. It would transform my life. Definitely.
For this section, the themes identified were: personal struggle; an ‘invisible’ condition; dealing with stigma; revealing the condition; personal history; impact on personal life; and impact on work life.

**PERSONAL STRUGGLE**

The interviews demonstrated that some sleep disorders, especially narcolepsy, are not well understood by the public. Patients described how this affects them.

**SUZY** Nobody understands it. It is not explained. It is very difficult to explain, and it is something that is rarely talked about, and when it is talked about, it is talked about in the extreme. And so people don’t think about there being different degrees or levels of how narcolepsy affects people.

**ANNE** People do see it as a bit of a joke. And it is hard to get people to recognise when you are feeling a bit tired, and you say ‘Can you help me out, I am feeling a bit tired’ and they go, ‘We’re all feeling tired.’ I try to explain it by saying if you imagine epilepsy, it’s sort of the opposite to that. It is like your brain having a mini seizure.

Tony is in his second year at university. Having been diagnosed with narcolepsy, diagnosis, he asked for mitigation but the support he received was not enough:

**TONY** There was stuff I was still struggling with from the year before. There was so much catching up, effectively I felt the mitigation just set me up to fail... I was on medication at this point. Part of the
reasoning was that because I was on medication they would treat me as a normal student for the exams. During the exam period, I was taking 400 mgs of Modafinil and about 180 mgs of caffeine each day, and I still found myself falling asleep. It ended up being very, very difficult.

Suzy finds it personally upsetting if she has a cataplectic moment at work:

**SUZY**
It lasts just a few seconds but it is noticeable! You can see people's faces slightly changing. And so if I can feel it at work, I really have to put my head down. But sometimes it comes out of the blue, and I try to turn, but sometimes everything is stuck. I don’t know what it looks like. I don’t want to.

Fred has constant dizziness which was triggered by viral encephalitis. He is being treated at the SDC for his sleep apnoea, as lack of sleep makes his condition worse. His dizziness is sometimes mistaken for drunkenness at work, which he finds embarrassing.

**FRED**
It feels like when you have had a lot to drink, and you get that feeling at night – you have to put your foot on the floor at the side of the bed to stop it spinning. My life is like that 24 hours a day. Now it has gotten into shorter spurts. There were times when I couldn’t walk straight. I couldn’t stand. At work I would walk with my hand on the wall to balance myself. They would all laugh at me.

ANNE

People think because you have narcolepsy you sleep more than the average person, but in reality you probably sleep less. Because a mouse will sneeze up the road and wake you up. Because your body isn’t comfortable putting you into a deep sleep. You are always in a light sleep which means you will always feel tired.

Simply managing what most people would take for granted is a challenge.

**ANNE**
Some days, we haven’t even had time for a lunch break because things are that busy. We are bathing our little one in the evening, putting him to bed, cooking dinner, doing the washing, and then weekends you fit everything else in. I feel frustrated but I try to remind myself that there are other people with narcolepsy who wouldn’t be able to achieve everything else that I have been able to achieve during the week. I am definitely less tolerant of people when they just want to lay in bed all day. I just think ‘What a waste, what a waste.’
Teetering constantly on the edge of sleep poses all sorts of social problems. Patients described a range of responses from lack of sympathy to sheer incomprehension. Sleepiness is easily misconstrued.

**TONY**  
Even talking to some of my best friends at university, they don’t really understand. They understand it in terms of the aspects of an outsider, but the problem is that the symptoms that you have, falling asleep and stuff, these are things that are commonly associated with things like laziness, hangover, not being able to get up in the morning: typical uni stuff... And I think that when my friends didn’t see me in university it was easy to assume – and I don’t blame them – that I was lazy.

**ROBERT**  
If you don’t know about something... you don’t know if someone is just forging it, or just putting it on, so you won’t believe that person.

The effects of the condition can be profound in terms of stress, security and even career choice.

**ANNE**  
I worry about being out and about and dropping off. Or if I’m going to be sitting on a park bench with my little one, and dropping off because I am too tired... I would be lying if I said I didn’t have those concerns. But I think people don’t deal with the emotional side of things. And that does create anxiety and stress. And maybe that is why some people with the condition, maybe don’t go to certain jobs because they worry that it won’t be understood.

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**DEALING WITH STIGMA**

Some patients described how they felt there was a social stigma associated with narcolepsy and cataplexy, which could be challenging to deal with.

**SUZY**  
I don’t want people to know because I think if they know they pigeonhole you. And it does feel like, it isn’t a disability but you look at that tick in that box – is it one? And I think that sometimes it is, but it would never be understood.

**ANNE**  
One of the common side effects for narcoleptics is the feeling of isolation because of the social stigma, because of the lack of knowledge, and with that there is a tendency for people to feel depressed. I can definitely relate to that. There are definite points when someone asks me directly and I think do I just lie or should I be open and honest about it, because you don’t know what the reaction is going to be. Because at the end of the day, you can’t even speak to your friends about it because they don’t really understand how you feel. And when people don’t understand how you feel, you tend not to bother saying anything because people think you are just making it up.

**ROBERT**  
If you don’t know about something... you don’t know if someone is just forging it, or just putting it on, so you won’t believe that person.

**TONY**  
When I first saw the clinician I must admit there was a reluctance on my part... I think at the time I thought I was being haunted by some sort of demon or ghost, and I obviously didn’t
want to mention it. Because when you go and see a doctor, especially when it is for something like sleep, you don’t associate it with things which you might imagine fell under the purview of mental health issues as opposed to physical. There is a quite a separation of the two in the common mindset.

With stigma and incomprehension goes a sense of isolation. Patients described how they would like the chance to talk to others about their condition.

**ANNE**  If I want to see a counsellor, I have the means to pay for one myself. But not everybody has that. I don’t think there is enough provision for people to have that outlet. It is only people like us being open and honest that will make things better for people in the future.

**TONY**  I think it is incredibly important to hear stories about how people cope with narcolepsy. I remember when I looked onto the internet, and there was a story by someone who didn’t know they had narcolepsy, and they had gone through Harvard Law School. And I thought, oh God, this is incredible. The strength and fortitude. It’s inspirational.

Robert and his mother missed the support they used to get from group meetings at the Paediatric Centre.

**ROBERT**  To be honest, I didn’t really communicate with everyone, but when they was talking, I listened. And I took in what they said, because a lot of things they talked about had happened to me and them. And I would think about it and I felt I was in a better way.

**ROBERT’S MUM**  They all had the same feeling about parents being over-protective. It was good to hear from them, as the parents were there also. So we got to hear what they wanted to say afterwards. So it helped us, to help them, and to better themselves.

**REVEALING THE CONDITION**

What makes people decide to reveal a condition that might be stigmatised, and how do employers react? For some patients it was relatively straightforward – the decision made itself, and the response was positive:

**FRED**  They had to know. At first they thought I was drunk. And I had to tell them what was going on. I work for a very large American company and they are very good. They are all about work ethic and they understand that they work us like dogs, and they don’t want it to be the effect of why you are ill, so they are very sympathetic about it.

**GINA**  I have told work because there have been a couple of incidents when I’ve fallen asleep in meetings and stuff. So I had to tell them, and they said ‘Make people aware of it. If you know you are feeling tired, don’t wait.’

**IVY**  I’ve got a fantastic boss. I can be flexi. I please myself. So if I have a real bad day, I can say I will work from home.
For others, letting people know would feel much more difficult.

**SUZY** It can be quite ruthless out there at work. You can’t really show any vulnerability, even in the public sector. It’s very competitive, and it’s like from senior level down you are only as good as what you are delivering. So for all of those reasons I don’t tell work. If something were to happen it would be ‘oh well’ or I would be looked at more or there would be more emphasis on looking to see... Rather now nothing has been questioned, so that’s fine. And it is my body, my health, my life and my career, and I don’t need another barrier.

Robert is still at school; as far as his mother is concerned it is absolutely essential that his friends know and understand about his narcolepsy, and that his school is repeatedly reminded.

**ROBERT’S MUM** At first he didn’t want to tell nobody. But I said to him it’s important, you’ve got to tell your friends, even your closest ones, so they understand, so if it does happen they can keep you safe when they’re with you, or they can contact me if they can’t bring you to or they’re worried... With the school, I had to keep on with them about him having the extra help, having the extra time for the exams, making sure they had everything in place. To help him, he should have a little nap, twenty minutes through his break time or lunchtime, whatever suited him. Sometimes it would be through the class, but I would remind the teachers, ‘Please wake him up, let him walk around and get some air so that he is not missing too much of his learning. Otherwise, if you allow him to sleep in class, then he is not learning nothing.’ So it was just a constant, always on their case.

**PERSONAL HISTORY**

What gives rise to a sleep disorder? Some of the patients identified autobiographical factors that they felt explained or contributed to their condition – and, in one case, helped them deal with it.

**FRED** Coming from South Africa, you were quite alert whilst you slept. Very aware of noises in the house. I grew up having a wife and child in South Africa, and you feel very protective of those around you whilst you sleep. You don’t go into that very deep sleep.

**IVY** I’ve never been a great sleeper due to the fact that oldest son is autistic. I used to be up to 12 or 1 at night, knowing that I have to get him up and start the day at 7. Once he went to boarding school it got better. But then I became ill with cancer. And after that, that was it.

**LOWE** I think my sleep problems come because I used to be a publican, and I never got to sleep until 3 or 4 in the morning. It’s the old habits still there.

**AHMED** I have had a very, very hard life. It [the insomnia] was beginning from that time because I was scared. My brother, father, sister, mother were all in one
THE DARK SELF

place, and I was living in another, and I was broken down with emotion. So, from that time it was happening for me.

ANNE I think what makes a big difference [to my coping] is that my twin sister has had diabetes since she was seven, and one of my sisters has epilepsy. One of them has polycystic ovaries. All of them are auto-immune responses. I think her having diabetes has helped, because every time my sister felt down about it, I can remember my mum saying, ‘They can’t take it away.’ That has definitely helped, because she didn’t cut her any slack: ‘You have to manage your diet, you have to manage your blood sugar. You can only be helped a certain amount, the rest of it is on you.’

IMPACT ON PERSONAL LIFE

The patient interviewees talked openly about the impact of their sleep disorders on their personal, emotional and family lives. Some have made difficult choices; others feel that unwelcome decisions are being made for them.

SUZY It is something that I feel very sad about. It is not like I am in a position, I haven’t been for a while, to have a baby with anybody, but now I don’t feel I could. I don’t feel I’m in a position to support myself not being at work, to be able to be off medication for long enough... I remember being six years old very, very clearly, and understanding for the first time that I could have children myself, and thinking it was the most incredible, marvellous and extraordinary thing that

THE PATIENT EXPERIENCE

I had ever learnt, and how excited I was! I was going to have loads of them... always. It was always what I wanted.

ANNE Even my family have – like my twin sister, she has got a one-year-old, and when my niece was born she was frightened to let me hold her for ages because of my cataplexy. Which was hard, because I wouldn’t have been frightened to leave my son with her because of her diabetes. If she’d had a hypo while she was looking after him, I would have totally understood that she had no control of it. But the other way round, she physically wouldn’t... wouldn’t tell me directly, but she made up a reason why I couldn’t hold her.

Even everyday bureaucratic transactions can have a sting in their tail.

ANNE I have just had my driving license renewed for three years. But the blooming dramas around getting it! I handed my license in voluntarily when I was diagnosed with narcolepsy. I physically volunteered for it. And it took them eighteen months to say yes, you can have your license. It’s the stress around that.

IMPACT ON WORK LIFE

It can be complicated to manage sleep disorders within the workplace. Some patients felt their condition had held them back; others regarded it more as a challenge to be overcome.

SUZY My career, well it’s a funny thing. I am on the same level I have been on for the last ten years. But I do sometimes think
when I have a bad day, how could it be possible for me to be at that much higher level? Where I can’t make an escape for ten minutes, excuse myself from something, pretend that I am late for something. Without exposing myself. And I think it is something that will not be understood. I just think I would be more exposed.

TONY It was ups and downs during my first year. I definitely struggled to keep up, as I have this year as well. For a long time I couldn’t understand it. I was going to lectures and falling asleep. I couldn’t understand why. I didn’t think it was a medical reason.

ANNE I am a commercial underwriter, so my job is stressful. To be able to go to work all day, and apart from those points of tiredness, to be able to get through it without needing to go and lay down and have a nap – for this condition, that’s a big achievement. So I have to remind myself when I get frustrated that this is a big achievement. I definitely feel for other people with the condition. People don’t know enough about it and people are not getting the right level of support.
Treatment begins with diagnosis. Getting a diagnosis, however, is not always straightforward. This is perhaps particularly true for patients with narcolepsy. It is a rarer condition which is somewhat difficult to diagnose because it is so unusual. The majority of patients interviewed for this study had a narcolepsy diagnosis, but it had taken them a long time to get one.

**DIAGNOSIS**

Patients described their experience of misdiagnosis and misreferral:

**ANNE**  It was suggested that it was an allergy to something I was eating. Brilliant – can you refer me to a dietician?

**TONY** So I went to see my GP and he told me about a clinician who was running the ‘Funny Turns’ clinic which was all about falls and trips, and people having those sorts of problems. I went to see the guy and he assessed me, and he did give the diagnosis. He said it was being caused by anxiety, long-term anxiety, with hypoventilation syndrome.

According to Professor Williams, one in 2,000 people in the UK has narcolepsy. This means that there are likely to be 30,000 sufferers nationwide, but only 6,000 to 7,000 have been diagnosed. This suggests that there may be a hidden population for whom a diagnosis can take years – often a very difficult period as witnessed by the patient narratives in this report, and sometimes one in which patients feel themselves to be battling to be heard.

**ROBERT’S MUM**  It took a long time before the doctors would actually refer him to the Sleep Clinic. And when I started really pushing them and saying
‘Look, this is happening at school, and it is affecting his schooling, and I need him to be seen as I can see the same pattern as when I was falling asleep, just nodding off anywhere. I don’t want it to upset his exams. I want him to be able to learn.’ That’s when they took me seriously and decided then, OK we can write off to the doctors. [It took] three or four years. He never got tested until he was eleven.

ANNE I took almost two years... Had I not been pro-active in taking on board what they were saying, and following it up, I don’t even know if I would be diagnosed at this point.

TREATMENT

There is no simple cure for most sleep problems. Historically, a doctor might recommend that a tennis ball was sewn into the back of your pyjamas to stop you snoring, and people who sleepwalked were tied to the bed-post. Today, sleep disorders are often managed through lifestyle changes, weight loss advice, mindfulness and CBT, drug therapies and the use of CPAP machines and mandibular advancement splints. Sleep disorders encompass the anatomical, the physical and the psychological, and the range of treatments available reflects this.

Medication is used in the treatment of many sleep disorders. Drugs like Modafinil and Ritalin can help manage the symptoms of narcolepsy, while Melatonin is sometimes prescribed for insomnia. However funding issues mean that treatments prescribed by the SDC are not always available in primary care, which a number of patients described as causing problems.

Many of the patients interviewed were on medication. Those with narcolepsy and cataplexy had come to terms with taking drugs for the rest of their lives – even if it was not the ‘silver bullet’ Tony had hoped for. And while patients like Ivy and Lowe are happy to take sleeping pills for their insomnia, doctors are increasingly reluctant to prescribe them:

DR WICKSTEAD My instinct is not to... because I have seen enough people who are addicted to them.

DR MITRA I try not to use drugs because they are addictive and they stop working.

For narcolepsy and cataplexy, drugs are the only treatment. For insomnia and other disorders, however, there are alternatives. Local GP practices are trying to promote CBT and other therapies so that patients can improve their sleep on their own without medication. At the SDC Professor Williams is researching and developing smartphone apps to help patients practise mindfulness techniques. While GPs already have access to CBT, they would like mindfulness to be more readily available.

DR MITRA We try and use a psychological approach. We have a CBT therapist at the practice.

DR WICKSTEAD Yes, we are very keen on mindfulness. And we have had a problem getting access to it, it seems quite hard getting access to mindfulness therapy. So some simple self-help mindfulness that we could give the patients could be very useful.

SLEEP CAUSES OTHER PROBLEMS

The amount of good sleep we get impacts on both our physical and mental health, as well as on our ability to function in the world.
It was evident from the interviews that many patients found the complications of living with their condition profoundly challenging – socially, psychologically, emotionally. These were symptoms that the drugs or other treatment couldn’t touch. Those with narcolepsy especially felt themselves to be suffering from an invisible and misunderstood condition, with a social stigma attached. My own conclusion from these personal testimonies is that a campaign to improve public awareness and understanding of these conditions would go some way towards destigmatizing them, helping relieve sufferers’ sense of isolation and thus generally improving their health.

**GP s AND THE SDC**

In response to the questions set out in the topic guides (see Appendix), the GPs reflected on their relationship with the SDC.

| DR WICKSTEAD | What would be very interesting would be to get feedback as to whether they thought our referrals [for sleep apnoea] were inappropriate, but usually they seem to come back with a CPAP machine which shows the referrals were right. We all don’t like to prescribe sleeping tablets... but I wonder what the Sleep Centre’s view is. I have one patient who is having loads of CPAP and getting |

Patients described how their sleep disorder affects them in all sorts of ways.

I stop breathing in the middle of the night. I panic – it’s like you can’t breathe. I open the window for air. Breathing – breathing loud, and then it stops, and then panic! It has got worse – I’m getting more tired every day. Most nights I sit up until three or four. I can’t fall asleep – my mind is worried about not breathing and I panic. I think I am going to die.

Even if I get a bit emotional, the cataplexy happens again. I fall down – I am covered in bruises. I fell backwards recently and bumped my head. It is caused by my laughing, crying, being over-excited, thinking about things. I just go down... I have three kids – 9, 11 and 16. They notice that I don’t leave home – I have to get them picked up from school. I’m in the house all the time because of my narcolepsy and cataplexy.

People are unkind if you fall – they think you are drunk. I now dress up when I go out – I need to get a medical bracelet. There is bad insomnia in my family. The narcolepsy was picked up when I fell asleep in an eye examination. I have between five and eight cataplexy attacks a day – about 40 a week.

I have fallen asleep in exams and when learning to drive. I get a really weird feeling that my body has changed shape. It feels like my legs are flat... It is dream-like but I know that I am still awake.
no sleep at all, and I looked at the Sleep Centre’s notes and they suggested a small dose of Zopiclone, which worked wonders. He is now using the machine much better. But there is always the fear that people get addicted to them, and it causes dementia. So I would be interested in what the latest view on that is from the SDC.

**DR MITRA**

It would be useful [to have a written summary of sleep disorders]. It would also be useful to have something web-based. Most of our patients go onto the web so that would be best.

I think there could be a bit more outreach from the Sleep Centre – come and talk to us about what you do, and about how to manage conditions. A bit more outreach and public education. Everyone is monitoring it and worrying about it so I feel a bit more general education about what is sleep and how much is good enough, would be very helpful. If you put on a lecture about sleep, I am sure that many people would come.

These suggestions from the GPs – for more feedback, clearer advice, and a request for better outreach – are incorporated in the recommendations of this report for action by the SDC.
An artist in the out-patient Sleep Clinic – what on earth can that mean? Having had the distinct pleasure of hosting artist Susan Aldworth in my weekly clinic, I think I can answer.

Susan has brought to the Clinic an artist’s intelligence, sensibility and responsivity: an ability to see and articulate what patients themselves try to understand and sometimes struggle to explain. In doing so she has not only allowed patients to express themselves more easily, but has highlighted the importance of sleep in maintaining health, personal and societal. Her ability to tease out patients’ subjective experiences is evident throughout the report. This information can also help us as clinicians in our treatment of patients, by letting us know how they feel and what concerns them most.

Most patients who come to the Sleep Disorders Centre have been referred from primary care. The transition is not always easy. Susan has successfully and sensitively identified the issues patients and GPs see as important. Her findings have encouraged us to explore new relationships between GPs and the Sleep Disorders Centre, and we plan to implement her recommendations. These are the organizational adjustments we can make.

To realise the full potential of the project, however, we need to build on Susan’s contribution as an artist. The whole environment in which treatment is delivered will be enormously improved by the works of art that will come out of this research. It is intended that these should be displayed in both the SDC and local GP surgeries, and by their reflection on the subject of sleep they will be a lasting legacy of this study.

Adrian Williams FRCP
Professor of Sleep Medicine, King’s College London, and Guy’s and St Thomas’ NHS Foundation Trust
**Categories of Sleep Disorder**

- **Hypersomnia**
  Excessive wake-time sleepiness (an Epworth Sleepiness Score >10) caused by lack of sleep, interrupted sleep as a result of obstructive sleep apnoea (OSA) or restless legs, or other medical problems such as asthma or pain, or by internal sleepiness from narcolepsy.

- **Insomnia**
  Difficulty getting to sleep, staying asleep or unrefreshing sleep with daytime consequences.

- **Parasomnia**
  Something unwanted happening at night.

**Sleep Disorders**

- **Cataplexy**
  The paralysis of REM in wakefulness; precipitated by emotion.

- **Narcolepsy**
  A central form of sleepiness characterised by an earlier entry into REM sleep at 1–20 mins instead of the usual 90 mins. When at sleep onset this is responsible for the dream images/hallucinations called *hypnopompic*.

- **Restless Legs**
  An uncomfortable feeling in the muscles that is relieved by movement, occurring in the evening.

- **Sleep Apnoea**
  Obstruction of the throat airway in sleep due to insufficient tone in the dilating muscles.

- **Sleep Paralysis**
  The persistence of REM paralysis into waking. Normal, affects 40% of people a few times.

**States of Sleep**

- **Deep sleep**
  Slow wave non-REM sleep (there are three levels of sleep; deep sleep is level 3).

- **REM sleep**
  Rapid Eye Movement sleep, when most dreams occur and the body is literally paralysed to prevent dream enactment. We progress in an orderly fashion from light NREM (non-REM) to deep NREM then REM, repeated four to five times nightly (known as sleep architecture).

**Glossary of Terms**

- **ENT**
  Ear Nose Throat surgical subspecialty.

- **Epworth Sleepiness Scale**
  Standard measure of daytime sleepiness.

- **Hypoventilation Syndrome**
  Reduced ventilation in sleep with consequent rise in carbon dioxide.

- **Oxymetry**
  Measure of blood oxygenation via a finger probe.

- **Upper Airways Resistance**
  Narrowing of the airway approaching obstructive sleep apnoea (OSA).

**Drugs Used in Sleep Medicine**

- **Diazepam**
  This is valium which is the chemical basis for all benzodiazepine hypnotics such as zopiclone and clonazepam. They help sleep.

- **Fluoxetine**
  An antidepressant used to limit cataplexy via effects on REM (REM restriction).

- **Hypnotics**
  Sleep aids (see above).

- **Melatonin**
  The natural hormone of the night secreted by the pineal gland and as a medicine used to re-time the body clock.

- **Modafinil**
  A wake-promoting drug.

- **Ritalin**
  An older stimulant, like amphetamine.

- **Zopiclone**
  A benzo (valium) derivative, which is a hypnotic.

**Other Treatments for Sleep Disorders**

- **CBT**
  Cognitive Behavioural Therapy for insomnia, sleep hygiene and restricted sleep.

- **CPAP machine**
  Positive pressure applied to the nose/mouth to provide a pneumatic splint to the pharyngeal airway.

- **Mandibular advancement splints**
  Dental device for sleep apnoea.

- **Mindfulness therapy**
  Non-religious meditation.

- **Sleepio (CBT) and Headspace (mindfulness) apps for sleep**

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These topic guides informed my interviews with patients and GPs for the project.

**FOR PATIENTS**

**Research aims:**
- Explore patient experiences of sleep and sleep disorders
- Explore patient experiences of treatment for sleep disorders

**Topic guide:**
1. Explore what is normal sleep and what is a sleep disorder from both patient and clinical perspectives.
2. Explore individual narratives of sleep disorders
3. Explore and understand the patient pathway from referral to diagnosis of the sleep disorder
4. Explore and appreciate the benefits of treatment for individual patients
5. Document the patients’ perspective of the journey

**FOR GPs**

**Research aims:**
- Explore GP experiences of treating patients with sleep disorders
- Explore GP referral pathway to SDC

**Topic guide:**
1. How many patients present with sleep complaints over a month?
2. How many patients come back repeatedly with sleep complaints?
3. What protocol do you follow for patients who snore:
   - a. ENT referral first?
   - b. SDC referral first?
4. Would your GP practice be interested in some initial screening test-tools to limit referrals to the SDC:
   - a. some specific questionnaires?
   - b. oxymetry testing?
5. What is your access to CBT?
6. Are you interested in finding out more about mindfulness initiatives to help patients self-treat their sleep disorders?
7. Would it be of value for your GP practice to have a written summary overview of sleep disorders?
8. Have you considered exploring the use of smartphone devices as part of your recommendations to patients to help with their sleep disorder?