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Faculty of Medicine

School of Primary Care, Population Sciences and Medical Education

Management of Paediatric Chronic Insomnia in Primary Care

by

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Thesis for the degree of Doctor of Philosophy

September 2022

University of Southampton

Abstract

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Doctor of Philosophy

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Behavioural insomnia, a form of chronic insomnia, is highly prevalent in children. Persisting sleep problems can have multiple impacts on the child and family. Behavioural/sleep hygiene interventions are effective management strategies, and primary care provides the potential for early management and prevention. This thesis explores the management of chronic insomnia in children within primary care.

A systematic review explored the evidence-base for primary care practitioners' (PCP) knowledge, beliefs/attitudes, and practice. A systematic narrative synthesis of 26 studies found that PCPs are aware of the impacts of chronic insomnia, perceive management to be within their role, and endorse behavioural management strategies, but have varied knowledge and confidence for management. However, the methodological quality of the studies varied, and they were from limited primary care settings and countries (usually UK health visitors or US paediatricians). Higher quality UK research for both GPs and health visitors was lacking.

A qualitative study analysed posts in online discussion forums to explore parental concerns about children's sleep problems, awareness of management resources, and perception of management within primary care. Results from 93 discussion threads across two forums suggested that: parents have multiple and varied concerns relating to their children's sleep; that parents often turn to one another online for emotional and practical support; and use resources online, non-PCPs (such as private sleep consultants) and books. It is uncertain how many of these resources are evidence-based. Parents posted about primary care less frequently but had mixed experiences of and attitudes towards health visitors, and limited experiences with GPs.

A mixed-methods study (surveys and qualitative interviews) of UK practicing PCPs was conducted to explore their knowledge, training, beliefs and practice for insomnia management in children up to the age of five. Survey findings (n=355, mainly GPs) suggested that PCPs perceive negative impacts of chronic insomnia on children and their families and believe that it should be addressed in healthcare. However, insomnia is infrequently discussed in consultations, PCPs have varied knowledge and confidence regarding management, and limited training and knowledge of resources. Interview findings (n=21) echoed the survey findings, providing greater depth and insight. Health visitors had greater training opportunities and were perceived to be more suited to in-depth management, whereas the general practitioner's role was perceived as excluding the presence of other conditions, brief advice and signposting to health visitors and other resources. GPs were interested in undertaking brief training.

Further health visitor research and support, increased discussions of insomnia in primary care consultations, improved access to GP training, and greater awareness of available resources has the potential to improve paediatric chronic insomnia management in primary care.

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Research Thesis: Declaration of Authorship

Print name: Samantha Hornsey

Title of thesis: Management of Paediatric Chronic Insomnia in Primary Care

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. Parts of this work have been published as:-

Hornsey S, Hill C, Stuart B, et al P031 Management of paediatric sleep problems in primary care: a systematic review. *BMJ Open Respiratory Research* 2019;6:doi: 10.1136/bmjresp-2019-bssconf.31

Hornsey S, Hill C, Muller I, et al P030 Exploring online forums to understand parents' and families' views about sources of support and resources for managing children's sleep problems in the community and primary care. *BMJ Open Respiratory Research* 2019;6:doi: 10.1136/bmjresp-2019-bssconf.30

Hornsey S, Hill C, Muller I, et al 50 A qualitative study of public online discussion forums: exploring parents' concerns about children's sleep problems and views about online, community and primary care support. *BMJ Open Respiratory Research* 2021;8:doi: 10.1136/bmjresp-2021-bssconf.44

Hornsey S, Hill C, Stuart B, et al. A survey and interview study exploring UK practicing primary care providers' management of chronic insomnia in children. *Sleep Medicine* 2022 100: S192-S193.

Research Thesis: Declaration of Authorship

Signature:Date:

Acknowledgements

Firstly, I am incredibly grateful to my amazing supervisors, Professor Hazel Everitt, Dr Cathy Hill, Dr Ingrid Muller and Dr Beth Stuart for their invaluable support, guidance, encouragement and wisdom throughout this research.

I would also like to thank the lead Clinical Research Network (CRN), nine other local CRNs and NHS Trust involved for their valuable help to recruit research participants.

Importantly, thank you also to the research participants for their time and data, making this research possible.

Thank you to the Patient and Public Involvement and Engagement contributors who gave valuable feedback at different stages of the research.

Thank you to the funders of this research programme. This study/project is funded by the National Institute for Health Research (NIHR) School for Primary Care Research. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

I would like to give personal thanks to those who have supported and believed in me over the years. A special thanks to my dad (who has always been there to listen and help), Lisa, brothers (Ben, Jamie and Daniel) and the rest of the family for their unconditional support, love and encouragement. Thanks to my friends and colleagues within and outside the University of Southampton, who have always supported me. A special thanks to my incredible partner James for always being there with endless support, encouragement, and patience.

Definitions and Abbreviations

BI	Behavioural insomnia
BIC	Behavioural insomnia in childhood
BNFC.....	British National Formulary for Children
BPS	British Psychological Society
CRN.....	Clinical Research Network
GP	General Practitioner
HCP	Healthcare professional
HV.....	Health visitor
ICSD	International Classification of Sleep Disorders
LCRN	Local Clinical Research Network
MCH	Maternal and child health nurse
MMAT	Mixed Methods Appraisal Tool
NHS.....	National Health Service
PCP	Primary care practitioner
PSS.....	Pediatric Sleep Survey
PPI	Patient and Public Involvement
PPIE	Patient and Public Involvement and Engagement
SATED.....	“Satisfaction”, “Alertness”, “Timing”, “Efficiency” and “Duration”: Five dimensions of sleep health and a potential scale to measure sleep health (proposed by Buysse ¹).
SCT.....	Social Cognitive Theory
SIDS	Sudden infant death syndrome
TPB	Theory of Planned Behaviour
UK.....	United Kingdom
US	United States

Chapter 1 Introduction

1.1 Normal Sleep

1.1.1 Neurophysiology of sleep

Knowledge of normal sleep is necessary to understand sleep problems in children and how they can be managed. Although there are different ways to think about normal sleep, the key paradigm for understanding sleep is through its neurophysiology. The basic neurophysiology of sleep defines it in terms of sleep stages. There are four different stages of sleep organised in two categories; Rapid Eye Movement (REM), otherwise known as dream sleep, and non-REM sleep (stages N1, N2 and N3)^{2,3}. Throughout sleep, these stages cycle in the order of N1, N2, N3 and finally REM sleep, before the cycle starts over (see Figure 1)^{2,3}. N1 is the transition between wakefulness and sleep, N2 is light sleep and occurs through much of the night, and N3 is the deepest stage of sleep, where the brain is less receptive to the external environment and is less likely to be 'woken up' by environmental stimuli. N3 occurs mostly earlier in the night, whereas N2 occurs more later in the night, along with more REM sleep^{2,3}. As seen in Figure 1, short periods of waking are a natural part of the sleep cycle that begins occurring after the initial phase of deep sleep, although the waking is not always remembered.

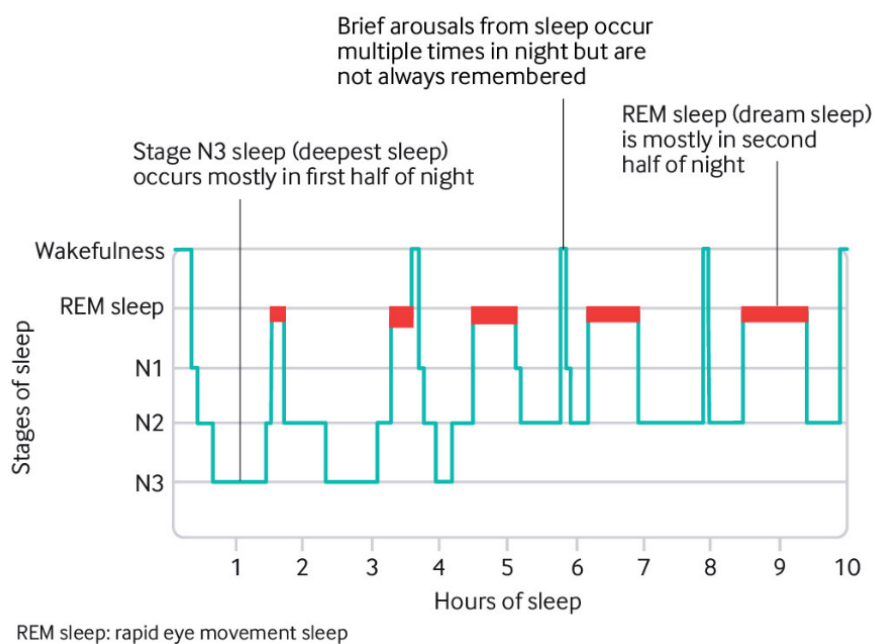


Figure 1 The typical cycles of sleep stages, reproduced from Hill and Everitt (2018) ³

1.1.2 Regulation of sleep

The timing of sleep during the 24-hour cycle is determined by two principle influences – the homeostatic (process S) and circadian (process C) drives to sleep⁴⁻⁷. The homeostatic drive is linear and cumulative with increased sleep pressure over time throughout wakefulness. This pressure decreases during sleep^{2,5-9}. Circadian rhythms are dictated by the biological clock (located within the suprachiasmatic nucleus in the hypothalamus¹⁰) which regulates a 24-hour sleep-wake cycle^{5,8,9,11}. The biological clock is in turn influenced by environmental factors, termed zeitgebers, (mainly light) but also behaviour (e.g. daily routine, diet and physical activity)¹¹. Melatonin (a sleep-inducing hormone) is secreted by the pineal gland in response to falling light in the evening and provides an additional signal to the biological clock (in this case that it is night-time). Melatonin secretion is suppressed by light (particularly light in the blue-green wavelength). It is at its highest throughout the night and decreases in the morning, promoting night-time sleep and daytime wakefulness respectively^{8,11}. The homeostatic and circadian drives work together to determine sleep/wake patterns in the 24-hour period^{5-7,12} (see Figure 2).

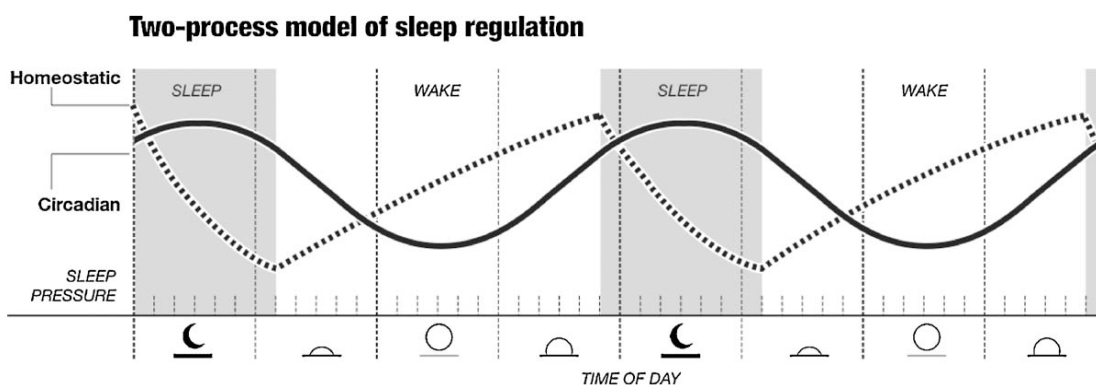


Figure 2 An illustration of the homeostatic and circadian drives to sleep. Reproduced from Glickman (2010)¹³ who adapted it from Achermann and Borbély (2003)⁴

1.1.3 Developmental changes in normal sleep from birth to five years

Sleep architecture and sleep requirements mature during early development². New-born infants' sleep stages are also described differently with 'active sleep' (similar to REM sleep), 'intermediate sleep' and 'non-active sleep' (similar to deep sleep). Sleep cycles are also shorter in duration (45-60 minutes each cycle) with more 'active' sleep⁸.

Circadian rhythms are not developed at birth and infants typically sleep through most of the day, without differentiating between day and night-time. Consolidation of sleep-wake cycles and establishment of circadian rhythms take place as the infants grow^{8,14-16}. Typically, infants have a

differentiated main nocturnal sleep phase with approximately two day naps¹⁷ by six months of age^{18,19}, and night wakings are considered normal at this age¹⁸.

Across childhood total duration of sleep in a 24-hour period decreases. Toddlers and pre-school age children typically have a longer sleep period throughout the night, but with a number of daytime naps which decrease with age. Normal total sleep duration in a 24 hour period continues to decrease as preschool children become school age children, then adolescents and then adults¹¹.

1.1.3.1 Recommended sleep duration and quality

Defining 'normal' sleep duration in children is challenging as there are likely ethnic differences^{20,21} and considerable inter-individual differences in sleep requirements world-wide. However, an expert panel convened by the National Sleep Foundation (NSF)²² reviewed a wide body of literature about the links of sleep duration (in healthy populations) with meaningful outcomes including impact on various health domains. They recommended optimal sleep durations for children, with wider margins of error (see Figure 3)²².

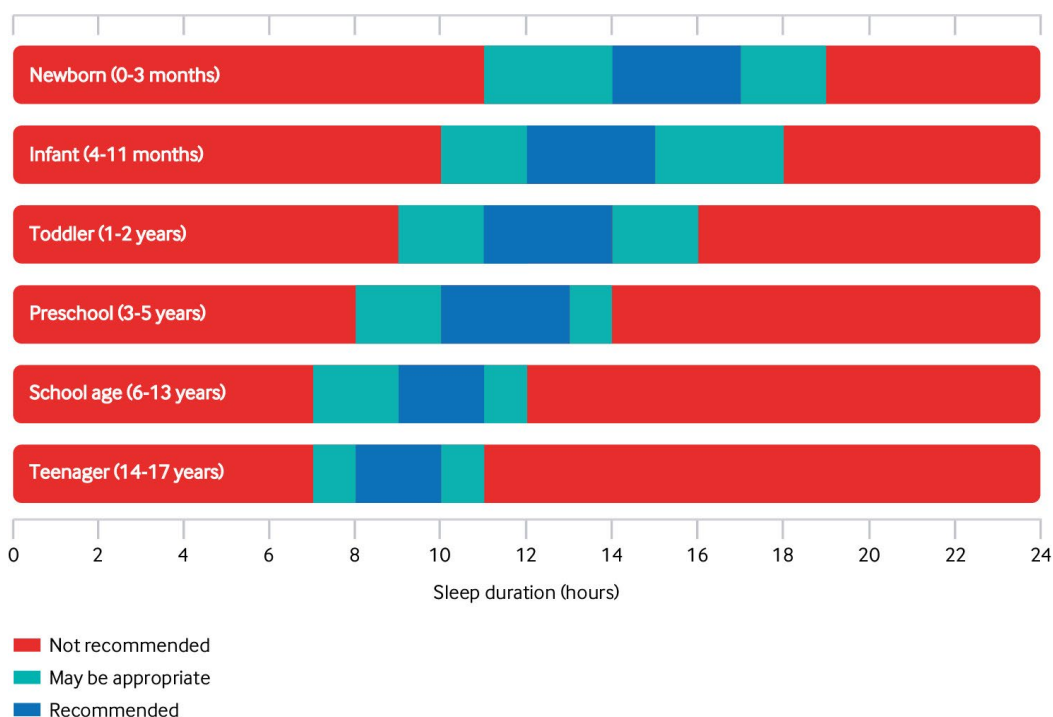


Figure 3 From Hill and Everitt's article³ illustrating the NSF's recommended total sleep duration²²

The NSF expert group also made recommendations for sleep quality specifically sleep onset latency (time to fall asleep) and number of night wakings for each age group²³. For sleep onset latency in children of all ages, up to thirty minutes was deemed acceptable, 31-45 minutes as may be appropriate, and more than 46 minutes as inappropriate.

For night wakings, the group decided that for toddlers, pre-school and school age children, up to one awakening was considered appropriate, two or three may be appropriate, and four or more awakenings as inappropriate ²³.

1.2 Prevalence and impact of poor sleep in children

Sleep can be considered in a number of different ways. Quantitatively, sleep can be defined in ways such as duration and number of night wakings. However, sleep can also be considered in terms of socially constructed 'problems', or in terms of medically constructed diagnosable sleep disorders. To be comprehensive, the literature in this section relates to all of these definitions, however the focus of this thesis will be on chronic insomnia (and symptoms of chronic insomnia) which is a disorder. Section 1.3.2 gives further information about chronic insomnia disorder.

1.2.1 Prevalence of sleep problems

Sleep is important to the health and development of children ²⁴. Nevertheless, it is suggested that up to 25-30% of otherwise healthy children typically experience sleep problems at some point in their childhood ^{25,26}. Sleep problems are generally more prevalent in children with comorbid conditions, such as neurodevelopmental disorders ²⁶. For example a recent meta-analysis²⁷ reported that collective prevalence of sleep disorders in children with Autism Spectrum Disorder was 13% compared to 3.7% general population, and a narrative review ²⁸ suggested up to 80% of children with ASD experience parent reported sleep problems. However, given that there is still a high prevalence in otherwise healthy children, populations of investigation in this thesis were limited to children without co-morbid conditions. This enabled exploration of the management of primary sleep problems, rather than the management of sleep problems that may be a symptom or consequence of another condition.

1.2.2 Associations and effects of poor sleep

Poor sleep here is defined as short sleep, poor quality sleep or sleep problems. In children, it is associated with many poor health outcomes. These associations are not only in physiological health domains, but also developmental, cognitive, behavioural, academic and emotional domains ^{24,29}. Moreover, poor sleep in children is also associated with poor outcomes in the family. This is further explored below.

1.2.2.1 Impact on the child

Matricciani and colleagues²⁴ conducted a meta-review of systematic reviews which explored the relationship between children's sleep duration and health outcomes. From 39 included systematic reviews, the authors found sleep to be important for the health and development of children; 614 positive associations were reported between children's sleep and health. In particular, there was strong evidence for the association of shorter sleep with more obesity and emotional problems. However, the review only explored aspects of sleep (such as duration and quality) and excluded reviews with studies of medically diagnosed sleep disorders, and some of the included reviews may overlap with each other in terms of included studies.

Important associations and some of the included reviews from the meta-review, alongside other notable or recent research, are explored below.

1.2.2.1.1 Physiological and developmental domains

Regarding physiological and developmental domains, Matricciani and colleagues²⁴ concluded in their meta-review that there is a strong link between sleep and obesity risk. Twenty-four out of 39 included systematic reviews explored this association and there were usually positive associations with sleep duration. For example, Chen and colleagues reviewed 17 studies (of which 11 were also included in a meta-analysis)³⁰ and found that in children under ten years old, shorter sleep duration was strongly associated with increased risk of childhood obesity. Cappuccio and colleagues conducted a meta-analysis of 30,000 child participants (age two to 20 years, but most under ten years old) from 12 studies³¹, and reported that children who had less than 10 hours of sleep had an increased risk of obesity. Similarly, a more recent systematic review³² also reported an association between shorter sleep duration and increased weight gain. These reviews suggest a strong association between short sleep duration and increased risk of obesity; however, most studies included were cross-sectional in design and the mechanisms underlying the associations are uncertain. Two examples of systematic reviews of longitudinal research include a review of over 35,000 children (up to 18 years) from 12 studies³³ and a review of over 56,000 children (up to 16 years at baseline) from 25 studies³⁴ which both indicated an increased risk of obesity from shorter sleep duration. The authors of one of these systematic reviews, Ruan and colleagues³⁴ explored whether baseline age (children under three years, three to four years, and five and over) moderated the association between shorter sleep duration and increased obesity risk. They reported there were no moderations by baseline age.

Although much of the physiological research focuses on weight gain and risk of obesity, some other physiological/developmental associations have also been found. Matricciani and colleagues

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²⁴ indicated that reviews exploring cardio-metabolic outcomes usually gave mixed or null findings, however, other research has indicated links with some other outcomes. For example, Dutill and colleagues ³⁵ conducted a systematic review of otherwise healthy children up to the age of 17 years and reported associations between sleep and some brain structures. For example, within the review, a longitudinal study of 720 children ³⁶ indicated parent reported sleep problems at an earlier age (2 years and above), were associated with reduced grey matter volume in later childhood - up to age seven years at study end. Furthermore, reported sleep problems were associated with specific differences in brain areas such as narrower prefrontal cortex, even when analyses controlled for different child and parent characteristics.

1.2.2.1.2 Cognitive domains

Regarding cognitive domains, Matricciani and colleagues ²⁴ meta-reviewed six reviews and reported that there are some associations of sleep with cognition, however there were a limited number of studies. Nevertheless, several included systematic reviews demonstrated an association between sleep duration and cognitive function in general populations of both preschool ³⁷ and school age ^{38,39} children. In particular, two meta-analyses found sleep duration to be positively associated with cognitive performance ($r = 0.08$, significant subdomains were executive functioning, performance tasks and school performance)³⁸ and full/verbal IQ ($r = 0.15$)³⁹. These indicate the importance of sleep even in healthy children without a diagnosis of a sleep disorder, and that inadequate sleep duration may lead to shortfalls in some aspects of cognitive functioning.

Regarding populations with reported sleep problems, a longitudinal study in the United States (US) of 568 twins from age four years ⁴⁰ indicated early parent reported sleep problems did not significantly impact later executive functioning, but that children with parent reported sleep problems which decreased more over time had better performance on executive functioning tasks in adolescence (approximately 17 years old) than those whose sleep problems did not decrease as much. Similarly, a US longitudinal study of 250 children from eight to nine years ⁴¹ indicated that over 3 years, an increase in sleepiness (assessed by child report on a 'sleepiness' scale) was associated with less improvement in verbal comprehension task over time, compared to children who experienced less sleepiness. The findings however were not present for their sleep and wake problems, though the authors noted that this may be due to different levels of resilience to sleep-wake problems. Other longitudinal research of an Australian birth cohort study ⁴² suggested that parent reported sleep problems in young children ($n=4204$) were significantly associated with problems in attention in adolescence (14 years), as measured by parent report (for age five years) and child report (age five and 14 years) using behaviour questionnaires.

More recently, an Italian study compared executive functioning in 45 preschool children with clinically diagnosed chronic insomnia to 167 otherwise healthy preschool children⁴³. Children with chronic insomnia, compared to the controls, had significant deficits in all aspects of parent reported executive functioning. Regression analyses indicated that in those with chronic insomnia, insomnia sub-scale scores within the Sleep Disturbance Scale for Children⁴⁴ (revised for use in young children) significantly predicted cognitive domains such as inhibition, emotional control and inhibitory self-control. However, both sleep problems and executive functioning were measured using parent report questionnaires rather than objective measures which may impact on the accuracy of measurement and bias the findings.

1.2.2.1.3 Academic domains

In academic domains, Matricciani and colleagues²⁴ indicated that from four reviews, there are associations with sleep and school performance, although effect sizes are small. For example, a meta-analytic review, published in 2010, reported that three types of sleep problems (insufficient sleep, poor quality sleep and sleepiness) were all related to worse school performance²⁹ with correlations of sleepiness and school performance the strongest ($r = -0.133$) followed by sleep quality and sleep duration ($r = 0.096$ and $r = 0.069$, respectively). Furthermore, a systematic review of health and sleep duration in school children⁴⁵ and a meta-analytic review of school aged-children³⁸ indicated that sleep duration was associated with academic performance. However, many studies within the reviews were cross-sectional in design or rated low in quality; therefore, limited inferences can be made about the causal direction of the associations.

A more recent longitudinal study in Norway⁴⁶ of children from ages 7-9 years to ages 11-13 years indicated that persistent problems initiating and maintaining sleep, were a significant predictor of poorer academic performance in the later age range. Both sleep problems and academic performance were measured by parent and teacher report, respectively, using a single rating style question. Though subjective report may affect the accuracy of the findings, the addition of teacher ratings in this study are beneficial because parents and teachers reported on separate outcomes, suggesting teachers were blinded to the report of sleep problems.

1.2.2.1.4 Behavioural, emotional, and psychological domains

Matricciani and colleagues²⁴ reported a link between psychosocial outcomes and sleep. For example, research has indicated associations of sleep with emotional and/or behavioural factors (i.e. internalising problems such as emotionality and mood disorder and/or externalising problems such as antisocial behaviour, hyperactivity etc). Astill and colleagues³⁸ reported in a meta-analytic review of 35,936 children aged five to 12 years, that shorter sleep duration was associated with

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increased behavioural problems in 30,938 participants. Specifically, it was associated with both internalising ($r = 0.09$) and externalising ($r = 0.08$) behaviour. Chaput and colleagues indicated in their systematic reviews of sleep duration and health outcomes in both preschool⁴⁷ and school age children⁴⁵ that shorter sleep duration was associated with reduced emotional regulation. However, many of the included studies were rated of low quality or cross-sectional by design. More recently, Marino and colleagues (2021)⁴⁸ conducted a meta-analytic review of studies looking at sleep duration and depression in children and youths (five to 24 years) and indicated that disruptions in sleep were significantly associated with depressive symptoms. However, in this review the effect size was small, the age range explored was wide (five to 24 year) and sub-analyses were not conducted for younger children, older children and young adults. Nevertheless, many of the populations within the studies were of school age.

Whilst many studies are cross-sectional and suggest associations between variables at one point in time, longitudinal research over childhood (whilst causality still cannot be inferred) gives value by analysing the associations between the same participants over their development. Recent longitudinal research in France has also indicated that in preschool children night waking is significantly associated with increased risk of emotional problems at 5-6 years⁴⁹ and that preschool children with persisting shorter sleep duration from ages 2-6 are at increased risk of hyperactivity problems⁵⁰. Quach and colleagues (2017)⁵¹ also demonstrated, in a sample of 4983 children in Australia assessed across various time points from four to 13 years of age, that parent reported sleep problems significantly predicted later parent reported internalising problems. They also predicted external behaviour problems, however, the externalising problems also significantly predicted later sleep problems, which suggested a bi-directional relationship between the two problems. More recently, Zheng and colleagues (2021)⁵² suggested the usefulness in improving poor sleep, by reporting that over 15 months for children in Denmark ages 2-6 years, an increase in duration of sleep overnight (60 minutes and above) was associated with a decrease in emotional/behavioural problems. Similarly, Muratori and colleagues⁵³ indicated that over the course of 1 year for children in Italy aged 6-10 years, an increase in sleep problems was associated with an increase in hyperactive problems.

1.2.2.1.5 Other outcomes

Finally, Chaput and colleagues also indicated in their systematic review of sleep duration and health outcomes, that several studies reported an association between shorter sleep and risk of injuries in preschool children associated in preschool age⁴⁷. However, the quality of the studies was generally low and there were more mixed findings for school age children⁴⁵.

1.2.2.2 Impact on the family

Poor sleep in children can not only affect the individual child, but also the family, such as parents or carers (hereafter described as parents) and siblings⁵⁴. Firstly, parents likely also experience sleep problems themselves. Studies have indicated that children's sleep problems are associated with parents' sleep problems^{55,56} and daytime sleepiness⁵⁷ and that the quality of children's sleep significantly predicted the quality of maternal sleep⁵⁸. In particular, Mindell and colleagues⁵⁹ surveyed more than 10,000 mothers from 13 different countries and found significant associations between children and mothers for bedtimes ($r=0.46$), waking ($r=0.58$), night waking ($r=0.49$), and night sleep duration ($r=0.28$). All associations were stronger for children up to 35 months than for older children. Though much research has focussed on mothers' sleep problems, some research has indicated that parent reported child sleep is associated with both maternal and paternal sleep^{60,61}. Sinai and Tikotzky (2012)⁶⁰ demonstrated a correlation between infant (four to five months old) and parent sleep, however the relationship was stronger with mothers than fathers. More recently, Urfer-Maurer and colleagues (2017)⁶¹ reported that objectively measured child sleep was associated with mothers' self-reported parental sleep problems, but not fathers' paternal sleep problems. Nevertheless, both mother's and father's own self-reported sleep problems were associated with subjective measures of their children's sleep problems (parent report using questionnaires).

Research has also specifically explored adverse outcomes, other than sleep, for parents with children who have sleep problems. For example, an Australian study of more than 5000 families of babies and nearly 5000 families of young children, indicated that poor sleep was associated with poor general health in mothers (baby and child sleep) and fathers (baby sleep only)⁶². Similarly, 30% of >10,000 mothers participating in Mindell and colleagues' survey perceived that their children's sleep impacted their daytime functioning. Although this perceived impact was for all ages it was higher for infants and toddlers (up to 35 months, 31.08%) than young children (36-59 months; 21.46%)⁵⁹.

Parents may also experience emotional or psychological difficulties, such as depressive symptoms, poor mood and stress. Recent research⁵⁶ indicated that, in a sample of 65 families of children aged two to 36 months, parents of those with sleep problems had significantly higher parentally reported distress than parents of those without. Mothers' sleep efficiency (the amount of time asleep whilst in bed^{63,64}) was positively associated with better mood after waking, whereas fathers who took longer to get to sleep, reported worse mood after waking⁵⁶. Similarly, In a sample of 293 parents of children aged 2-12 years⁵⁵, there were significant differences in parentally reported mood in those with children who had sleep problems compared to those

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without. The sleep problems also partly moderated the effect of parental sleep quality on mood. Other research has indicated that sleep problems in babies are associated with increased anger and symptoms of depression in a sample of 102 fathers⁶⁵ and that even in mothers who had no previous problems with depression, sleep problems had a significant impact on maternal psychological distress (more so than those with a history of depression)⁶².

Furthermore, previous studies have trialled behavioural treatments of children's sleep problems (further detail in 1.4) and thereby also highlighted the impact of sleep problems on parent's emotional state, using experimental studies. Mindell and colleagues⁶⁶, conducted a randomised trial of a bedtime routine intervention on 267 mothers and infants/toddler dyads, compared to a usual routine control group of 139 dyads. Children's sleep problems and maternal mood both significantly improved whereas there was no improvement for the controls. Similarly, Lee and colleagues⁶⁷ treated children with sleep onset problems by educating parents about children's sleep and behavioural sleep training (interventions for sleep problems are discussed in more detail in 1.4). Significant symptoms of maternal depression were associated with lower marital intimacy before the treatment of the children's sleep problems, but both improved afterwards.

Although much of the above research suggests that sleep problems have an impact on parental sleep, day-time functioning, mood and marital satisfaction, many of the studies were cross-sectional and directional causality cannot be inferred. Therefore, though it is likely that children's sleep problems have an impact on the family, it is also possible that the sleep problems themselves could be the consequence of these factors. For example, some longitudinal studies have examined bidirectional effects of children's sleep problems and parenting factors. Bell and Belsky⁶⁸ found that children's sleep problems were not only affected by family factors (such as maternal negative emotions, decreased maternal closeness and sensitivity) but that family factors were also predicted by childhood sleep problems. More recent longitudinal research in infants up to six months old⁶⁹ found that babies slept more and with less distress when mothers were more emotionally available, but that babies' distress overnight also influenced maternal emotional availability. These bi-directional relationships between infant sleep and family functioning highlight the importance of considering the children's sleep problems themselves as well as individual differences in families.

Finally, there may also be associations between children's sleep problems and siblings, however research into the associations between children and sibling outcomes, is limited. Nevertheless, a recent longitudinal study of 582 twins indicated that more conflict between the siblings was associated with shorter duration with sleep and more sleep problems⁷⁰.

1.3 Sleep problem or sleep disorder?

Sleep problems (difficulty falling asleep, maintaining sleep, waking early, daytime sleepiness) are shared symptoms of many different sleep disorders. Sleep disorders are defined by the International Classification of Sleep Disorders (ICSD) ²⁶ (see further detail in 1.3.2). However, whether parents and children consider their sleep a subjective ‘problem’ is more complex. This is discussed in the relevant subsections (1.3.1 and 1.3.2) below.

1.3.1 Subjectivity in the definition of sleep problems

Firstly, sleep problems are subjective; perceived sleep problems and their impact may differ depending on individual family’s social context, parental and cultural expectations, and socioeconomic factors such as family routine, housing, and level of social support. For example, at what point does a child’s sleep become problematic, particularly in the infant phase of life? Blunden and colleagues ⁷¹ suggested that crying during the day could be perceived differently to waking and crying throughout the night. For example, in the day, it can be seen as a way of communicating a need to the parent, whereas for babies/infants who no longer have a physiological requirement for night feeds, crying throughout the night may be seen as a ‘want’ that can be attended to minimally. Further, tolerance for night-time crying may differ between parents ⁷², which may influence their perception of whether their child has a sleep problem. Night-time crying is discussed in more detail in Chapter Two.

Families’ views on what constitutes a sleep problem and what impacts are reported have been studied. A recent qualitative study of US paediatric providers and parents highlighted how socioeconomic and family factors are associated with sleep perceptions, for example, homelessness and family routines ⁷³. In the study one participant explained that sleep may not be a priority for a parent without a home, and some parent participants favoured bed-sharing due to familial tradition. Other factors which have been associated with reporting of sleep problems are stress, work and family structure. For example, babies’ and maternal sleep problems were associated with higher stress in mothers still on maternity leave (n=25), as opposed to being back at work (n=25) ⁶⁰ and higher maternal distress in single mother families (n=39) compared to two-parent families (n=39) ⁷⁴.

Furthermore, perceptions of sleep problems are culturally determined ⁷⁵. A recent systematic review of 23 studies demonstrated cultural differences in relation to childhood sleep problems and factors associated with them ⁷⁶. In particular, Sadeh and colleagues ⁷⁷ surveyed parents of over 29,000 children up to 3 years old, from 17 different countries finding that predominantly Asian (PA) countries were more likely to report problematic sleep than predominantly Caucasian

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(PC) countries. For families in PC countries, objective sleep characteristics (such as night waking) were more likely to predict parents' definitions of sleep problems, whereas for families in PA countries, sociocultural variables such as child/parent age and parental education were more likely to predict parents' definition. Similar findings were demonstrated in an Australian study of Caucasian and South East Asian families⁷⁸, whereby Caucasian parents were more likely to believe children needed more sleep than South East Asian parents, and attitudes towards sleep also differed between parents. For example, more South East Asian parents appeared to perceive late nights at the weekend as acceptable, even though fewer South East Asian parents compared to Caucasian parents felt that their children had enough weekend sleep. Interestingly, there were no differences in sleep duration between the children, other than the timing of when they went to sleep and woke up. In contrast, a more recent survey of mothers of over 10,000 children in 13 countries⁵⁹ suggested that there were no differences between PA and PC parents in relationships between maternal and child sleep patterns, but that PC parents had stronger associations between perceptions of their children's sleep problems and their personal poor sleep. These studies highlight cultural differences in not only defining sleep problems, but also the perceived impact of sleep problems.

Sleep practices may also be perceived differently in different families or different parts of the world⁷⁵, highlighting the need for cultural and familial consideration in defining and managing sleep problems. Research regarding co-sleeping indicated that independent settling/sleeping behaviours are more common in PC than PA countries⁷⁹. A systematic review exploring international literature on reasons for mothers and babies co-sleeping reported that in nine of 34 studies bed-sharing was influenced by cultural or family tradition reasons⁸⁰. Another reason cited in 15 studies, was that co-sleeping improved the babies sleep. Similarly, there are conflicting perceptions of other strategies for managing behaviourally based sleep problems, such as extinction-based sleeping practices (varying forms of leaving the child to cry) between families and different cultures, which further highlight the importance of individual, familial and cultural considerations⁷¹. Theory based debates regarding sleep practices such as co-sleeping and extinction methods are discussed further in Chapter Two.

These social differences emphasise the difference in familial and cultural preferences and it is therefore important to consider family perspectives, regardless of whether a 'disorder' is diagnosed. If a family present to a healthcare professional (HCP) reporting that the lack of sleep is problematic or having a negative impact on the child or family's everyday life, it is important to help the family to improve the sleep, and subsequently help reduce the impact on the child and family.

1.3.1.1 Measuring sleep problems

Despite the subjective nature of sleep problems, there are different tools which offer varying levels of objectivity⁸¹. For example, many validated questionnaires exist which may be used by clinicians as screening tools, with questions that clinicians could ask parents when they take a sleep history⁸². Questionnaires can relate to sleep problems generally, or to specific sleep disorders. However, a recent review of the available questionnaires suggested their reliabilities vary, and there is a lack of questionnaires for children under six or over 12 years of age⁸². Another way of measuring sleep problems is the use of sleep diaries which can be completed by parents or carers over a period of time^{83,84}.

Nevertheless, the diagnosis of a sleep disorder, such as chronic insomnia, that relies on parental report of behaviours is inevitably more subjective than for sleep disorders with objective diagnostic tests e.g. Obstructive Sleep Apnoea or Narcolepsy. Other objective forms of measurement include actigraphy (whereby a watch is worn to record the sleep and rest cycles over a period of time) and can be used clinically for assessment of certain sleep disorders, including insomnia^{85,86} but are very rarely used in primary care. Actigraphy is more used commonly in sleep research⁸⁷. Neurophysiological sleep studies can be conducted within sleep clinics² and are used in sleep research⁸¹. Galbraith, Bull and Hill⁸⁸ designed another potential tool for objective support of a parent reported sleep problem - a scoring algorithm which in combination with video evidence, could support clinical diagnosis of chronic insomnia or support research outcomes. This was demonstrated to be reliable in three children aged three to 12 years who had previously had brain tumour treatments⁸⁸. Although this sample was in children with additional health needs, the results still demonstrate the potential usefulness of a tool to support assessment of chronic insomnia disorder in otherwise healthy children.

The measurement of sleep problems, particularly objective assessment of sleep problems, is not within the scope of this thesis as the focus is the management of sleep problems in primary care where such objective methods of sleep measurement are not used.

1.3.2 ICSD-3 defined Chronic Insomnia Disorder and Behavioural Insomnia of Childhood

The ICSD Third Edition (ICSD-III)²⁶ includes “Chronic Insomnia Disorder” as a sub-category of “Insomnia”, one of seven major diagnostic sleep categories. Other major diagnostic categories include “sleep-related breathing disorders”, ‘central disorders of hypersomnolence’, ‘circadian rhythm sleep-wake disorders’, ‘parasomnias’, ‘sleep-related movement disorders’ and ‘other sleep disorders’.

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Chronic insomnia disorder diagnostic criteria include a report of: (1) difficulties with initiating sleep, maintaining sleep, early waking, sleep schedules or sleeping without a parent/caregiver intervention, (2) impact related to the sleep problem, (3) the sleep problem cannot otherwise be explained by circumstances or another sleep disorder, and (4) the problems occur at least 3 times per week for at least 3 months. Despite these diagnostic criteria, the ICSD-3 notes that many of the diagnostic variables and impacts are based on subjective report ²⁶.

Adults and children can have Chronic Insomnia Disorder, however, behavioural insomnia in childhood (BIC) is noted as a form of Chronic Insomnia Disorder which is specific to children. BIC previously had its own classification in the ICSD-2 ⁸⁹, however the latest ICSD edition ²⁶ now notes it as a subtype of (or alternative name to) Chronic Insomnia Disorder as described above.

Nevertheless, it is sometimes still referred to or explained as behavioural insomnia (BI), which “illustrate the struggle of patients and their families and help explain the rationale for behavioural treatment strategies” ⁹⁰(p. e173). BIC is the most common childhood sleep disorder ³ and involves difficulty initiating and maintaining sleep. According to the ICSD-III ²⁶, it presents as sleep-onset association type, limit-setting type or a mixture of the two. These difficulties are described below.

1.3.2.1 Sleep-onset association type

Sleep-onset association type ^{26,89} is a type where children learn to fall asleep in particular environments or with particular triggers, and then cannot fall asleep without these same environments or triggers, on their own at either bedtime or during the night. As presented in Figure 1, Hill and Everitt’s hypnogram ³, it is normal within sleep cycles to experience brief wakings throughout the night, however these are not usually remembered. As children develop, they can usually settle themselves after the natural night wakings, however, children who develop negative sleep onset associations are unable to settle themselves back to sleep after the natural wakings. For example, a child may learn to only fall asleep when being rocked by a specific person. If that person (the sleep onset association) is then not present to rock the child to sleep, the child will not be able to fall asleep during the night when they spontaneously wake up.

1.3.2.2 Limit-setting type

Limit-setting type ^{26,89} is where children resist bedtime limits. The parents may have difficulty in enforcing rules consistently for the child at bedtime. For example, when the parent indicates that it is bedtime to the child, the child may make unnecessary trips to the bathroom, or ask for repeated bed-time stories etc. to resist going to sleep.

1.3.2.3 Mixed type

Often, both sleep-onset association problems and limit-setting problems can occur together, making it difficult for the child to fall to sleep at bedtime as well as after natural night wakings. This can result in the reliance on problematic sleep associations in order to initiate and maintain sleep⁹¹.

1.3.3 Chronic insomnia / behavioural sleep problems as a focus within this thesis

Given the high prevalence of BIC and the possible consequences of persisting poor sleep in children and the family, it is imperative that it is addressed adequately in healthcare. Therefore, the focus throughout this thesis will be Chronic Insomnia (specifically BIC). Further, due to the subjectivity around the reporting of behavioural sleep problems, the focus will include (1) symptoms of chronic insomnia disorder in children/ BIC, (2) a diagnosis of chronic insomnia disorder in children / BIC, and (3) parent/carer or clinician report of sleep problems in children which are likely to be behavioural such as problems initiating or maintaining sleep.

1.4 Managing or treating Chronic Insomnia in childhood

Due to the risks of persisting sleep problems outlined in 1.2.2, it is important to try to manage BIC. Whilst sleep problems are common in infants/children, they can persist⁹². There are different ways to manage BIC. Although, there are both pharmacological and non-pharmacological management strategies⁹³⁻⁹⁷, behavioural interventions and good 'sleep hygiene' are the preferred method of treatment^{3,25,98-100}. In otherwise healthy children, pharmacological strategies such as melatonin or antihistamines, when recommended, would usually be alongside behavioural strategies¹⁰¹. However, in the United Kingdom (UK), antihistamines are not recommended for children, and melatonin is only for use in certain populations, e.g. those with Autism Spectrum Disorder, and prescribed by specialist HCPs when behavioural management is unsuccessful^{100,102}. Sleep hygiene and behavioural interventions are described in more detail below.

1.4.1 Sleep hygiene

Sleep hygiene comprises the changeable situational, environmental and personal factors that can improve sleep or prevent sleep problems^{3,8,99}. For example, bedtime routines, level of caffeine intake, and other daytime activities and sleep environment (such as TV distraction in the bedroom) can all have an effect on the child's sleep initiation, quality and duration¹⁰³. Bedtime routines are an important aspect of sleep hygiene¹⁰⁴ and have been evidenced in a range of research as being associated with good sleep outcomes in children such as fewer night wakings

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and increased sleep duration (particularly in children up to the age of five) ¹⁰⁴⁻¹⁰⁶. There is also a wealth of research highlighting associations between screen use and poor outcomes in children ¹⁰⁷⁻¹⁰⁹. A recent systematic review and meta-analysis¹¹⁰ showed that screen use in infants, and children up to the age of five was associated with poorer outcomes. The opposite associations were found for physical activity whereby more physical activity was associated with better sleep outcomes. Sleep hygiene may be improved as a standalone intervention to help manage sleep problems in children, or it may be used in conjunction with behavioural interventions. A national survey of 1473 parents in America indicated that various aspects of 'good sleep hygiene', such as appropriate bed times and independent sleeping were associated with better sleep across age ranges from 0-10 years ⁹⁹. More recently, a systematic literature review of children's sleep recommendations ¹¹¹, provided supporting evidence for aspects of children's sleep hygiene recommendations such as: age appropriate bedtimes; bedtime routines; limiting electronic uses to certain times; ensuring children's needs are met throughout the day; and learning to self-settle. Evidence for other aspects however, such as some aspects of exercise and diet, are limited with need for further research.

1.4.2 Behavioural interventions

Various types of behavioural interventions ^{2,96,97} can be used for the management of chronic insomnia in young children. Methods include variations of 'extinction' techniques, stimulus control techniques or parental education techniques. The different methods are described below.

1.4.2.1 Extinction-based techniques

Some of the most well-known types of intervention are extinction-based techniques which aim to 'extinguish' the child's behaviours, such as requesting attention, when it is bedtime. Extinction-based techniques vary and are incorporated into many behavioural interventions. A well-known method is Unmodified Extinction, also known as the Cry-it-out method. Mindell and colleagues ⁹⁷ noted that the first formal use of this method was documented by Williams in 1959 ¹¹². This method aims to remove any negative behaviour from the child, by giving them no attention or response to cries, other than that for safety checks, throughout the night ². This approach is effective ⁹⁷; however, it requires persistence and consistency, particularly because in the short term, it can result in increased crying (extinction burst) before it takes effect ¹¹³. Though effective, extinction techniques can be uncomfortable for and disliked by parents for many reasons, such as distress listening to their child cry and fear of adverse psychological outcomes ¹¹⁴ (discussed in more detail in Chapter Two) and there is limited data on the effectiveness in older children and children with co-morbid conditions ⁹⁶ (see 1.4.2.4). There are two variations of unmodified

extinction, 'Graduated extinction' and 'extinction with parental presence', which are gentler approaches to unmodified extinction ².

Graduated extinction is otherwise known as controlled crying, controlled comforting, sleep training or the Ferber method ^{2,97}. The aim is also to remove any negative behaviour by not giving attention, however, rather than by ignoring the child completely, the parents will return to the child at pre-arranged times or intervals with minimal interaction. The intervals can be the same or increase in duration over time ^{2,97}. A small randomised controlled trial (RCT) of mothers of infants aged six to 16 months ¹¹⁵, indicated that graduated extinction (n=14) improved sleep onset, night time wakings and time taken to sleep after wakings, compared to controls (n=14). Moreover, at 12 months of follow up, there were no differences in attachment styles or emotional problems.

In extinction with parental presence, otherwise known as Gradual retreat or 'camping out' the parents must continue to ignore the child's wish for attention ². However, the parent will be present in the room and will gradually increase the distance between themselves and the child whilst doing so. This may be done in increments and will happen slowly over time². In a sample of 33 families, sleep duration was improved following application of this technique ¹¹⁶. However, it must be noted that there was no control group in this study with which to compare the results.

1.4.2.2 Other techniques

1.4.2.2.1 Scheduled awakenings

Another type of technique for recurrent night waking in childhood chronic insomnia is scheduled awakenings ^{2,97}. This involves pre-determining a time to wake the child, before they would usually wake. The amount of times this happens is then gradually reduced as sleep improves ¹¹⁷.

1.4.2.2.2 Faded bedtime with response cost (delayed bedtime)

Furthermore, 'faded bedtime with response cost', has been described as another method for improving bedtime resistance². The parents typically delay the bedtime until the time the child would usually fall asleep, so that the conflict at bedtime is reduced. Once the child falls to sleep without conflict, the bedtime will gradually be brought forward in increments until the child falls asleep at an appropriate bedtime. The RCT described previously which indicated the effectiveness of graduated extinction ¹¹⁵, also indicated an improved sleep onset for a faded bedtime group (n=15) in comparison to controls (n=14).

1.4.2.2.3 Parental education, anticipatory and preventative guidance

Another, broader type of intervention is parental education ¹¹⁸ which aims is to increase parental knowledge about sleep in general, sleep hygiene and behavioural interventions. As discussed in 1.3.1, perceptions of normal child sleep duration may differ between parents, and there is subjectivity in the definition of sleep problems between family's social context and parental/cultural expectations. Moreover, a 2017 systematic review of eight studies indicated that parental knowledge of children's sleep, such as knowledge of healthy sleep habits and knowledge of normal sleep) is limited ¹¹⁹.

Parental education can be delivered as a treatment in response for BI, or as anticipatory/preventative guidance ¹²⁰ though it often includes both preventative and anticipatory guidance ¹¹⁸. Anticipatory guidance aims to equip parents or carers with the knowledge of what to do if/when these common sleep problems start (for example, information about self-settling interventions to improve sleep problems ¹²¹). Preventative guidance aims to prevent the problems arising, (for example information on good sleep behaviours given to parents antenatally or in routine visits to prevent development of sleep problems ^{121,122}). The 2017 systematic review that indicated that parental knowledge of children's sleep is limited also suggested that parents with more knowledge generally reported healthier sleep practices (although these are associations and cannot imply causation) and that following parental education, sleep knowledge improved. ¹¹⁹ This highlights the potential value of parental education in the prevention of sleep problems; however, the authors did note that further research into the effect on sleep itself is needed.

1.4.2.3 Mode of delivery

There are different types of behavioural interventions and the concepts and teaching of the interventions can be given to parents in different ways. For example, online or in person ¹²³. Adachi and colleagues indicated that an educational leaflet intervention (n=103), along with only 10 minutes of group guidance decreased parental responses to night crying that may reinforce night waking night waking, in comparison to a control group (n=100) ¹²¹.

1.4.2.4 Systematic review evidence for behavioural interventions

A wealth of research supports behavioural interventions for chronic insomnia ^{96,97,120}. A systematic review conducted by Mindell and colleagues in 2006⁹⁷ included 52 intervention studies for infant and young children's sleep problems. Overall, the 52 studies comprised of more than 2500 participants and the studies tested various intervention types, including various extinction methods, positive bedtime routines, positive reinforcement, parental education, scheduled awakenings and bedtime fading with response cost. Findings indicated that for problems at

bedtimes and waking in the night, 49 out of 52 studies indicated clinically significant improvements. Although, the majority of these studies indicated these positive effects for the wide variety of intervention types, the strongest empirical support was for extinction (unmodified and graduated) and parental education. Most studies included extinction methods and there were only 5 studies for parent education, however the parent education studies consisted of over 1000 participants, with findings being both significantly and clinically meaningful. As this review was limited to infants and young children, however, findings may not be generalisable to older children and adolescents.

Meltzer and Mindell, in 2014⁹⁶ conducted an updated systematic review (of 12 within-subject studies) and a meta-analysis (of 16 controlled trials) of behavioural interventions for paediatric insomnia, but looked at a broader age range, including adolescents and older children. Again, there were over 2500 participants, collectively. Similar to Mindell and colleagues' earlier 2006 review, studies indicated that there is moderate evidence for such interventions in young, normally developing children. Specifically, in the controlled trials, these effects seemed to be for sleep-onset latency, night wakings and efficiency in sleep. Further research is needed to explore their efficacy in older children and adolescents. This review was more rigorous in eligibility criteria and used GRADE methodology to assess the quality of the evidence in more detail. As a result, fewer studies were included than in the previous review.

More recently, Reuter and colleagues¹²⁰ conducted a systematic review of 12 studies published between 2007 and 2017 reporting treatment strategies for children under two years of age with behavioural sleep problems or crying. Five RCTs within the review explored behavioural interventions, of which two explored controlled crying or camping out^{124,125}, and three bedtime routines^{66,126,127}. All indicated positive effects of the interventions. Findings for parental education were more inconsistent but indicated that timing of education may have an influence.

1.4.2.5 Differences in use of interventions

Although the research indicates that various sleep hygiene and behavioural interventions are effective, it is important to note the different situations for which different interventions may be more or less beneficial. For example, age of the infant or child is an important factor; bed time routines and good sleep hygiene are suggested as appropriate for all ages, whereas behavioural interventions such as extinction-based techniques are only appropriate after six months^{117,128,129}. Research has also indicated that some extinction-based techniques are only effective for young children whose parents are more tolerant of infant crying¹³⁰ or are moderated in effectiveness by infant separation anxiety¹³¹. Moreover, Meltzer and colleagues¹³² conducted a recent scoping review of behavioural interventions for chronic insomnia in childhood and found that from 120

included studies with more than 9500 participants, over 80% of the included studies combined different treatments. The authors emphasised the importance of individualised treatment approaches for different families. This is explored in more detail in Chapter Two.

1.5 Sleep in paediatric primary care

Given the common occurrence of chronic insomnia in young children and the possible consequences of persisting poor sleep, it is important to treat or manage these problems early and ideally to prevent them. As part of their role HCPs should consider and help parents to manage paediatric chronic insomnia. Primary care in particular such as general practitioners (GPs), nurse practitioners and health visitors (HVs) provides substantial opportunity to address sleep problems in children early. First, primary care is more accessible and universal to parents; in the UK, every family has opportunity for contact with primary care, including visits for childhood vaccinations, antenatal/postnatal visits and HV developmental checks. Sleep could be discussed for prevention or at early onset of sleep problems. Second, addressing children's sleep problems early reduces the risk of consequences that arise from persisting problems. Third, by addressing children's sleep problems in primary care, costs and resource use in secondary care may be reduced, allowing more time and resource for complex medical sleep disorders in secondary care clinics. Moreover, a recent qualitative interview study with sample of 15 UK mothers suggested parents would like easily accessible advice regarding their children's sleep as they develop¹³³, further suggesting the usefulness of addressing behavioural sleep problems in primary care.

Although there are evidence-based interventions for paediatric chronic insomnia, and primary care is an optimal setting to for management, it is uncertain how this is managed in UK primary care. Honaker and Meltzer¹³⁴ conducted a review of the literature up until 2014, which looked at how various types of sleep problems are screened, diagnosed and managed in paediatric primary care across the world. Findings indicated that primary care provider report of the number of consultations for sleep problems in primary care, vary in the literature, but are most common in infants and young children. In one US study, in a 3-month period, paediatric nurse practitioners reported seeing 36.9 patients on average for sleep problems¹³⁵ (with a range of 0-400 across different ages). In another US study¹³⁶, primary care practitioners (PCPs) indicated consulting on average 89 patients with significant sleep problems, in a 6-month period (though the total population sampling frame was not reported). This review suggested that sleep management is rarely discussed in primary care and that while effective interventions are available, children who have been recognised as having sleep problems often did not receive a referral or recommendation for treatment by their PCP. Moreover, a possible barrier appeared to be medical education in relation to paediatric sleep. It was suggested that PCP education in paediatric sleep

was inadequate, that practitioner sleep knowledge appeared to be low and that across studies, practitioner's confidence in discussing paediatric sleep was low to moderate.

This review¹³⁴ suggests that paediatric sleep management in primary care may be lacking. However, it did not include all aspects of primary care, such as HVs, where sleep management may be central, and did not focus specifically on chronic insomnia, but also included other sleep problems such as sleep disordered breathing. Furthermore, many of the studies were based in the US where the definition of primary care differs; paediatric PCPs in the US are more specialist to paediatrics, so it is expected that they would have more knowledge on this topic. Further, while this review highlights important findings, there were some limitations to its methodology. Firstly, it is unclear as to whether the method was systematic or narrative. Search terms of "sleep" and "primary health care" are noted in the paper, however there are many different words for these terms and searches may not have been particularly sensitive. Moreover, 18 out of 30 included papers were found through backwards citation search of the 12 already included papers. Finally, because the literature was searched until the year 2014, many more papers may have been published in the years following its publication.

Since Honaker and Meltzer's review¹³⁴, some studies have explored medical education for paediatric sleep problems. Ersu and colleagues¹³⁷ tested an education programme in a population of Turkish paediatricians, described in a primary care setting. The programme was a training session covering topics such as the physiology of sleep, common childhood sleep problems, and behavioural interventions. Baseline data indicated that over 80% of the participants had previously received no formal paediatric sleep management training. For 117 paediatricians who received the education programme, there were significant increases in sleep knowledge, compared to 70 in the control group with no significant increase. However, there was limited confidence in managing children's sleep problems for participants and this lack of confidence continued to be high after the intervention. This study was conducted in Turkey and therefore may not be generalisable to other countries and particularly to all primary care systems. Moreover, not all of the data was specific to behavioural problems. Nevertheless, the need for increased training is supported by Hatton and Gardani¹³³ who reported that in a qualitative sample of 15 UK mothers, parents perceived HCPs' (such as GPs and HVs) knowledge of child sleep to be inadequate.

Current, limited literature therefore suggests that knowledge and management of paediatric chronic insomnia in primary care may be lacking but that further research is needed in this field. Specifically, there are limited research findings relating to the management within the UK.

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Chapter Three explores this further through a systematic review of the published literature specifically for the management of paediatric chronic insomnia in primary care.

Due to the varying types of primary care worldwide and the varying definitions used, primary care within this thesis needs to be clearly defined. Within this thesis, it is considered as 'any healthcare which is the first point of call for patients and their first level of healthcare'. For example, in the UK, this will therefore include not only GPs and practice nurses, but also community-based PCPs such as HVs and nursery nurses, who would also be a first point of access for parents struggling with their children's sleep.

1.6 Theoretical background

Chapter Two discusses theoretical concepts and discussions relating to the management of chronic insomnia in children.

1.7 Summary of the current literature

The current literature provides evidence that sleep is vital to the health and development of children²⁴. It indicates that poor sleep (short sleep, poor quality sleep and sleep problems) in children is common and is associated with adverse physiological and psychological outcomes of both child and family^{24,54}. Research indicates that it is often possible to manage behavioural sleep problems effectively with behavioural interventions and/or changes to sleep hygiene^{96,97,111,120}. However, although such behavioural interventions have been indicated as effective in this area, little is known about how often they are used and how sleep problems are addressed and managed in UK community and primary care.

Potential topics for further research include PCP knowledge of management of chronic insomnia in children, attitudes and perceptions of their role with regards to chronic insomnia, current practice and what resources are available to them and their patients to aid in their consultation and management. A greater understanding of how and where parents access information on their children's chronic insomnia and the role of primary care in supporting effective management of children's sleep problems could identify areas for improvement to ultimately improve outcomes for children and parents. Exploring, and eventually optimising, paediatric sleep management within primary care could not only address behavioural sleep problems at an earlier stage (avoiding possible consequences of persisting sleep problems), but it could also potentially help with effective use of healthcare resources, by reducing the number of families who may be referred to secondary care. Importantly, addressing sleep in primary care (and in particular at

universal primary care visits, such as antenatal visits and postnatal visits) may help parents prevent later sleep problems, by providing them with important information about children's sleep early on or as preventative guidance.

1.8 This thesis

1.8.1 Research questions and aim

The overall aim of this thesis was therefore to explore how children's chronic insomnia (specifically BIC) is managed in primary care and the community by PCPs. This includes both PCPs' and parents/carers' perspectives current attitudes, knowledge, role perceptions, available resources, and current practice for children's sleep management in primary care. Though all ages were included in some parts, there was a particular focus on infants and preschool children (ages 0-5 years). Specific research questions were:

1. What are PCPs' knowledge, attitudes and beliefs regarding paediatric chronic insomnia? (Addressed in studies one and three).
2. What is the current practice and discussion regarding management of children with chronic insomnia during consultation in primary care? (Addressed in studies one, two and three).
3. What are parents'/families' knowledge and perspectives on the management of children's chronic insomnia within primary care? (Addressed in study two).
4. What resources are available online and in the community for parents and caregivers of children with chronic insomnia? (Addressed in study two).
5. What resources/interventions are currently available or accessible in primary care for parents and families of children with chronic insomnia or for PCPs? (Addressed in studies two and three).
6. What are PCPs' beliefs about various online community resources for parents/caregivers of children with chronic insomnia? (Addressed in study three).

1.8.2 Thesis overview

The following chapter (Chapter Two) outlines the theory and research methodology relevant to this thesis. Subsequent chapters (chapters three to six) present a series of research studies which were conducted to explore the above research questions:

1. Chapter Three: A systematic review which explored published literature about PCPs' understanding, knowledge, role perceptions and practice regarding children's sleep problems.

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2. Chapter Four: A qualitative study of parent's discussions in online public forums. This study explored the parent's perspectives of their children's sleep management, such as how they perceive current management from PCPs and what resources they believe are available online, in primary care and the community.
3. Chapters Five and Six: A mixed-methods study comprising of surveys (chapter five) and qualitative interviews (chapter six) of UK PCPs exploring their views, knowledge/training and current practice regarding chronic insomnia in children.

Chapter Seven presents the concluding discussion of this thesis (comparing the findings of the research studies above with each other and relevant literature) to provide an understanding of the current management of paediatric chronic insomnia in primary care and inform future research and clinical practice.

Chapter 2 Theory and Research Methodology

2.1 Overview

This chapter considers the theoretical and methodological underpinnings of the management of behavioural sleep problems within health care, and primary care specifically. It discusses in further detail the theoretical assumptions for defining optimal sleep health and sleep problems. The chapter also discusses the theoretical assumptions and debates regarding the behavioural mechanisms behind the treatment of behavioural sleep problems, in particular extinction-based methods. It then discusses the possible theoretical mechanisms which are useful to consider in relation to PCPs treating such problems, such as factors affecting their management approaches and how they acquire knowledge about behavioural sleep problems in children. Finally, this chapter outlines the philosophical stance of the researcher and how this influenced the research methodology used within this thesis.

2.2 Theoretical Considerations and Frameworks

Theory is important to healthcare research for many reasons. For example, theory can influence research design, such as how and what information is collected, and the focus of research questions. It can also influence analysis such as the method used, and researchers' interpretation of the findings.¹³⁸ Theory can also be developed from research and can in turn shape further research and clinical practice¹³⁹. Theories can present in different ways, such as theoretical definitions of something or a framework to guide practice¹³⁸. In relation to the management of chronic insomnia in children within primary care, it is relevant to explore several theoretical constructs to underpin this thesis.

2.2.1 Defining sleep health and sleep problems

A key area is the definition and conceptualisation of sleep health and sleep problems in children. Multiple factors are involved with the conceptualisation and management of chronic insomnia in children, rather than merely focussing on the need to increase the duration of sleep.

As discussed in Chapter One, there are diagnostic criteria for chronic insomnia (such as the criteria in the ICSD third edition²⁶), but there is also subjectivity surrounding the perception of behavioural sleep problems and sleep disorders. Whilst it is important to consider the various definitions of sleep problems and sleep disorders, it is also important to consider the definition of

'sleep health', a term that is less commonly used or explained in the literature ¹. Understanding factors of sleep health enhances understanding of measuring sleep problems such as chronic insomnia in children, but also increases awareness of promoting optimal sleep. Both sleep health, and sleep problems (chronic insomnia in children), are discussed below.

2.2.1.1 Sleep health

Non-specific to chronic insomnia and non-specific to children, Buysse in 2014 ¹ indicated that sleep health is not often used or defined in the literature but is important to explore. Buysse¹ reviewed the literature on sleep in relation to health and suggested a framework of five dimensions that contribute to sleep health (SATED); "satisfaction", "Alertness", "Timing", "Efficiency" and "Duration" (health SATED), which could be used for a self-report scale. The following definition was proposed:

"Sleep health is a multidimensional pattern of sleep-wakefulness, adapted to individual, social, and environmental demands, that promotes physical and mental well-being. Good sleep health is characterized by subjective satisfaction, appropriate timing, adequate duration, high efficiency, and sustained alertness during waking hours." ¹ Page 12.

Whilst the definition above is for adult sleep health, Buysse suggested that it could be adapted for younger populations. More recently, Meltzer and colleagues ¹⁴⁰ considered each dimension of Buysse's framework within the context of childhood sleep. For example, they discussed the importance of parental perceptions in relation to "satisfaction/quality" and the parental influence of sleep "timing". Furthermore, the authors added a sixth dimension to the framework, "Behaviours", to become 'Peds B-SATED'. The "Behaviours" dimension suggests that sleep practices (such as bedtime routines, sleep associations, parental presence at bedtime, and electronic use) can enhance or hinder children's sleep. They therefore revised Buysse's definition of sleep health ¹ to be specific to children which read:

"Good sleep in pediatrics is characterized by subjective or caregiver-rated satisfaction, appropriate timing, adequate duration for age, high efficiency, sustained alertness during waking hours, and healthy sleep behaviours" ¹⁴⁰

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Meltzer and colleagues ¹⁴⁰ suggested that the Peds B-SATED framework can be useful for clinicians in either screening for sleep health, or for use in the context of interventions for sleep problems (e.g. recommendation of bedtime routines). The adapted definition is also useful because it

highlights the influence and involvement of parents in perceptions and management of their children's sleep.

2.2.1.2 Sleep problems

As discussed in Chapter One, the different definitions of sleep problems are important, and whilst there may be diagnostic criteria for sleep disorders such as ICSD-3 defined chronic insomnia²⁶, sleep problems which may be an expression of chronic insomnia are subjective for many reasons (e.g. social and contextual influences). The influence of parent perception, family routines and circumstances, cultural norms and differing perceptions of sleep practices were previously discussed^{59,60,73-79}, highlighting the importance of helping any family or child who present with a behavioural sleep complaint.

Furthermore, Wiggs¹⁴¹ discussed the definition of 'sleeplessness' and suggested that questioning the amount of sleep children get is not enough to determine whether children are having optimal sleep. Rather, Wiggs suggested that sleeplessness in children should be defined by two different dimensions: "biologically-defined sleeplessness" and "socially-defined sleeplessness". The former comprises of the question of whether children get enough sleep for their biological needs; something that can be measured objectively. The latter comprises of the child and/or parent subjective report of the difference between the child's actual sleep and what they would like the sleep to be like. The parent/child report of sleep can include different types of problems such as sleep initiation, night waking, and early morning waking, and this perception can be influenced by societal and contextual factors and it can impact on the parents and children in varying ways. Whilst there is significant evidence linking shorter sleep duration to adverse outcomes in children such as risk of obesity²⁴, Wiggs' conceptualisation of sleeplessness also emphasises the importance of parental, familial and social considerations in both the assessment and management of paediatric behavioural sleep problems.

2.2.1.3 Sleep problems as defined within this thesis

Considering the discussions within this chapter and Chapter One about what constitutes a sleep disorder and the feeling of potential ambiguity for this in parents, carers and clinicians, research within this thesis focuses on both Chronic Insomnia Disorder and sleep issues described as behavioural in nature. This includes suspected chronic insomnia disorder, rather than requiring a formal diagnosis of Chronic Insomnia Disorder. For example, a parent or child consulting for 'sleep problems' that are described as behavioural in nature, such as with problems initiating and/or maintaining sleep. This definition applies to all studies that follow in subsequent chapters. For example, the mixed methods study reported in Chapters Five and Six, asked PCPs to respond

about experiences with parents or carers that have consulted with their children for sleep problems that are described in this way.

2.2.2 Behavioural learning theory, sleep problems and sleep interventions

Whilst there are varying definitions and perceptions of sleep health and sleep problems, it is important to consider what factors may contribute to problems such as troubles with bedtime, initiating sleep, night waking and waking early. Behavioural psychology helps to explain how these sleep problems may be 'learned' by young children, and therefore behavioural interventions based on behavioural learning theories can help to manage behavioural sleep problems (by learning better sleep behaviours, or by removing negative sleep behaviours) ¹¹³.

2.2.2.1 Behavioural learning theories

Classical conditioning is a form of behavioural learning by association whereby a neutral stimulus becomes paired with another stimulus which would elicit a behaviour, until that behaviour takes place with the neutral stimulus alone ¹⁴². For example, in Pavlov's work, a dog would only salivate at the sight of food, however, after repeated exposure to the sound of a bell going shortly before the food was given, the dog would then also salivate to the sound of the bell alone. 'Extinction' may occur whereby the conditioned response disappears if the stimulus (e.g. food) is then continually not given after the neutral stimulus. However, the association may not disappear permanently, because Pavlov noted that 'spontaneous recovery' of the conditioned response can happen if the two stimuli are paired again.

Operant conditioning ¹⁴²⁻¹⁴⁴, otherwise known as instrumental learning, on the other hand is a form of behavioural learning by responding to the environment. Operant conditioning involves a positive or negative association with consequences of a behaviour. For example, Skinner created a 'chamber' for rats who learned that when a lever in the chamber was pressed, food would be released. They learned that by pressing the lever, they would get the positive reward of food. There are different types of operant conditioning; (1) 'positive reinforcement', as demonstrated in the rat example, whereby the frequency of a behaviour is increased by positive consequences (2) 'negative reinforcement' whereby the frequency of a behaviour is increased by the removal of a negative consequence, (3) 'punishment' whereby the frequency of a behaviour is decreased by a negative consequence, and (4) 'response cost' whereby the frequency of a behaviour is decreased by the removal of something positive. 'Extinction' is a further type of operant conditioning, whereby a behaviour is followed by no response, or a previously given response is no longer given, and therefore the behaviour eventually 'extinguishes'.

An example of operant conditioning in relation to the onset of children's behavioural sleep problems may be where children associate a positive reward (i.e. the presence of the parent) when they cry for their attention in the night. In regards to sleep onset or limit setting, Meltzer¹⁴⁵ suggested that inconsistent limits set by parents at bedtime may be why some children seek parental attention or refuse bedtime; that they believe that eventually they will get the outcome they want. This would be in comparison to more consistent limits on bedtime (consistently ignoring attention requests), which could extinguish the requests for attention or outcomes other than going to bed.

2.2.2.2 The role of behavioural learning theory in treating sleep problems

Behavioural learning theory such as classical and operant conditioning have therefore been incorporated into sleep interventions to help behavioural sleep problems in children^{113,145}. Meltzer¹⁴⁵ stated that various interventions are based on operant conditioning, and the treatment of BIC (now included within chronic insomnia), can comprise consistent sleep schedules (appropriate to age), consistent bedtime routines and the teaching of independent sleeping¹⁴⁵.

Bedtime routines incorporate behavioural learning principles to help improve behavioural sleep problems. For example, a consistent bedtime routine can be associated with the time to soon start initiating sleep¹¹³. Positive reinforcement can also be included whereby children can take part in appropriate but fun pre-bedtime activities (e.g. story reading) or are praised when they behave positively during the bedtime routine and positive behaviour can even be reinforced with rewards such as sticker charts^{113,145}. Similarly, the positive reinforcements can be removed (response cost) if the child is not adhering to the routine, and the unwanted behaviour is ignored¹⁴⁵.

Variations of extinction interventions as discussed in Chapter One (unmodified extinction, graduated extinction and extinction with parental presence) are based on extinction principles from operant conditioning and can be used to promote independent sleeping¹⁴⁵. For example, by ignoring the child's cries at bedtime or during the night, the previously reinforced behaviour of seeking attention is extinguished by taking away the reinforcement of giving in to the child (extinction). This will teach them to fall asleep (and return to sleep after normal night wakings) independently. There are some important considerations when implementing these interventions¹⁴⁵. First, 'extinction bursts' may take place, whereby when the intervention is first implemented, it is common for the undesired behaviour (i.e. crying for parental attention) to worsen for a period before it starts to get better^{113,145}. If parents are unable to tolerate this, it may lead to responding to the cries inconsistently which can not only make the intervention more difficult to implement but can also make it unsuccessful^{113,145}. Therefore, a second consideration is the cry

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tolerance of the parents, taking into account whether extinction methods, and which extinction methods, are most appropriate for the parent. A third consideration is informing parents of the information regarding extinction bursts ahead of implementation so that they know what to expect ¹⁴⁵.

Whilst the scientific literature notes the usefulness of various types of extinction in reducing night-time sleep problems in children, conflicting theoretical stances must be considered. Blunden and colleagues ⁷¹ challenged the use of extinction techniques and highlighted conflicting arguments as to whether they have a positive or negative effect on children's needs. Blunden and colleagues ⁷¹ raised some considerations for this argument, in particular, whether infant crying should be ignored. Some of these are described in more detail below.

2.2.2.3 Conflicts between extinction methods and parental presence

2.2.2.3.1 Opposing extinction methods

As noted in Chapter One, not only can perceptions of infant and child sleep problems differ, but there are also differences around perceptions of infant crying at night ⁷¹. These perceptions can influence the beliefs about extinction sleep interventions and whether they are morally right. Blunden and colleagues ⁷¹ noted critical discussions around infant crying and questioned whether night cries should be ignored, and particularly whether they should be ignored simply because they take place during the night rather than the daytime, when often young infants are unable to distinguish between the two. Blunden and colleagues discussed theoretical debates around whether night-time crying in infants should be considered a physiological and psychosocial need, as opposed to a 'want' for attention, because it is often the only form of communication in pre-linguistic children. Some psychological theories which Blunden and colleagues discussed in opposition of extinction methods for this reason are described below.

Attachment Theory ¹⁴⁶, which focuses on the reciprocal relationship between a child and caregiver and suggests that these relationships when children are young can influence the types of attachment the children form later in life. Ainsworth ¹⁴⁶ suggested that there are different types of attachment styles: "secure attachment", "anxious-avoidant" and "anxious-resistant". More recently, "disorganised-disorientated" has also been proposed¹⁴⁷. In longitudinal and meta-analytic research it has been indicated that mothers' behaviours and parenting styles have been associated with attachment type in the children ^{148,149}. This theory therefore highlights potential problems with extinction methods because they aim to ignore infant cries at a time when it may be most crucial. Etherton and colleagues ¹¹⁴ conducted a literature review exploring why parents may find extinction-based techniques difficult and suggested that some parents believe that

ignoring these cries may impact the formation of the reciprocal relationship and lead to negative attachment styles in later life.

Furthermore, humanistic psychology, such as Maslow's hierarchy of needs¹⁵⁰ may also oppose the use of extinction-based sleep interventions. Maslow's hierarchy of needs (from bottom to top) includes (1) "physiological needs", (2) "safety needs", (3) "attachment needs", (4) "esteem needs", (5) "cognitive needs", (6) "aesthetic needs" and at the top (7) "self-actualisation". Maslow argued that each level of the hierarchy, starting from the bottom, must be fulfilled before the next to eventually reach self-actualisation. In regard to this theory, cries from an infant during the night, whether for physiological needs or for attention are a need regardless. For example, though some people may think that crying at night is more of a want than a need, Maslow's theory suggests that ignoring a child's cries may in fact be ignoring a basic need of feeling loved, safe and attended to.

Furthermore, though the mechanism of extinction techniques may stem from classical and operant conditioning, whereby an infant or child will eventually learn to self-settle, behavioural psychology would also suggest that irregular reinforcement (due to differences in night and day responsiveness) may confuse the infant, particularly if they are not yet able to understand the difference between night and day¹⁵¹ as cited in Blunden and colleagues 2011⁷¹.

Blunden and colleagues⁷¹ described the opinion that "caution should be extreme" (page 331) even if it is uncertain as to whether there are long term effects of extinction. Blunden and colleagues concluded her article suggesting that extinction methods should not be removed completely, and that unnecessary sleep problems are still important to address, and that it is important to address the parents' lack of sleep. She suggested that a "middle ground" approach between extinction methods and inconsistent approaches would be optimal.

Furthermore, whilst extinction-based interventions are effective at improving sleep, there is evidence to suggest that parents have unaddressed concerns¹⁵². Etherton and colleagues¹¹⁴ explored and discussed potential reasons as to why parents may find extinction-based techniques difficult to implement. The reasons involved 'fear of repercussions', 'enduring crying' and 'incongruence with personal beliefs', 'misinformation', 'cultural practices', 'parent wellness' and 'practical considerations'¹¹⁴. Some of these concerns support the theories mentioned above, whereby 'fear of repercussions' could involve fear of unmet needs for the infants and attachment styles later in life. Anxieties of the parent must be considered, because extinction techniques increase night-time crying in the short term but decrease it in the long term¹⁵³. It is understandable that a parent would feel anxieties over leaving their child to cry at night and a parent must feel comfortable and well informed when trying behavioural settling strategies.

2.2.2.3.2 Favouring extinction methods

Whilst there are concerns from parents regarding extinction-based sleep interventions, and theoretical stances which suggest there may be adverse outcomes from such interventions, there are many reasons to favour the use of extinction-based sleep interventions. In particular, Sadeh and colleagues¹⁵⁴ responded to Blunden and colleagues' article⁷¹ with differing views. Firstly, they reiterated that sleep is not merely a problem perceived by the parents as they believed Blunden and colleagues⁷¹ suggested, but that insufficient sleep has significant associations with adverse outcomes for both child and family. Secondly, that sleep interventions for children can also have a positive impact on parental emotions and mood⁶⁷, which in turn will benefit parent and child. Thirdly, that professionals do not always advocate independent sleeping over co-sleeping, but that they generally acknowledge cultural and social differences and aim to inform families of a variety of choices.

Sadeh and colleagues¹⁵⁴ also responded to Blunden and colleagues' concerns around ignoring infant cries throughout the night. Sadeh and colleagues highlighted that many variations of extinction interventions (such as graduated extinction and extinction with parental presence) still include a response and/or type of presence from the parent. For example, with graduated extinction (controlled crying) parents still routinely check on the child, but the checks are consistent with pre-arranged time schedules. Another example, extinction with parental presence (camping out), involves presence of the parent remaining in the same room, with distance gradually increasing between the child and parent. This highlights that for parents who are anxious about the idea of cry-it-out methods, graduated extinction, ('controlled-crying') or extinction with parental presence ('camping out') may be seen as an in-between strategy which still provide comfort and reassurance to the child, whilst also teaching them to self-soothe. These have been indicated to be effective⁹⁷.

Furthermore, despite potential concerns regarding extinction-based techniques, they are helpful in securing self-soothing when sleep problems are a concern. As described in Chapter One, a multitude of research has indicated their effectiveness in alleviating sleep problems in children. Rigorous and high-quality systematic reviews and meta-analyses of the literature have indicated that all variations of extinction methods are very effective^{96,97,120}. In particular, in Mindell and colleagues' 2006 review⁹⁷, the strongest evidence in support of interventions were for unmodified extinction, graduated extinction and parent education, even compared to other effective interventions such as scheduled awakenings.

Moreover, Sadeh and colleagues¹⁵⁴ reiterated that the concerns around long-term adverse effects of extinction-based interventions are not demonstrated by the empirical literature.

Further, some studies have explored long-term outcomes from extinction-based interventions and indicate no long-term adverse effects. For example, Hiscock and colleagues^{125,155,156} conducted a randomised controlled trial of intervention (N=174, interventions included but were not exclusive to graduated extinction or extinction with parental presence) versus usual care (N=154), for mothers and seven-month-old infants with behavioural sleep problems. At age ten months and 12 months old, both infant sleep problems and mother's well-being improved¹²⁵ in the intervention compared to usual care group. The impact on mother's well-being was maintained two years later, and there were no recorded negative effects on parenting practices or mental health of the child¹⁵⁵. At age six years¹⁵⁶, there was no evidence of differences between intervention and control on any outcomes such as children's outcomes (including emotion, behaviour, sleep, stress and psychosocial functioning), mothers' emotional or parenting style outcomes, or relationships between mothers' and children (relationship or attachment). This longitudinal study therefore suggests that there are no adverse outcomes of using extinction-based techniques (graduated or with parental presence) and although there are no positive long-term outcomes on the infant's sleep itself, they can be used at least for successful improvement of sleep for shorter time periods when families are in need of more sleep.

Finally, as also described above, classical and operant conditioning describe the mechanism by which infants may learn to self-settle; through association and reinforcement¹¹³. Though Blunden and colleagues⁷¹ argue that extinction methods might encourage parents' responsiveness to be different in the night than the day, once a child reaches the age of being able to distinguish between the two, could it be that this is no longer inconsistent?

2.2.2.3.3 Importance of an individualised approach to managing sleep problems

To summarise, extinction methods remain somewhat controversial and there is currently no consensus between various professionals' and various parents' viewpoints. Trials looking at the efficacy of extinction methods indicate that they are very effective⁹⁷, however it is understandable that some parents may experience distress¹¹⁴. The debates around extinction methods emphasise the importance of having flexible options, listening to parents' concerns, acknowledging their situational differences, cultural beliefs and educating them about all possible options.

Recently Whittall and colleagues¹⁵⁷ conducted a literature review to explore the potential barriers for implementing extinction-based interventions in order to guide HCPs with possible solutions. The authors concluded that there are different barriers for HCPs advising parents about extinction-based interventions, and for parents who try to implement them: "socio-cultural factors", "infant factors" and "parent factors" (See Figure 4). To address the barriers, the authors

suggested various solutions. These included a stepped care approach whereby different families may need different levels of intervention (some families may only need basic information and support, whereas others may have tried many interventions already and need support with extinction-based techniques). To overcome individual and situational barriers, they also suggested careful planning of implementing interventions (e.g. level of familial support, and work routines) and improvement of social support prior to intervention implementation. Furthermore, to overcome emotional barriers, the authors suggested HCPs can use behavioural techniques such as “motivational interviewing”, “emotional regulation”, “cognitive reappraisal” (changing perspective of infant crying) or “distraction”.

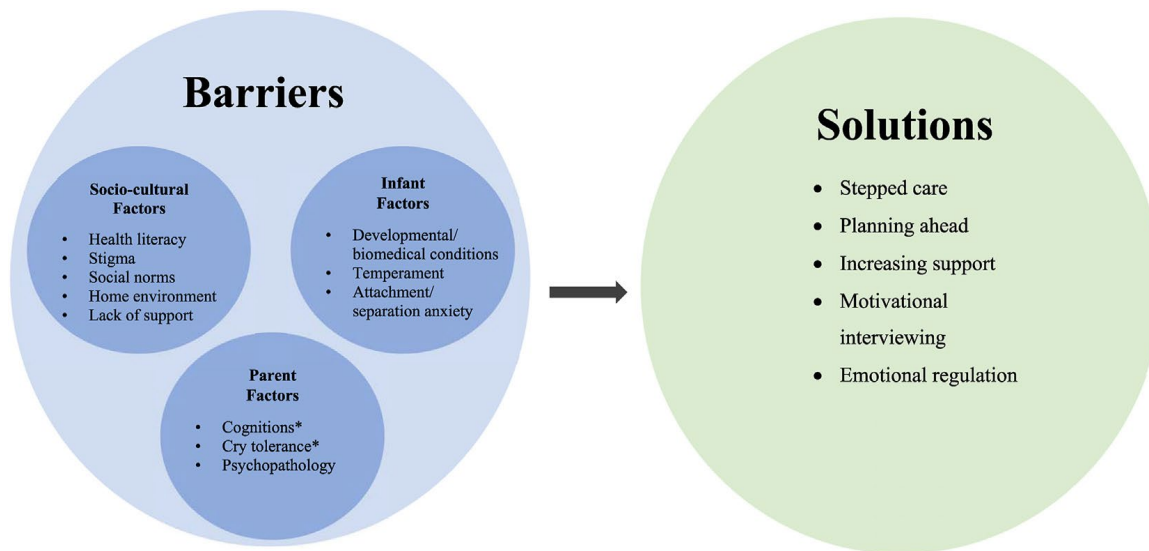


Figure 4 Model of barriers and solutions to extinction-based methods. Reproduced from Whittall and colleagues ¹⁵⁷

Whilst this model highlights potential ways for HCPs to overcome barriers when advising parents about extinction-based techniques (or for parents to overcome barriers for implementing them), it still highlights the individual differences in families and suggests that sociocultural, infant and parent factors all need to be considered when advising on appropriate interventions for each family (whether extinction-based or not).

Another example of how individual differences can be considered in sleep interventions comes from Blunden and colleagues in 2016 ¹⁵⁸ who applied Bronfenbrenner’s Ecological Systems Approach ¹⁵⁹ to the enhancement of the efficacy of school-based sleep education programmes. Through this, Blunden and colleagues suggested the importance of flexibility in different sleep strategies. The details of each system applied to school-based sleep education are described in Table 1.

Table 1 Application of Bronfenbrenner’s Ecological Model to school-based sleep education programmes, as described by Blunden (2016). Table adapted from Blunden and colleagues’ article ¹⁵⁸.

“Individual child”	Impacted by individual differences in sleep need and importance of sleep. Also considers other individual differences such as age, gender and differences in coping with sleep. This indicates that advice/recommendations need to be tailored individually to the child.
“Microsystem”	Impacted by ‘family preferences’, ‘parental influence and education’, ‘peer pressure’, ‘closed community perceived importance of sleep’. This indicates that advice/recommendations need to be tailored individually to the differences within families.
“Mesosystem”	Recognise relationships between the microsystem domains.
“Exosystem”	Education policy such as increase sleep education in medical curricula. Differences in SES -priorities may be different (indicates who needs targeting most)
“Macrosystem”	Cultures’ sleep behaviours’ are different (e.g. co-sleeping). This indicates that sleep education needs to be culturally sensitive
“Chronosystem”	Sleep changes as children age. This indicates that sleep education needs to be age-specific.

Though Blunden and colleagues compare Bronfenbrenner’s model to school-based sleep education programmes (rather than sleep interventions provided by HCP for children under five years old), these principles emphasise the importance of having a variety of effective and flexible treatment strategies. For example, this article emphasises the importance of considering individualities in children and familial and cultural preferences. It also emphasises the importance of HCP training about children’s sleep. These emphasise the importance of exploring the different views and practice regarding different behavioural approaches throughout this thesis.

2.2.2.4 Consideration within this thesis

Given the current debate over whether extinction methods are useful or harmful, it is timely to research PCP’s views on behavioural treatment recommendations and explore a variety of effective treatment approaches that might satisfy various sides of this complex picture to be able

to offer flexible options to suit different family cultures in different settings. Blunden emphasises this importance of flexible options and medical education in behaviour change by applying Bronfenbrenner's Ecological Approach to the enhancement of school-based sleep education programmes. The wide-ranging discussions that surround different behavioural strategies for the management of chronic insomnia, are considered throughout the studies conducted within this thesis. For example, in the mixed-methods study of UK based PCPs reported in Chapters Five and Six, the survey asks about a variety of treatment strategies, and the qualitative interviews prompted participants to discuss these strategies further. This allowed the research to explore views and beliefs about different treatment strategies as well as capture a picture of whether there are tailored or flexible options offered to different families and for different circumstances.

2.2.3 Theories relevant to HCPs supporting families with sleep problems

Whilst the concepts of sleep health and behavioural sleep problems, and the theoretical debates regarding behavioural sleep interventions are important considerations, other important considerations are those involving the HCPs who advise and manage behavioural sleep problems. For example, it is important to consider theoretical concepts around the beliefs and behaviours of HCPs in relation to their practice, and what influences their beliefs, behaviours and practice.

Consideration of theories can influence research design and analysis for exploring and supporting HCPs who manage childhood insomnia. For example, a theory which suggests multiple components could influence a person's behaviour, indicates exploring multiple factors is important rather than focussing on one aspect. Including questions at the research design stage, which relate to the different components could highlight areas for improvement.

Consideration of theories could also influence potential development of suitable support tools in the future. For example, by considering what influences the beliefs, behaviours and practice of a HCP, development of suitable support tools or interventions could be targeted to address these different factors.

2.2.3.1 The HCP

Historically HCPs' knowledge has been regarded as purely objective and derived from their professional medical education, which is then simply given to the patient. More recently, there has been a shift to also focus on the personal and "human" side of HCPs due to varying experiences, both professionally and personally¹⁶⁰. It is therefore important to consider not only professionals' formal education on the topic of managing behavioural sleep problems in children,

but also factors such as their beliefs and practices. Theories involving factors that contribute to HCPs' knowledge, behaviour and practice must therefore also be considered.

Greenhalgh ¹⁶¹ discussed psychological theories which are particularly relevant in both primary care and the management (not specific to sleep) from HCPs, such as social learning theory ¹⁶² and experiential learning theory ^{163,164}. Other models which are of considerable importance are behaviour change models, for example The Theory of Planned Behaviour (TPB) ¹⁶⁵⁻¹⁶⁷, which may help explain what influences professionals' decision making in management, or help to understand their understanding of behavioural sleep problems in children. Some of these theories are discussed below.

2.2.3.2 Self-efficacy theory and social cognitive theory

Self-efficacy theory was originally proposed by Bandura ¹⁶⁸. Self-efficacy theory refers to how much an individual believes that they can successfully carry out a particular behaviour and Bandura defined it as "the belief in one's ability to organise and execute the courses of action required to manage prospective situations" (page 2 ¹⁶⁹). Bandura believed there are factors which influence this belief, such as (1) successful and unsuccessful experiences with the behaviour, (2) vicarious learning whereby one sees others performing the behaviour, (3) psychological or physiological responses from the individual performing the behaviour, and (4) social feedback whereby peers encourage or discourage a particular behaviour to influence their beliefs about their chance of success ¹⁶⁸.

Social cognitive theory (SCT) was also originally developed by Albert Bandura in 1986 ¹⁷⁰ and was an extension to Bandura's social learning theory ¹⁶². Bandura suggested that there is an interactive and reiterative process between behaviour, the self and the environment. Bandura also suggested that there are different factors influencing learning and behaviour; (1) one must have the capability to perform the behaviour successfully, (2) observational learning whereby one observes behaviour in someone else and they can reproduce that behaviour (3) behaviour is reinforced either positively or negatively, which can contribute to the increase or decrease of the behaviour (3) one anticipates the consequences or outcome of a behaviour and (4) self-efficacy which is an integral part of SCT.

Whilst SCT and self-efficacy theory, in the health promotion and behaviour change world, are often discussed in terms of patients' behaviour change, they are also related to the beliefs and actions of the HCPs advising patients. For example, in relation to SCT, a PCPs' approach to management of a young child presenting with behavioural sleep problems may depend on multiple factors, not just their knowledge. For example, their level of understanding regarding

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sleep problems and ability to communicate the appropriate management strategy to the parent may influence their decision and management, and their expectations for the consequences of recommending a particular strategy, or any strategy at all (e.g. how successful an impact they believe a particular strategy will have on the family) will have an impact on their management decision. Moreover, their self-efficacy for how much they have confidence in their approach and management decisions may influence their management. For example, if they are not confident in recommending a strategy such as controlled crying, they may not recommend it at all. Furthermore, their experiences with previous patients, and whether the outcomes were successful or not, are likely to influence their self-efficacy in future consultations.

Whilst research exploring self-efficacy in HCPs managing sleep problems has not been undertaken, some studies have explored self-efficacy in HCPs for other health reasons. For example, Zamani-Alavijeh and colleagues¹⁷¹ qualitatively interviewed 23 HCPs (a range of hospital staff and HCPs from doctors' offices and health centres) about what influences their self-efficacy when educating people about health. Many of the main categories aligned with Bandura's self-efficacy theory. For example, 'quantity and quality of experience' whereby participants' lack of experience influenced low self-efficacy and successful experiences increased self-efficacy and 'receiving feedback' whereby feedback either from patients or official feedback influences self-efficacy. Other themes which were in line with Bandura's theories were 'vicarious experiences' whereby seeing other HCPs' positive experiences influenced their self-efficacy. Within the study, participants also referred to arousal states which impacted their self-efficacy, such as anxiety and stress, which also align with Bandura's theory.

Whilst SCT is a useful theory to consider potential variations in PCPs' management of children with behavioural sleep problems, some limitations must be noted. For example, it does not suggest whether any one factor is more influential than others for actual behaviour, and it suggests that external factors will lead to changes in personal factors. Nevertheless, SCT is a useful theory to consider in relation to exploring the management of childhood chronic insomnia by PCPs. Considering SCT and self-efficacy theory highlights that it is important to explore PCPs knowledge, self-efficacy, and experiences with this topic, rather than merely asking them what they recommend in consultation.

2.2.3.3 The theory of planned behaviour

The TPB proposed by Azjen¹⁶⁵⁻¹⁶⁷ is based on aspects of SCT principles. Azjen¹⁶⁵⁻¹⁶⁷ proposed that attitudes (positive or negative beliefs about the behaviour such as its outcomes), subjective norms (beliefs about what others think of the behaviour) and perceived behavioural control (beliefs about whether one can carry out the behaviour, which includes controllable and

uncontrollable factors) influence behavioural intentions, which in turn lead to behaviour. In relation to the TPB^{166,167} and HCPs' management of behavioural sleep problems in children, the attitudes may refer to the clinicians' beliefs about different management strategies (e.g. how effective they are and for whom). Subjective norms could refer to what they think other professionals would recommend, or what they feel they should recommend as a particular HCP, e.g. a GP might think about what a HV would recommend. Perceived behavioural control may relate to internal or external factors which inhibit or facilitate their management. For example, time pressures of a GP consultation may inhibit the GPs perception that they can talk through different options, or explain an option with a parent effectively, whereas evidence-based guidelines, or experience personally of trying a strategy with their own children may facilitate the intention of discussion with the parent about particular options.

Research exploring the TPB and HCPs' management of sleep problems in children is limited. However, it has been evidenced regarding HCPs and other conditions. Godin and colleagues¹⁷² conducted a systematic review of 78 studies which explored social cognitive theories and the intentions and behaviours of HCPs. Most included studies explored the TPB^{166,167} or the theory of reasoned action (a previous version of the TPB, prior to the addition of the perceived behavioural control element)¹⁷³. The findings suggested that the TPB is a useful theory for the influence of factors on behaviour.

A more recent study conducted by Webb¹⁷⁴ explored GPs prescribing and referring behaviour (based on the TPB^{166,167}), for patients with mental health problems. Questionnaires completed by 127 GPs suggested that attitudes and subjective norms both influenced decisions around pharmacological treatment, and attitudes influenced referral for psychological treatment. However, there were no significant influences of perceived behavioural control. Similarly, Rashidian and Rusell¹⁷⁵ surveyed 122 GPs, exploring the TPB and prescribing behaviour for Asthma. They supported the usefulness of the TPB in anticipating professionals' intentions but also concluded that the TPB dimension 'perceived behavioural controls' predicted intentions the most. Moreover, Kortteisto and colleagues¹⁷⁶ surveyed over 800 Finnish specialist HCPs, about the use of clinical guidelines. They concluded that all dimensions (attitudes, subjective norms and perceived behavioural control) supported the use of the TPB in relation to intentions to implement clinical guidelines in practice. Further, they concluded that perceived control was of highest influence for physicians, whilst for other HCPs, subjective norms were of higher influence. Limitations to all of these studies, however were that they were questionnaire based studies relying on personal report, so the findings may differ slightly from what actually happens in clinical practice.

Whilst this theory suggests factors which influence HCPs' behavioural intentions and behaviours, it does not explain the reasons behind differences in behavioural intentions and actual behaviours (the intention-behaviour gap ^{177,178}). There are also conflicting findings between research studies regarding predictability of the dimensions for intentions versus behaviour. Nevertheless, it is a useful theory in conceptualising various factors which may contribute to variability in HCPs' management. In relation to exploring the management of childhood chronic insomnia by PCPs, it highlights the need to explore PCPs' attitudes, subjective norms and perceived behavioural control. These would likely have an influence on PCP management and decisions.

2.2.3.4 Experiential learning theory

Another theory to consider is Experiential Learning Theory ¹⁶⁴. Greenhalgh ¹⁶¹ described this as a theory important to primary health care, but it may also be important in relation to PCPs' knowledge and understanding for the management of behavioural sleep problems in children. Specifically, it suggests that people learn by experience, and it may help explain ways in which HCPs may gain understanding and knowledge about health problems, without limits merely to education during professional training. Specifically, Lewin ¹⁶⁴ (¹⁶³ as cited in Greenhalgh¹⁶¹) proposed a 'cycle' whereby an individual has an experience of something ('concrete experience'), reflects on that experience ('reflective observation of the new experience'), learns from the experience, and plans or tries out what is learned, before starting the cycle over.

In relation to primary health care, this theory highlights that PCPs also gain knowledge through experience in consultation, by evaluating those experiences, and by experiencing them again, where they either change their approach to consultation by learning that one approach was not successful, or repeat the same approach based on past experiences of success with that particular problem. In relation to the management of sleep problems in children, this could therefore be experiences of consultations with families whereby the more experience a clinician gains in successes or failures of their management strategies, the more they learn about how to manage families the next time a consultation arises. Moreover, experiential learning theory could explain differences in knowledge in HCPs from different backgrounds, e.g., whether a HCP has had personal experience caring for children or not.

There are some limitations to this theory, however. Whilst it highlights the usefulness of learning by experience, it does not consider learning by education and or many other factors involved with learning. For example, a systematic review of 86 studies suggested a variety of knowledge sources for HCPs ¹⁷⁹. Nevertheless, in relation to exploring the management of childhood chronic insomnia by PCPs, this theory highlights the need to not only explore their professional training, but it also suggests the importance of exploring PCP experiences with this topic.

2.2.3.5 The use and relevance of SCT/ social learning theory, the TPB and experiential learning theory within this thesis

These theories suggest important factors to explore when researching the management of chronic insomnia in children within primary care. They demonstrate that it is not simply a question of what PCPs recommend for this issue, but that it is equally important to explore their beliefs, knowledge, training, experiences and confidence. Therefore, the empirical studies reported within this thesis were designed to explore all of these different aspects. For example, the quantitative survey reported in chapter five and qualitative interviews reported in Chapter Six both asked PCPs about their knowledge, beliefs and current practice.

Undertaking exploratory studies, to guide future research, highlights current practice by PCPs, helps explain current practice and highlights any potential areas for improvement. For example, in relation to the TPB¹⁶⁵⁻¹⁶⁷, if a PCP describes a positive attitude towards the management of chronic insomnia, but a describes a lack of training. This could indicate that their 'perceived behavioural control' is inhibiting management of this issue. This would therefore be an area to address in future research and intervention / support tool development. Theories are discussed in relation to the research findings reported throughout this thesis.

2.3 Research Methodology

2.3.1 Ontology and epistemology, epistemology, and philosophical positions underpin research methodology

Different philosophical stances influence different research methodologies and are underlined by one's ontological and epistemological assumptions¹⁸⁰.

2.3.1.1 Ontology and epistemology

Ontology concerns beliefs about the reality of knowledge; what there is to know and what the truths are in the world¹⁸⁰. There are various ontological positions, however they are generally thought of as being along a continuum, from realism to relativism¹⁸¹. Realists for example, believe there is one reality or one truth to something, an objective truth that can be measured.

Alternatively, relativists believe that there are multiple realities/truths which are contextual and subject dependent¹⁸¹. Other ontological positions come in between the two ends of the continuum, such as critical realism^{181,182} for example. Critical realists tend to believe there is one reality, but that it is interpreted differently, or not always accessible¹⁸².

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Epistemology similarly concerns the nature of knowledge but also how knowledge is acquired¹⁸⁰. Epistemological positions are too thought of as being along a continuum. Objectivism, similar to realism, indicates the belief that the truth or reality exists and is fixed, regardless of the individual or researcher. Constructionism on the other hand, similar to relativism, indicates the belief that the meaning behind truths and realities are constructed by an individual or researcher; they are interpreted and created by each individual's thoughts and actions¹⁸⁰

Both ontological and epistemological positions underpin each individual's philosophical approach to conducting, analysing and interpreting research (see Figure 5). For example, a Positivist's approaches are based on realist and objectivist assumptions, the belief that an independent truth exists which can be measured.¹⁸³ Generally, positivist assumptions are related to quantitative research (described in more detail in 2.1.1.2). A constructivist on the other hand would believe this may not to be possible; that multiple meanings and truths are influenced by each individual's perceptions, experiences and contexts surrounding them¹⁸⁴. Therefore, constructivist approaches are more generally related to qualitative research¹⁸⁴ (described in more detail in 2.1.1.2).

Alternatively, critical realism is a stance that is suggested to somewhat mix the two types; it "bridges a divide between positivist and interpretivist research approaches by marrying a realist ontology with a constructionist epistemology"¹⁸⁵ (page e5) and is often suited to research methodology that mixes both quantitative and qualitative methods. Despite different philosophical stances generally being evident in different methodologies, such as positivists in quantitative research and constructivist in qualitative research, these are not set. For example, there can be different philosophical approaches within different qualitative methodologies, although the different approaches will guide their research questions and qualitative approach¹⁸³

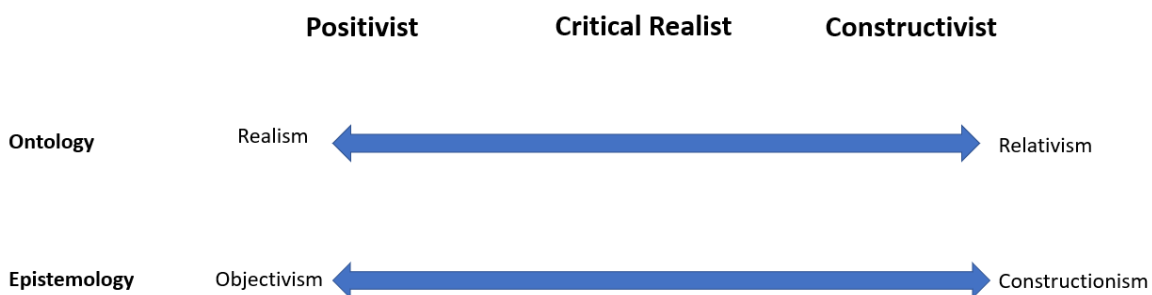


Figure 5 Diagram of philosophical stances, epistemological and ontological assumptions. Figure adapted from Sullivan (2010)¹⁸¹

2.3.1.2 Quantitative and qualitative research

Quantitative research consists of numerical data whereby researchers generally seek to find an objective truth, often with experimental procedures to generate causal explanations or to test hypotheses.¹⁸⁴ Quantitative data collection therefore involves the use of structured surveys/interviews with closed questions, observations and measurements of quantifiable and specific information. Analyses are undertaken with a variety of mathematical and statistical methods¹⁸⁶. Quantitative research typically includes larger numbers of participants which are randomly selected or representative of a population to be able to generalise the results outside of the research conducted.

There are both strengths and limitations to quantitative research. Data can be collected and analysed quickly and objectively (for example with short questionnaires) and a large number of participants can be involved. When the research is conducted reliably and with a randomised or representative population, the results can be generalised to that population. Further, in experimental quantitative research, causal effects can be tested and the conditions of the research can be manipulated to limit bias and increase internal validity¹⁸⁴. However, whilst this type of data can be informative, it does not explain the wider context and meaning of the findings. For example, numerical responses in a questionnaire limit the amount of data a participant can give, and they are unable to explain their responses.

On the other hand, qualitative research consists of non-numerical data and is more focussed on the meaning behind the data, to understand and explore phenomenon considering many factors involved such as experiences, attitudes, and behaviour¹⁸⁷. It is more subjective and usually with fewer participants than quantitative research but gives an in-depth understanding of phenomenon. Qualitative data collection involves the use of unstructured or semi-structured surveys, interviews and focus groups, with the use of open-ended questions whereby participants can talk freely in further detail. A variety of analytic methods can be employed in qualitative research, such as thematic analysis^{182,188,189}, discourse analysis¹⁹⁰, content analysis¹⁹¹ and many more^{183,192}. Choice of analytic methods can be (but are not always) influenced by one's philosophical position on the continuum of epistemology and ontology. Thematic analysis is flexible and an approach which is independent of theory.¹⁸²

There are also strengths and limitations to qualitative research. For example, data collection and analysis are more time consuming than for quantitative methods and with fewer participants. However, the data is much more in depth and is analysed rigorously to provide a wider context to the topic being studied. Further, whilst there is more bias, this is acknowledged and managed with researcher reflexivity, whereby the researcher influence is considered throughout the

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research process. Whilst a smaller number of participants means that the findings are not generalisable to a population, the findings can be transferable to other contexts. Qualitative research is also often in a more naturalistic setting, enhancing external validity¹⁸⁴.

Qualitative and quantitative methods often are assumed to oppose each other in criticisms and benefits of their methodologies. For example, quantitative research could be argued by constructivists to be limiting to real world experiences, by creating un-natural and situations lacking meaning. On the other hand, qualitative research is often argued by positivists to be too subjective allowing many beliefs based on unscientific opinion¹⁸⁴. However, qualitative and quantitative methods can complement one another. There are various ways of combining qualitative and quantitative methodologies, such as alongside each other, or whereby one precedes the other, and the findings can then be triangulated with each methodology addressing the limitations of the other. Qualitative research can inform the design of quantitative research by providing context, or it can be used to further explore specific findings from quantitative research. Similarly, quantitative research can explore interesting findings from qualitative research to enhance generalisability, or to generate findings which narrow down topics of interest for further exploration in qualitative research.^{193,194}

2.3.1.3 Pragmatism and mixed-methods research

An alternative philosophical stance, Pragmatism, focusses more on the importance of the research question and what would be most appropriate to answer the question, as opposed to a preference of one philosophical position over another^{193,195}. Pragmatism often incorporates a mixed-methods approach, whereby researchers are not limited to one theoretical stance.¹⁸⁴ Mixing the methods appropriately, by acknowledging the strengths and limitations of its methodological parts, can give advantages such as a more holistic understanding¹⁸⁴. Each type of methodology can be valued separately for their findings, and then triangulated appropriately to answer the research questions^{184,196}.

2.3.2 Overview of the methodology used throughout this thesis

The philosophical stance underpinning this research is pragmatism. The methodology used within this thesis is therefore one of mixed methods, to explore a variety of research questions in relation to how chronic insomnia in children (specifically BIC) is managed in primary care. The thesis seeks not only to explore what happens in practice, but also the individual perceptions of both PCPs and parents, regarding their beliefs, knowledge and management surrounding paediatric chronic insomnia in primary care. This is to provide as holistic an answer to the research questions as possible. Methodology for each study conducted are described below.

The first empirical study (reported in Chapter Three), a systematic review of the published literature about PCPs' knowledge, beliefs, role perceptions and management regarding childhood chronic insomnia, employed a mixed-methods approach. To include as much literature as possible on the topic, both quantitative and qualitative research studies, and professional and parent/family studies were eligible. To consider all relevant data and due to heterogeneity in study designs and outcomes, a systematic narrative synthesis¹⁹⁷ was employed. This applied equal importance to both objectively measured data such as sleep knowledge measured through validated questionnaires, and qualitative data to explore a variety of views and perceptions.

The second empirical study (reported in Chapter Four) employed a qualitative approach to explore parents' discussions in public online forums about the management of their children's sleep problems online, in the community and in primary care. The focus of this study was to explore multiple different perspectives from parents and carers, not only on the management within primary care, but also children's sleep management within the community and online. A qualitative descriptive analysis¹⁹⁸ was applied to the data collected (see Chapter Four for further details) in order to categorise parents' discussions about the topic; to gauge their comments about their feelings, see which resources are available to them online and in the community, and to understand how they described their children's sleep to have been managed within primary care consultations. Ultimately, this allowed exploration of each user's interpretation of their 'reality' regarding the management of children's sleep problems.

The final empirical study (reported in Chapters Five and Six) consisted of a mixed-methods approach to explore UK-practicing PCPs' views, understanding and practice regarding the management of paediatric chronic insomnia in children up to five years old. Similar to the previous studies, the aims were to gather both quantitative data (e.g. knowledge scores using questions from validated questionnaires, and to quantify differences between various management practices) and qualitative data (to explore more in depth perceptions of the topic and each sub-topic). Again, this allowed exploration of a general consensus, but also considered the individual 'reality' perceived by each professional.

Within the qualitative research methodology, Braun and Clarke's reflexive thematic analyses^{188,189,199} were originally planned to be used because it is not necessarily underpinned by one philosophical or theoretical approach over another^{182,188}. However, a qualitative descriptive analysis¹⁹⁸ resulted; please see Chapters Four and Six for further details. An inductive (bottom-up) approach was used in analysis, whereby descriptive themes were interpreted from the data itself (using iterative steps similar to those described by Braun and Clarke^{182,188,189,199} but which were of a more descriptive nature) rather than driven through theory. This was because the

research was exploratory and it was to base analysis and interpretation of the data on what each individual said, without fitting the data to pre-existing ideas or hypotheses. Moreover, reflexivity was considered throughout the research process to reflect on researcher influence, whereby notes were kept throughout both data collection and analysis, and audit trails of themes and codes in the various versions of 'coding manuals' were also recorded.

2.3.3 Patient and Public Involvement and Engagement (PPIE)

Alongside the research methodology for this thesis, it was important to ensure that the research was conducted in a way that was relevant to people with lived experiences of having children with sleep problems. Therefore, Patient and Public Involvement and Engagement (PPIE) was incorporated throughout the research and PPIE contributors were reimbursed at standard PPIE rates. In total, four patient and public involvement (PPI) contributors were involved throughout the research for this thesis.

A main PPIE contact was recruited early on in research programme. Soon after recruiting the project's main PPIE contact, a telephone interview was conducted, to talk through individual study plans, and overall PhD thesis plans. She herself had experience with sleep problems with her primary school aged child and had gone through various processes to try and get help for this. Regarding comments about the overall research plans, (before each individual study plans were discussed), she suggested that it would be beneficial to study PCP attitudes and knowledge (GP, HVs and school nurses in particular) about managing sleep problems. She thought this was important because she herself had had negative experiences of support for her child's BI in this setting. She also agreed that the overall aim of the thesis was relevant (exploring the management of chronic insomnia by PCPs in children up to five years old). These general comments not only reinforced the relevance of the overall thesis aims, but also the aims of individual studies.

Further into the thesis research, an advert was circulated to recruit a small virtual panel of PPIE contributors. This was with the aim of gaining PPIE feedback on preliminary findings from more perspectives, particularly for the larger mixed-methods study of PCPs. The advert gained interest from six potential PPI contributors. Three of which were involved with the research for this thesis and all had personal experience with their children having experienced behavioural sleep problems. For preliminary findings of the individual research studies, there was PPI feedback from one contributor for the systematic review (reported in Chapter Three), one contributor for the internet forum study (reported in Chapter Four), and three contributors for the Interview findings

(reported in Chapter Six). PPIE input for each specific study is discussed in detail in the associated chapters.

Chapter 3 Primary care practitioners' knowledge, beliefs, and practice regarding the management of chronic insomnia in children. A systematic review.

3.1 Overview

This chapter provides an overview of the first study within this thesis: a systematic review exploring PCPs knowledge, perceptions of role and current practice, regarding the management of paediatric chronic insomnia. This systematic review addresses aims one and two of this thesis, highlights the gaps in the literature and informs later studies in this thesis.

3.1.1 Background and rationale

As set out in Chapter One, good sleep is important to the health and development of children²⁴, and it is often possible to manage chronic insomnia with behavioural and/or sleep hygiene interventions^{96,97,111,120}. Chapter One also discussed how primary care seems the optimal healthcare setting to address possible sleep problems early, though there is limited research into how sleep problems are managed in primary care. Additionally, primary care systems vary worldwide. Honaker and Meltzer¹³⁴ conducted a review of the literature up until 2014, which suggested that paediatric sleep knowledge in medical education is lacking, as is the confidence in discussing it, and that sleep is often not discussed in primary care settings with patients, and/or children are often not referred for suitable treatment if they do present with sleep problems. However, the review was narrative rather than systematic and the search terms were limited. Many of the studies included in this review were conducted in America, where the first point of contact for children's sleep problems may be a paediatrician and therefore, these US practitioners may have greater knowledge about children's sleep than GPs in other settings such as the UK.

Therefore, it would be beneficial to update the literature and specifics parts of the review conducted by Honaker and Meltzer¹³⁴, focussing more specifically on chronic insomnia and on the PCP, specifically their knowledge and understanding, role perceptions and current practice. Exploring these areas will provide a more detailed insight into the topic and will guide later studies.

3.1.2 Research questions and aims

The aim of this review was to explore PCPs' understanding, knowledge, perceptions of their role and current practice, regarding the management of chronic insomnia in children.

3.2 Method

3.2.1 Planning, protocol and registration

A number of possible foci were considered including reviewing all paediatric sleep intervention studies. After initial scoping of the literature and a first draft of the search terms, the focus of the systematic review was refined (please see further details in section 3.3.2). The scoping exercise revealed that systematically searching for all intervention studies conducted in primary care was not feasible because many may not mention primary care in the title or abstract, or they may test interventions in secondary care which could be used in primary care. Scoping also revealed published reviews^{96,97,120} of paediatric sleep intervention studies evidencing their efficacy.

Thus, the focus of the systematic review was finalised as PCPs' perspectives of their role, current practice, understanding and knowledge regarding management of chronic insomnia. After also considering the published review conducted by Honaker and Meltzer¹³⁴, this focus serves not only as an update to some of its areas, but is more specific to chronic insomnia, more systematic and with broader, more sensitive search terms.

A protocol was created for this systematic review it was registered on Prospero (registration number CRD42020183633).

3.2.2 Eligibility criteria

It was initially decided to keep each aspect of the eligibility criteria broad, to capture as much relevant data as possible, acknowledging that they might need to further be refined later if the data became unmanageable.

For example, in the population of interest, it was decided not to limit the age criteria to 0-5 years a priori, as some papers might not specify age range within the abstract, but to explore this age range in its own section if possible, at a later time. The population was, however, limited to healthy children with BI, and with no physical or mental health co-morbidities because this focused the review on sleep problems as the primary problem, whereas children with comorbid conditions may have sleep problems as a consequence or symptom of another condition. The sleep outcomes were also limited to studies which investigated chronic insomnia separately,

rather than with sleep disorders such as sleep disordered breathing or enuresis. Community settings were included where relevant to PCPs, such as a HV or nursery nurse to include all aspects of primary care.

The eligibility criteria were initially created (appendix A.1). After running the final searches and screening the titles/abstracts of many papers, it was evident that the search was identifying an unmanageable number of full texts (approximately 1000) to assess in the given time frame. The aim of the review was to explore what PCPs currently practice, know, believe, and what interventions PCPs are aware of and use, but not which interventions work. Therefore, a further refinement of the eligibility criteria was undertaken in September 2019 to exclude papers looking at testing the effectiveness of new interventions. The final eligibility criteria are listed in table two.

Table 2. Final eligibility criteria

	Inclusion	Exclusion
Population	GPs treating paediatric behavioural sleep problems (or similar such as HVs / community nurses), or parents/carers of children presenting in primary care with any behavioural sleep problem (only if they report on what their PCP recommended)	<p>A study sample that does not include PCPs, or parents (or carers/families) of children with sleep problems) discussing their PCP.</p> <p>Studies which are about children with co-morbid physical or mental health problems/disabilities.</p> <p>If the sleep problem is not a behavioural sleep problem or only refers to enuresis / sleep disordered breathing or movement disorders such as rocking.</p>
Setting	<p>General Practice or the community (if the community setting is based from PCPs, such as HVs or community nurses etc).</p> <p>Primary care is also considered if it is clear/described as the first point of</p>	<p>Not in a primary care setting or community setting that is based from HCPs such as HVs or community nurses.</p> <p>PCP's healthcare that is based on referrals or not the first point of call</p>

	call, instead of being named specifically 'primary care'.	(e.g. clinic run by HVs, but which needs a referral for access).
Intervention	<p>If the intervention is clearly an already implemented (potentially available) service/ or a trial includes a baseline measure of what PCPs currently do, understand / perceive their role to be, regarding the management of BI.</p> <p>Papers were also included If there is a baseline/control group (e.g. usual care) which indicates what PCPs currently do, understand and perceive their role to be.</p>	<p>Intervention studies that generated data only for novel interventions that are not currently available/accessible for general use. Intervention studies such as trials that do not give data for what PCPs currently practice, believe or understand regarding behavioural management of BI in children.</p>
Comparisons	N/A	N/A
Outcome	<p>PCPs' understanding, knowledge, perceptions and current practice regarding behavioural management of children's sleep problems in primary care. The primary outcomes are attitudes, knowledge, understanding and current practice regarding the management of BI in primary care.</p> <p>Sleep problems in this review refer to aspects of BI, such as insomnia, dyssomnia, bedtime resistance, sleep quality and efficiency, duration, onset latency, hygiene, routine, night awakenings, daytime napping, daytime sleepiness and/or sleep stability.</p>	<p>Not about PCP's beliefs, understanding and knowledge, or practice regarding management of BI in children. Not collecting data on the desired outcomes of interest.</p> <p>Pharmacological treatment studies.</p> <p>Sleep outcomes that are only about enuresis, sleep disordered breathing disorders or movement disorders (e.g. rocking).</p>
Study design	Any primary research. Qualitative, quantitative or mixed-methods research. Descriptive and exploratory studies, cross-sectional and	Non-primary research (e.g. review articles, book chapters etc)

	longitudinal studies. RCTs and non RCTs (only if they measure current PCP practice).	
Language	English language versions	Non-English language versions
Publication	Any year. Peer reviewed	Non-primary research or not peer-reviewed. Unpublished research (e.g. unpublished thesis) or protocol/abstract-only publications.

3.2.3 Information sources and search strategy

Six electronic databases were systematically searched on the 14th and 15th February 2019. The search was then refined (please see below for further details) and re-run on 28 March 2019: MEDLINE, EMBASE, PsycINFO, CINAHL, Web of Science and The Cochrane Library (CENTRAL).

Free text searches were the same for all databases and included relating terms for sleep and insomnia (such as “sleep”, “insomnia”, “dyssomnia”, “bedtime resistance” and “limit setting disorder”), for child (such as “child”, “paediatric”, “toddler” and “baby”) and for primary care (such as “primary care”, “first line care”, “health visitor*”, family doctor and “general practitioner”). Relevant subject headings were also used for each database and were matched as closely as possible in relation to the free text terms within the searches and each other.

However, after beginning screening from the searches ran in February 2019 (approximately the first 150 results after de-duplication), the database search results were compared to the reference list of the previous, wider review by Honaker and Meltzer¹³⁴ which identified a potential issue. Eleven of their resulting papers were not identified in the initial search. Reviewing the search criteria again, the missing papers were missing at least one keyword from the original searches. Many of the titles included the term ‘pediatrician’ or similar which could be a term for a primary care clinician in America. With advice and guidance from the Faculty of Medicine Research and Engagement Librarian (who initially helped with the development of the search terms), the search terms were revised. Thus this (along with the English spelling) was added into in the HCP section of the search, to pick up these papers, as were more terms and subject headings for “community health care” to increase the sensitivity of the search. The searches were rerun, with the revised criteria on the 28th March 2019. This picked up more, but not all, of the references in the other published review¹³⁴. After further reviewing the title and abstracts of the missing papers, some did not mention sleep or primary health care, and furthermore, they

mentioned broader terms, such as mental health terms, which if added would make the results of the search strategy unmanageable.

The authors of this review ¹³⁴ were contacted to ask whether they would be happy to share their search terms, however they indicated that the search terms used were those written in their paper: “sleep” and “primary healthcare” which the strategy of this review already included. This did not indicate a replicable or systematic search and suggested their review to be a critical, not systematic review.

Reflecting on the information above, it was determined to use the revised search strategy (28 March 2019) as the final search strategy. See appendix A.2 for the full search strategy. This search was re-run as an update on 24th August 2021. Forward and backward citation chasing in this review was also conducted to ensure that any other papers were identified.

3.2.4 Study selection

3.2.4.1 De-duplication and title/abstract screening

All results were imported from the database searches into a single Endnote file and de-duplicated. Any uncertainties in duplicates were retained in the file before exporting the remaining results to Rayyan ²⁰⁰, an online tool designed to facilitate the screening process in systematic reviews.

The titles and abstracts of the results uploaded to Rayyan were screened for potential eligibility, applying reasons, using a specific strategy, as to why results were excluded (see appendix A.3). These exclusion reasons were created and tested with the screening of the initial searches conducted prior to revising the search strategy and revised in supervision meetings. Twenty percent of the titles and abstracts were also screened again by an independent reviewer (BS). Any conflicts and uncertainties were discussed and resolved between SH and BS by discussion and consensus.

3.2.4.2 Full text screening

Potentially eligible articles were downloaded from Rayyan into an endnote file for a second screening process: full texts of the downloaded articles were assessed for full eligibility using the final eligibility criteria and the strategy of listed exclusion reasons (appendix A.3) to aid decision making. Approximately ten percent of the full texts were assessed independently by a second reviewer (BS) and discrepancies discussed together to be resolved. See appendix A.4 for the exclusion reasons for the full list of references for which full texts were checked.

3.2.4.3 Challenges in full text screening

Some screening challenges should be noted. Firstly, it was challenging to determine whether some papers were referring to primary care or other levels of care. As primary care differs worldwide, country's healthcare systems (which were unfamiliar to the researchers) were explored on an individual basis to determine their eligibility to the review. It was still difficult at times to determine what was meant by primary care. For example, one Turkish study¹³⁷ referred to the HCPs as paediatricians. After researching the healthcare system for that country online, it was apparent that their system had changed in the last decade²⁰¹, and eligibility was still not clear. Following this, if there was not enough description in the papers, the approach of self-judgement was taken to decide whether the HCPs in question were a first point of call for the patient (based on how the paper was written / HCPs described). This decision was difficult for approximately 12 papers. Though these decisions are subjective and therefore some data may have been missed, the decisions were made pragmatically to be as confident as possible that this systematic review did not include secondary care data.

Secondly, it was challenging to determine whether some papers were specific to behavioural sleep problems (or chronic insomnia). Many papers simply referred to the problem in question as 'sleep problems' or similar. Due to the risk of including papers that researched or included other types of sleep disorders, such as sleep disordered breathing, narcolepsy or enuresis, it was decided to only include a paper if it: 1) specifically named the problem with a term such as Chronic Insomnia, BI or behavioural sleep problem; 2) named many types of sleep problems, but specifically conducted analyses /discussed behavioural sleep problems separately; or 3) if it did not define further than sleep problems, but the introduction and description of the sleep problems explicitly described that of a behavioural nature.

3.2.5 Citation searching

Forward and backward citation chasing from included studies were conducted when possible, to identify any other potentially eligible papers. Forward citation chasing was conducted on the Web of Science (WoS) database initially. If the already included papers were not registered in the WoS database, their forward citation chasing was conducted on PubMed, Scopus or Wiley. For three studies, forward citation searching was not possible either because the articles were not found on the databases for which the citation searching was conducted, or there were no 'cited by' results.

3.2.6 Data collection process and data items

Data were extracted from the included papers into data extraction tables, and this will be checked by another reviewer prior to publication. The data extraction tables include a table for general study details and methodology, and tables for extracting relevant outcome data. Tables for extracting outcome data included key/relevant findings (PCP type, study design, knowledge/understanding, practice, perceptions of role and beliefs). The tables were pilot tested with the first five included studies and revised accordingly, to best indicate and compare the key findings and conclusions across the papers.

3.2.7 Risk of bias in individual studies

A quality appraisal of the included studies was performed using the latest version (2018) of the Mixed Method Appraisal Tool (MMAT) ²⁰²⁻²⁰⁴. This tool was chosen because it allows for appraisal of both quantitative and qualitative studies. Study types in the tool are (1) 'Qualitative', (2) 'quantitative RCTs', (3) 'quantitative non-randomised', (4) 'Quantitative descriptive' and (5) 'Mixed methods'. Each design type is accompanied by five criteria to be met (please see Appendix A.9 for further information). Responses were rated as Yes (Y), No (N) or cannot tell (C). For the purpose of providing an overall summary rating for each study, 'C' was scored as if it was 'N', as recommended for the MMAT version 2011 ²⁰⁵. The authors also recommended that for the mixed-methods criteria, overall ratings are given based on the lowest rating section.

The authors also recommend presentation of the overall quality and contrast results, rather than simply a score ²⁰². Where applicable, the ratings are accompanied by comments (please see appendix A.9 for the full quality appraisal with comments on individual criteria) and the quality of studies are compared to one another. The authors recommend that studies rated low in quality, are not excluded from analysis ²⁰². Therefore, studies with low methodological quality in this review are included, however the weighting of their findings on the review findings are considered in the synthesis and discussion.

3.2.8 Synthesis of results

Several considerations determined selection of the synthesis method most appropriate for this review. Initial thoughts were to conduct a meta-analysis of any intervention studies (if possible), a thematic analysis of qualitative studies and a systematic narrative synthesis of quantitative studies. Due to the change in research question/eligibility criteria to remove possible interventions, as well as widely varying types of data and outcome measures across the included studies, and due to more studies from the March 2019 search being quantitative / descriptive

statistics, use of a systematic narrative synthesis based on guidelines by Popay and colleagues 2006¹⁹⁷ was decided for all included studies. This allowed a range of different types of data and outcome variables to be synthesised together, drawing conclusions in a systematic way, which guided further research studies reported within this thesis.

Popay and colleagues¹⁹⁷ described the narrative synthesis process in terms of four elements:

1. 'Developing a theory of how the intervention works, why and for whom': Popay and colleagues acknowledged that not all authors will include this element and as such, it did not apply to this review and was not included.
4. 'Preliminary synthesis': Popay and colleagues suggested that "it is important to use the review question(s) to inform decisions about how to group the included studies" and that they can be grouped according to study design, the type of results reported, intervention type, setting/context of intervention and/or the population it is directed towards. The most suitable approach to this review was to group the preliminary syntheses according to the type of results being reported, which also formed parts of the research question. The groups were 'understanding/knowledge', 'current management' and 'views, attitudes and perceptions of role'. The data were further grouped within the groups. 'Tabulation', 'textual descriptions' and 'groupings/clusters' were used to aid this reviews' preliminary synthesis.
5. 'Exploring relationships within and between studies': The most suitable and informative approach for the research question in this review, seemed to be 'subgroup analyses'; explore relationships and differences between the country it was conducted, the type of PCP the study was about, and the type of participant involved (PCP or parent).
6. 'Assessing the robustness of the synthesis': This refers to the assessment of both the robustness of the methodological quality of the included studies, the overall quality of the evidence and the quality of the review itself. Please see sections 3.2.7 and 3.2.9 for details of these assessments.

3.2.9 Risk of bias across studies

Careful consideration went into the reduction of meta-biases. It was initially planned to use the GRADE criteria²⁰⁶ to look at the quality of the evidence overall. However, this plan was revisited after the synthesis method was finalised and conducted. Because there is no GRADE criteria for assessing risk of bias from integration of mixed-method, qualitative and quantitative evidence²⁰⁷, it was decided that this would not be suitable for the current review. It may have been possible to use the GRADE criteria separately for qualitative and for quantitative studies, however because the criteria could not be combined, it would not give an assessment of the risk of bias across all

Chapter 3

studies. Therefore, the methodological quality of the individual studies overall within this review are discussed throughout the synthesis, in terms of how many studies for different outcomes are rated as different levels of methodological quality as reported by the MMAT.

Furthermore, to explore whether all of the research has come from just one country or research group, it was considered how many studies were included from different research teams in different countries and whether the studies reflect participants in different primary care settings, or whether there is a gap in the populations presented.

3.2.10 PPIE

As described in Chapter Two, a telephone interview was conducted with the main PPIE contact early on in this research, whereby she commented on overall thesis research plans, and on plans for individual research studies within. When discussing the systematic review plans specifically, she confirmed relevance and seemed enthusiastic about the idea of this study and what it could find. She also seemed interested to know how many papers were in a lay language that anyone could understand and followed on to say that it would be interesting to have an online facility for this information. This further confirmed the relevance and appropriateness of the systematic review, but also confirmed relevance of the second study within this thesis about where parents access information online (see Chapter Four).

One other PPIE contributor commented on a lay summary of the emerging findings from this review. The feedback confirmed relevance and general readability of the emerging findings and agreed with the groupings of findings and the emerging conclusions. There were minor comments to change some of the wording throughout the summary to enhance readability further and to incorporate studies exploring pharmacological management. Unfortunately, due to the scope and capacity of the review, it was not feasible to incorporate pharmacological studies.

3.3 Results

3.3.1 Study selection

From the final search in March 2019, there were 7578 results. Endnote highlighted 3319 as possible duplicates and 2073 were removed after de-duplication, leaving 5505. Some were still considered possible duplicates in Endnote, which were not excluded due to uncertainty as to whether they were truly the same paper. 5505 titles were uploaded to Rayyan for title/abstract screening. After initial screening and after SH and BS discussed and resolved a small number of uncertainties, 486 references were included for full text screening. After full text screening and

after SH and BS discussed and resolved uncertainties, 18 papers were subsequently included from the March 2019 search in the review.

One paper was found through another source. Two papers were included from forward citation searching and then five more papers were included from updating the electronic database searches in August 2021. 26 papers were ultimately included in the review.

See the PRISMA diagram in Figure 6. Please note, within the 'records identified' and 'records screened' sections of the PRISMA flow diagram, there may be some overlap due to duplicates within the search and with other methods of identification. For example, a record identified from backwards citation searching may already have appeared in the database search, and the search re-run was conducted from the beginning of 2019, so there may be some duplication from results dated between January to March 2019 which already resulted in the initial search. These duplications are not present in the 'reports sought for retrieval' sections onwards.

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources

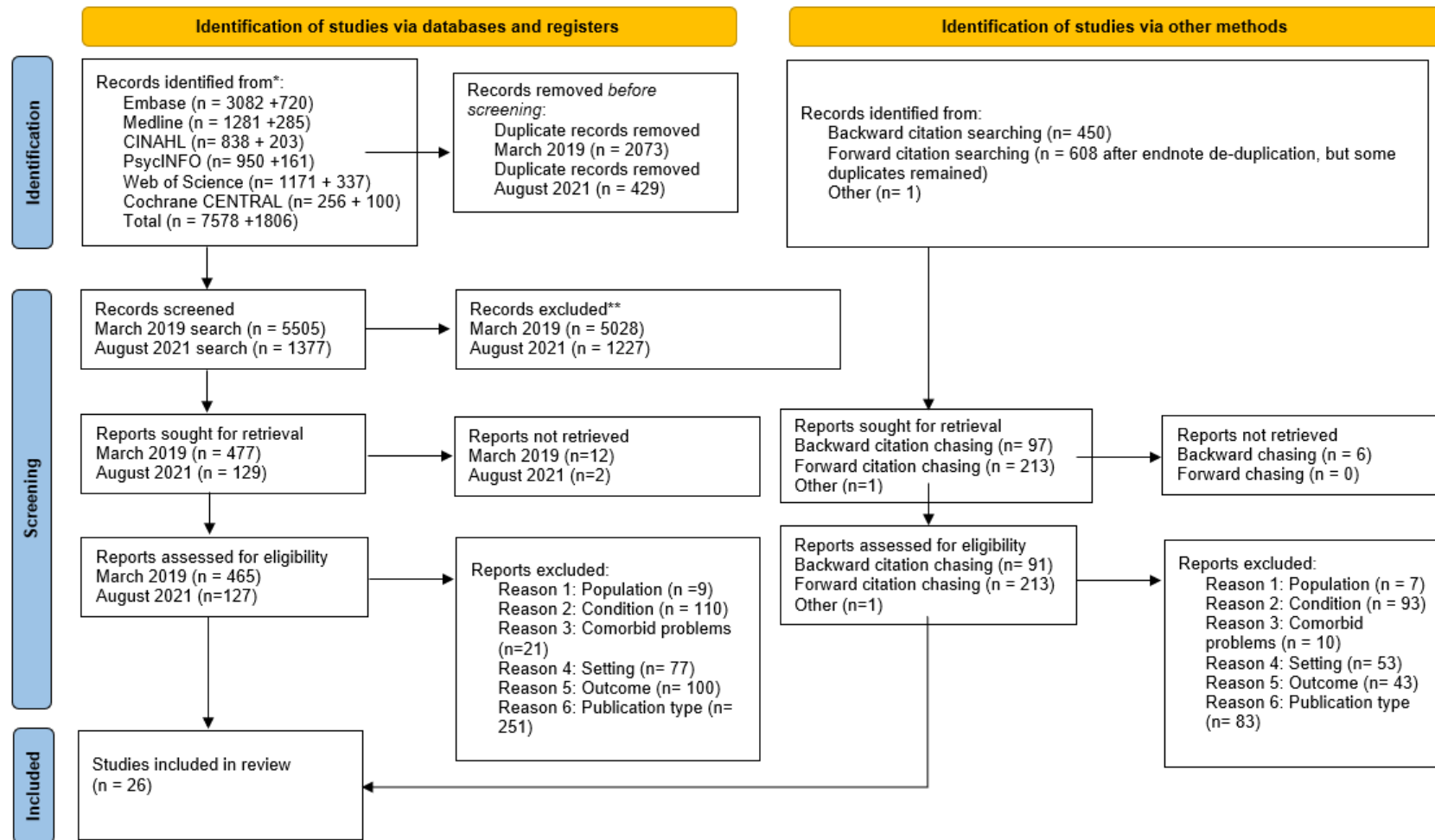


Figure 6 PRISMA flow diagram²⁰⁸

3.3.2 Data extraction

3.3.2.1 Study characteristics

The 26 included studies were conducted in a variety of countries (US, UK, Australia, Italy, Turkey, Canada and Vietnam) and reported on a variety of PCPs (paediatricians, HVs, community-based nurses, GPs). Studies were either quantitative, qualitative (with either small amounts of relevant data available, or themes within the studies), or of mixed-methods design. It must be noted, that though at the time of the study the data/findings (e.g. treatment recommendations) were 'current', many of the quantitative studies were conducted some years ago. Table 3 summarises the key study characteristics relevant to this review. See Appendix A.6.1 for a detailed table of study characteristics. This review synthesises the data in terms of 'Knowledge/Understanding', 'Management/Practice' and 'Views, Attitudes and Perceptions of Role', referring to differences between countries, PCP type and participant type (parent or PCP). See Appendix A.6.2 to A.6.4 for the full data extraction tables.

Table 3 Summary of key study characteristics

Study	Study design	Country (and type of PCP reported about)	Sample			Data collection method	Analysis	Relevant outcomes reported on
			Type	N	Other key details			
Abbott and Bryar (2015) ²⁰⁹	Qualitative	UK (HV)	HV	7	Female = 100%	Semi-structured interviews	Not specified	Practice, attitude

Study	Study design	Country (and type of PCP reported about)	Sample			Data collection method	Analysis	Relevant outcomes reported on
			Type	N	Other key details			
Bonuck and colleagues (2020)²¹⁰	Mixed	US	Head start staff	31		Survey Semi-structured interview	Descriptive statistics Thematic analysis	Beliefs, attitudes, perception
Bruni and colleagues (2004)²¹¹	Quantitative	Italy (paediatricians)	Paediatricians	627 67 controls	Male = 334 Female = 293	Survey and interview control	Descriptive statistics	Knowledge, practice, views and attitude
Carter and Mason (1989)²¹²	Quantitative	UK (HV)	HV	42		Questionnaire	Descriptive statistics	Views
Chavin and Tinson (1980)²¹³	Quantitative	UK	Parents	62		Survey via interview	Descriptive statistics	Practice

Study	Study design	Country (and type of PCP reported about)	Sample			Data collection method	Analysis	Relevant outcomes reported on
			Type	N	Other key details			
Cheng and colleagues (2020) ²¹⁴	Mixed	Australia (CFHN)	CFHN	Survey = 90 Interview = 20	Female = 100%	Survey and semi-structured interview	Descriptive statistics and thematic analysis	Knowledge, practice, attitude
Cook and colleagues (2020) ²¹⁵	Qualitative	UK	Parents	182		Online questionnaire – open ended question	Thematic analysis	Knowledge, practice
Crawford and colleagues (1989) ²¹⁶	Mixed	UK (HV)	HV case notes	1 HV, 9 children		Record of cases		Practice
Ersu (2017) and colleagues ¹³⁷	Quantitative	Turkey (paediatrician)	Paediatricians	117 intervention 70 control	Female = 75% Male = 25% Female = 73% Male = 27%	Questionnaire prior to testing teaching intervention	Descriptive statistics	Knowledge / attitudes

Study	Study design	Country (and type of PCP reported about)	Sample			Data collection method	Analysis	Relevant outcomes reported on
			Type	N	Other key details			
Faruqui and colleagues (2011) ²¹⁷	Quantitative	US (paediatrician)	Paediatricians	346	Male = 128 Female = 222	Survey	Descriptive statistics and t-tests	Knowledge, practice and views, perception, attitude
Hall (2019) and colleagues ²¹⁸	Mixed. Relevant data qualitative	Canada (nurses)	Public health nurses	10 PHN 23 NRPH&ES nurses		Focus group and guided discussion	Qualitative analysis not specified	Knowledge
Hatton and Gardani (2018) ¹³³	Qualitative	UK (HV and GP)	Parents	16	Female = 15 Male = 1	Semi-structured interviews	Grounded methodology	Practice and knowledge
Hewitt and colleagues (1989) ²¹⁹	Quantitative	UK (HV)	HV	7		Rating scales / structure validation interview	Descriptive statistics	Practice, perception, attitude

Study	Study design	Country (and type of PCP reported about)	Sample			Data collection method	Analysis	Relevant outcomes reported on
			Type	N	Other key details			
High and colleagues (1998) ²²⁰	Quantitative	US (paediatric residents and nurse practitioners)	Families (2 groups)	Group 1: n=51 Group 2: n=100	Female=47% Female=44%	Cross-sectional comparison with. Historical control	Descriptive statistics	Practice
Kanoy and Schroeder (1985) ²²¹	Quantitative	US (program in paediatric primary care clinic)	Parents	25 Sleep concerns (n=60)		Follow-up evaluation of clinic	Descriptive statistics	Practice
Mindell and colleagues (1994) ²²²	Quantitative	US (paediatrician)	Paediatrician	88 (questionnaire) 181 (survey)		Surveys, including the 'Sleep survey' knowledge questionnaire	Descriptive statistics	Knowledge, practice, views
Mindell and Owens (2003) <small>135</small>	Quantitative	US (paediatric nurse practitioner)	Paediatric nurse practitioner	317	Female = 99.7%	Survey	Descriptive statistics	Attitude

Study	Study design	Country (and type of PCP reported about)	Sample			Data collection method	Analysis	Relevant outcomes reported on
			Type	N	Other key details			
Murray and colleagues (2019) ²²³	Qualitative	Vietnam	Doctors Nurses/midwives	4 4		Interviews/ focus groups	Deductive thematic analysis	Practice
Olson and colleagues (2004) ²²⁴	Quantitative	US (paediatrician)	Paediatrician Parents	1100 2068 children	Male = 47.3%	AAP periodic survey NSECH survey	Descriptive statistics	Practice
Owens (2001) ²²⁵	Quantitative	US (paediatrician)	Paediatrician	626	Female = 49.7%	Survey (PSS)	Descriptive statistics	Knowledge, practice, views
Paton and colleagues (2019) ²²⁶	Mixed	Australia (school nurses)	School nurses	24 survey 15 focus group		Surveys and focus groups	Descriptive statistics and thematic analysis	Knowledge, Attitude, perception
Sadler and colleagues (2020) ⁷³	Qualitative	US (paediatric providers)	Paediatric providers	10		Semi-structured interview	Thematic analysis	Knowledge, practice, views, perception

Study	Study design	Country (and type of PCP reported about)	Sample			Data collection method	Analysis	Relevant outcomes reported on
			Type	N	Other key details			
Stallard (1998) ²²⁷	Qualitative case study	UK (HV)	HV / family	1	Female	Case study description	Not specified	Practice
Thomas and colleagues (1982) ²²⁸	Quantitative	UK (HV)	HV	53		Rating scale questionnaire	Descriptive statistics	Belief, attitude, perception, views
Williamson and colleagues (2020) ²²⁹	Qualitative	US	PCPs	22		Interview	“Integrated approach” thematic analysis	Knowledge, practice, views, perception, attitude
Wynter and colleagues (2015) ²³⁰	Mixed	Australia (MCH nurses)	MCH nurses	343		Survey	Descriptive statistics. Thematic analysis	Practice and perception

Chapter 3

Note: Table 3 abbreviations are HV = Health Visitor; GP = General Practitioner; CFHN = Child and family health nurse; PHN = public health nurse; NRPH&ES = Niagara Region Public Health and Emergency Services; AAP = American Academy of Pediatrics; NSCEH =National Survey of Early Childhood Health; PSS = Pediatric Sleep Survey

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3.3.3 Risk of bias within studies

The MMAT²⁰² suggested the included studies were of a varied methodological quality. Generally, the more recent studies were higher in quality and the more dated UK ones for (for HV research) were lower in quality. However, often papers simply did not report enough information to decide either way. Please see the table below, and Appendix A.7 for the full quality appraisal which also gives comments alongside the overall ratings.

Table 4 MMAT ratings for each included study

Author (year)	Country	Study type	Criteria and response					Overall rating
			.1	.2	.3	.4	.5	
Abbott and Bryar (2015)²⁰⁹	UK HV	1	Y	Y	C	Y	C	Medium
Bonuck and colleagues (2020)²¹⁰	US	5	Y	Y	Y	Y	N	Low, high, low – overall low
		1	Y	Y	Y	Y	Y	
		4	N	N	C	Y	Y	
Bruni and colleagues (2004)²¹¹	Italy	4	Y	Y	Y	Y	Y	High
Carter and Mason (1989)²¹²	UK	4	Y	C	C	N	C	Very low
Chavin and Tinson (1980)²¹³	UK	4	Y	C	Y	Y	Y	Medium
Cheng and colleagues (2020)²¹⁴	Australia	5	Y	C	C	Y	C	Medium, high, good – overall medium
		1	Y	Y	Y	Y	Y	
		4	Y	C	Y	Y	Y	
Cook and colleagues (2020)²¹⁵	UK	1	Y	Y	Y	Y	Y	High

Author (year)	Country	Study type	Criteria and response					Overall rating
			.1	.2	.3	.4	.5	
Crawford and colleagues (1989) ²¹⁶	UK	3	N	C	N	C	Y	Very low
Ersu and colleagues (2017) ¹³⁷	Turkey	3	C	Y	Y	Y	Y	Good
Faruqui and colleagues (2011) ²¹⁷	US	4	Y	Y	Y	Y	Y	High
Hall and colleagues (2019) ²¹⁸	Canada	5	Y	Y	C	Y	C	Medium, low, medium – overall low
		1	Y	Y	C	C	C	
		4	Y	Y	C	C	Y	
Hatton and Gardani (2018) ¹³³	UK	1	Y	Y	Y	Y	Y	High
Hewitt and colleagues (1989) ²¹⁹	UK	3	N	Y	N	N	Y	Low
High and colleagues (1998) ²²⁰	US	3	Y	Y	C	Y	Y	Good
Kanoy and Schroeder (1985) ²²¹	US	4	Y	N	C	Y	Y	Medium
Mindell and colleagues (1994) ²²²	US	4	Y	Y/C–	Y	Y	Y	Good/High

Author (year)	Country	Study type	Criteria and response					Overall rating
			.1	.2	.3	.4	.5	
Mindell and Owens (2003) ¹³⁵	US	4	Y	N	C	C	Y	Low
Murray and colleagues (2019) ²²³	Vietnam	1	Y	Y	Y	Y	Y	High
Olson and colleagues (2004) ²²⁴	US	4	Y	Y	Y	Y	Y	High
Owens (2001) ²²⁵	US	4	Y	Y	Y.	N	Y	Good
Paton and colleagues (2019) ²²⁶	Australia	5	Y	Y	C	Y	C	Medium/good
		1	Y	Y	Y	Y	Y	High
		3	Y	C	Y	Y	Y	Good
Sadler and colleagues (2020) ⁷³	US	1	Y	Y	Y	Y	Y	High
Stallard (1998) ²²⁷	UK	4	N/A – did not pass screening stage					N/A
Thomas and colleagues (1982) ²²⁸	UK	4	Y.	N	C.	C	C	Low
Williamson and colleagues (2020) ²²⁹	US	1	Y	Y	Y	Y	Y	High
Wynter and colleagues (2015) ²³⁰	Australia	5	Y	Y	Y	Y	N	Good, high, good – overall good
		1	Y	Y	Y	C	Y	
		4	Y	C	Y	Y	Y	

3.3.4 Systematic Narrative Synthesis

3.3.4.1 Understanding and knowledge

Eight studies, of medium to high methodological qualities, reported varied quantitative data on PCPs knowledge. Five of which reported on knowledge using scores on questionnaire assessments, and two reported other quantitative data. Four studies, of low to high qualities also reported mixed qualitative data. All are compared below.

3.3.4.1.1 Knowledge assessments

Mindell and colleagues²²² (US paediatricians) and Bruni and colleagues²¹¹ (Italian paediatricians) both used the 'Sleep Survey' a knowledge questionnaire developed by Mindell and colleagues²²² (please see appendix A.8). Relevant subsections of the questionnaire were 'sleep hygiene' and 'developmental', each consisting of 6 true/false items. Owens²²⁵ (US paediatricians) developed the 'Pediatric Sleep Survey' (PSS, please see appendix A.9), and the relevant (also true/false) subsections were 'behavioural sleep disorders' and 'developmental'. Higher percentage scores indicated better understanding and varied across studies. Average sleep hygiene scores were 73.5% (SD=17.07) and 57.89% (n= 627, SD=20.31) in Mindell and colleagues and Bruni and colleagues' samples, respectively. Developmental scores were an average of 77.5% (SD=15.12), 60.55% (SD=21.51) and approximately 75% in Mindell and colleagues, Bruni and colleagues, and Owens studies, respectively. Owens also reported approximately 60% items correct for the behavioural subscale. Authors did not state which items scored well, however Bruni and colleagues noted that problematic questions within 'sleep hygiene' were about rocking to sleep, and a teenager sleeping until noon at weekends being sleep deprived.

Ersu and colleagues¹³⁷ when investigating the effects of a potential educational intervention on Turkish paediatricians, reported the knowledge scores of a control group, and an intervention group at baseline. Relevant questions and respective percentages of participants scoring correctly were about the "long term negative consequences of sleep problems" (62%, 64%), "minimum sleep requirement in childhood" (40%, 41%), "minimum sleep requirement in adolescence" (46%, 46%), "Behavioural Insomnia in Childhood (BIC)" (57%, 56%), "sleep physiology" (47%, 45%) and "recommendations for the prevention of BIC" (66%, 61%). These also suggested varied knowledge. Faruqui and colleagues reported that 34% and 50% of 346 US paediatricians answered correctly in response to true/false questions about school aged children napping during the day, and about pubertal developmental changes causing delayed sleep onset, respectively. However, these questions relate to children older than five, which are not the primary focus of this thesis.

3.3.4.1.2 PCP perceived knowledge

Other good quality quantitative findings were from Australian studies and suggested varied perceived knowledge. For example, 16.7% of Australian school nurses in one study²²⁶ felt prepared for management, whereas 96.7% of Australian Community and Family Health Nurses in another²¹⁴ felt they were able to access parental education materials. Although Cheng and colleagues' study²¹⁴ was rated as medium in methodological quality (due to not being clear in how the mixed-methods findings were integrated), the quantitative aspect was rated good.

One high quality UK qualitative study suggested that UK parents perceived PCPs to be either varied or lacking in knowledge on this subject. Hatton and Gardani¹³³ interviewed 15 UK mothers and presented a quote relating to the perceived knowledge of HVs.

'Participants were, however, almost of unanimous opinion that professionals did not have adequate objective knowledge in the area..... "They [health visitors] show absolutely no consistent training in sleep...so I am quite sceptical about health visitors, I probably wouldn't have gone to them. I think if I had been really worried, I probably would have gone to my GP but I'm not entirely sure that GPs have very much training..."' (Hatton and Gardani, 2018)

Three qualitative studies of PCPs (two of US PCPs and one of Canadian nurses) however, presented conflicting PCP's perceptions of their knowledge. Sadler and colleagues reported that in their sample of US paediatric providers⁷³ that many demonstrated knowledge of sleep needs in different ages and the importance of bedtime routines. On the other hand, Williamson and colleagues²²⁹ interviewed US PCPs and developed the theme 'Lack of education/knowledge about pediatric sleep'. Both studies were rated of high quality.

Hall and colleagues²¹⁸ looked at evidence-based interventions for children's sleep disorders and reported some qualitative data specifically on PCP perceived knowledge of sleep. When assessing a piloted workshop in Canada, public health nurses indicated that the workshop helped with their current knowledge gaps about infant developmental sleep changes which "would assist their efforts to assist parents to manage behavioural sleep problems" Though this gives some indication of the nurses' perceptions of their knowledge having gaps, the paper does not expand on this. It was reported as part of a series of studies and the paper received a low rating on the MMAT. In particular, the qualitative inferences were not supported by illustrative quotes and it was unclear what data analysis was used, thus ratings were due to 'cannot tell' and there are limited inferences that can be drawn from this paper.

3.3.4.2 PCP practice

Most identified studies ^{73,133,209,211,213-217,219-225,227,229,230} totalling 5938 participants explored how likely PCPs would be to make individual recommendations for behavioural sleep problems, how they manage or advise about behavioural sleep problems, or how they discuss management with families. A variety of behavioural or sleep hygiene recommendations were discussed within the studies (such as graduated extinction, bedtime routines, extinction methods etc) along with recommendations that sleep problems are normal and anticipatory guidance.

3.3.4.2.1 Likely recommendations

Four studies of good to high methodological quality favoured likely recommendations such as gradual extinction, positive reinforcement, components of sleep hygiene and parent education. These are discussed below.

The surveys used by Mindell and colleagues ²²² (88 US paediatricians) and Bruni and colleagues ²¹¹ (626 Italian paediatricians) asked how likely they would be to recommend particular interventions, from a given list. Both studies reported percentages of paediatricians that would be likely to recommend each strategy. In both studies, bedtime routines were most popular, at 95.1% (Mindell and colleagues) and 83.41% (Bruni and colleagues). In Mindell and colleagues' sample, this was followed by the "Ferber method" (84.6%), "nap schedule" (52.8%), "Rock child" (23.1%), "feeding schedule" (20.3%), "ignore the child" (18.1%), "keep the child up before bedtime" (17.6%), and "no intervention" (3.3%). In Bruni and colleagues' sample, the most popular strategy was followed by "changing the nap schedule" (49.76%), "music/rocking at bedtime" (44.34%), "graduated extinction" (35.57%), "keep the child up before bedtime" (20.10%), "change feeding schedule" (17.54%), "no intervention" (6.7%) and "ignore the child" (2.23%). In both studies, graduated extinction appeared preferable to cry-it-out methods. In Mindell and colleagues' sample, recommendation of graduated extinction was 84% in comparison to 18.1% for 'ignore the child' (unmodified extinction), with a difference of 66 percentage points. In Bruni and colleagues' sample the percentage for graduated extinction was still higher than unmodified extinction (35.57% compared to 2.23%), but the difference between extinction methods was smaller (33 percentage points) than Mindell and colleagues' sample. Nevertheless, the percentage for unmodified extinction in Bruni and colleagues' sample was extremely low and 4.47 percentage points lower than paediatricians recommending no intervention at all. These differences could be due to cultural differences between the US and Italy, whereby the US may be more likely to favour independent sleeping ^{79,231}. These studies, however, do not specify how often these recommendations would likely be recommended.

Using Owen's PSS ²²⁵, Owens ²²⁵ asked 626 US paediatricians how often they would be likely to make individual recommendations in specific scenarios. They reported the percentage of participants who would recommend each strategy at least half the time. For "frequent night wakings in a 14-month old routinely rocked to sleep at bedtime", the most frequent behavioural response (90%) was for graduated extinction, followed by increased parental intervention (24.5%), no intervention (13.2%) and co-sleeping (3.4%). For "bedtime resistance in a pre-schooler with a sudden onset of night-time fears", the most frequent behavioural response was transitional object (83.6%) followed by positive reinforcement (73.5%), ignoring the fears (20.6%) and TV at bedtime (8%). For "insomnia in adolescents attributable to poor sleep habits", the most frequent behavioural response was to have a consistent sleep schedule on school and non-school days (85.5%) followed by restricting non-sleep activities in bed (64.8%) and catch-up sleep on weekends (25.8%). These findings suggest graduated extinction, transitional object and positive reinforcement appear preferred.

Wynter and colleagues on the other hand, asked 343 community nurses (via online survey) what they would be likely to do in response to a mother of a six-month-old who wakes frequently, and the responses were grouped into the categories 'General assessment' (n=280), 'education' (n=220), 'referral' (n=147) and specific advice (n=247). Within 'specific advice'; feed advice (n=60); settling strategies (n=221). Specific settling strategies were not specified in 125 cases, though among ones which were specified, more than 25 strategies were discussed. Wynter and colleagues ²³⁰ also noted qualitative themes within the categories of responses. Within 'specific advice', themes were 'settling strategies' (within were 'controlled crying/comforting' and 'patting, sshhhing baby'), 'Infant should self-settle', 'partner support/settle infant overnight', 'resettle without feeding', and 'increase daytime feeds, rollover feed'. Within 'Education', themes were 'infant sleep needs/ sleep associations / tired cues', 'consistency, routine', 'feed-play-sleep routine', 'infant development at 6 months' and 'sleep environment, bedtime'. These themes further indicate the reinforcement of various settling strategies and parental education.

3.3.4.2.2 Practice

Many quantitative and qualitative studies asked about actual practice, were of mixed methodological qualities and presented mixed data. Because they were of various designs and some were of very low quality, the higher quality studies are presented first. In general, studies of PCPs suggest that PCPs endorse behavioural recommendations (including graduated extinction), parent education and bedtime routines. Parent perspective studies suggest a perceived inflexible approach or recommendations of cry-it-out. These are discussed below.

Faruqui and colleagues²¹⁷, the only good or high-quality quantitative study for this outcome, did not specify individual behavioural interventions in detail, but noted the use of some behavioural interventions, nonetheless. When asked about practices with most school age children's sleep problems, US paediatricians' responses were 52.9% "behavioural therapy". Other responses are not reported here due to not focussing on behavioural sleep problems.

Two high quality UK qualitative studies of the parent perspective^{133,215} provided data in regard to PCP recommendations. Hatton and Gardani¹³³ as described above, presented small amounts of data whereby parents discussed HVs specifically, which suggested the parents were advised to try 'cry-it-out' methods and avoid co-sleeping: *"They gave us to let him fall asleep by himself...we stopped because we couldn't take it...she [health visitor] came back and we said but...she kinda insisted on doing it again..."*. Cook and colleagues²¹⁵ reported quotes which suggested a HV recommended unmodified extinction:

"Standard answers which leave you feeling like you are doing something wrong. Crying it out is NOT the way to fix anything. When I explained my reservations to the HV [health visitor] she told me that I would have to do it anyway. Horrifying that some mothers may then do this as a result of the appalling information issued"

Three high quality qualitative studies reported on the PCP perspective. Sadler and colleagues⁷³ and Williamson and colleagues²²⁹ interviewed US paediatric providers and suggested positive practices from the PCPs. Sadler and colleagues developed the themes 'bedtime routines for everyone' and 'providers sleep recommendations': describing giving advice for bedtime routines, recommending parent education and behavioural techniques. For example; *"providers uniformly advocated reading books at bedtime and healthcare providers also advised about behavioral sleep interventions (structured approaches for promoting independence in falling asleep, self-soothing, and returning to sleep after brief awakenings at night) for older infants and young children"*.

Similarly, Williamson and colleagues described the endorsement of parent education by PCPs and also developed the theme 'Importance of empowering and collaborative care'. For example:

"...rather than giving a prescriptive sleep or bedtime routine, I ask parents for their own suggestions about what may work for their family. Because it doesn't work the same way for everybody". On the other hand, Murray and colleagues²²³ suggested a lack of management of infant sleep problems by Vietnamese doctors and primary care midwives. Young infants (under 6 months) would be fed as normal when waking for feeds throughout the night, and *"participants did not mention behavioural interventions such as feed-play-sleep programs, or any other specific advice for infants older than six months of age"*. The primary focus of this study however was on

feeding practices. Nevertheless, differences in sleep recommendations may be due to cultural factors.

Three quantitative studies, of medium quality, reported some other practices. However, these only lacked in methodological quality ratings due to lacking detail in reporting. Kanoy and Schroeder²²¹ described a US primary care service provided by a psychologist within a paediatric primary care office. A range of follow up evaluation data from participating families (n=60 for sleep problems) was collected. Recommendations reported by families for sleep problems were “reward appropriate behaviours” (n=14), “ignore the behaviour e.g. cry it out” (n=19), “rearrange sleep schedule” (n=10), “be supportive/reassuring” (n=12), “story and ritual before bed” (n=8), “environmental change” (n=7) and “information on what to expect” (n=2). These findings suggest the advice most often given was to ignore the behaviour, reward appropriate behaviours and/or rearrange the child’s schedule. However, this is from a small sample that may not be representative, and data collected may be subject to recall bias. These results therefore need to be interpreted with caution. Similarly, Cheng and colleagues²¹⁴ reported that amongst 88 Australian nurses, 85.2% discuss infant sleep and settling strategies at least half of the time. This study was of medium quality because could not be certain whether the quantitative/ qualitative findings were integrated clearly. The quantitative aspect was good, but not clear on representativeness. Chavin and Tinson²¹³ asked UK parents who they thought had been most helpful and the response for GPs was 34% and 40% for HVs. These were compared to ‘no support’ (45%) and other types of sources such as relatives, other mothers, and a hospital. This suggests that GPs and HVs may be perceived as helpful sources of information to parents. Moreover, the biggest percentage of the sample indicated no support which may suggest an unmet need. However, this cannot be certain because it is not known whether those participants had approached particular PCPs for help.

Abbott and Bryar²⁰⁹, a qualitative study of medium quality (also due to lack of reporting in the paper), evaluated a toolkit to empower HVs. The authors described that the HVs are given information packs as part of training and that they passed them on: *“We have got like little packets of information about different sleep training techniques, which have been very useful to give out to parents (HVS)...”* Though this suggests that information packs were given out by HVs, it must be noted that the paper is not clear in what the information packs specifically consist of or advise regarding sleep training techniques. Moreover, the analysis type was not reported in the paper.

Whilst conclusions of papers rated of low quality must be treated cautiously, the studies are still important to note. These particular studies were UK HV studies. Hewitt and colleagues²¹⁹

examined UK HVs who had received an annual 2-day behavioural workshop. Pre training quantitative assessments indicated that sleep problems were the least likely to be referred to clinical psychology (even less likely after training), compared to other common behaviour problems, and that the HVs thought their advice as “specific”, instead of general advice (mean = 8.29). Their specific advice is not described; however, the workshop describes that sleeplessness is addressed by focusing more on reducing the amount of night-wakings, rather than systematic ignoring during wakings. This rating did not significantly shift after the training. However, the quality of this study was rated low because the sample was small and not representative, but also because it was unclear whether other criteria were met.

Two other UK HV studies of low or very low quality due to limited reporting and small sample size may also be noted. Crawford and colleagues²¹⁶ reported a case series (9 children) of one HV following attendance of a behavioural workshop course. Stallard²²⁷ described a case study reported by a HV about an 18-month-old girl who had problems initiating and maintaining sleep. Both studies reported recommendations related to parental consistency, bedtime routines, self-settling and altered daytime sleep. However, Stallard’s study did not pass the screening stage of the MMAT, due to not specifically stating a research question and therefore the quality was not assessed.

3.3.4.2.3 Discussion with parents about management

Six studies, all of good to high methodological quality, reported on the types of management discussion, or lack of discussion. These related to suggesting that the problems are normal, providing anticipatory guidance, and PCP accessibility inhibiting discussion. These are discussed below.

Bruni and colleagues²¹¹ and Mindell and colleagues²²² asked paediatricians whether they say that the child will outgrow the problem, of which 77.89% and 48.9% reported ‘usually’ or ‘always’. Mindell and colleagues discuss that this may be misinformation, whereas, the mixed-methods study reported by Wynter and colleagues²³⁰ reported that 55/343 community nurses would normalise night waking / say that it is common, and reported a qualitative theme “reassure some night waking is normal”, implying a positive view of the responses.

Two US studies of good to high quality indicated a lack of anticipatory guidance about bedtime routines. For example, High and colleagues²²⁰ (only unclear on complete outcome data) evaluated the implementation of a US primary care clinic intervention of book sharing for bedtime reading and parental education. Those who received the intervention received more anticipatory guidance about sleep behaviour (P =0.02) than a historical control, however there were no

differences found for bedtime routines ($P=0.30$). Olson and colleagues²²⁴ reported the topics of guidance that parents received at different age points. Night waking was discussed for approximately 70-75% (for '4-9 month old') and 65% (for '10-18 month old') of parents. Bedtime routines were discussed less (45% in a '19-35 month old'). This suggested that anticipatory guidance about bedtime routines may be lacking, however it was not clear if parents wanted such guidance. Regarding both parent and paediatrician perspectives, the percentages of parents who reported discussion with a paediatrician about night waking and fussing for a '4-9 month old' and a 10-18 month old were 74.4% and 66.6%, respectively. For paediatricians, the percentages were 52.8% and 52.3%. For bedtime routines for a '19-35 month old', 46.5% of parents reported discussion and 53.9% for paediatricians. However, the proportions of parent and paediatrician data cannot be directly compared, because the questions were related to different frequencies. Percentages for parent report were for in the last year, and percentages for paediatrician report were for at least once or more with >75% of parents). Though these data cannot be directly compared, it indicates that there are mixed experiences about anticipatory sleep guidance.

Hatton and Gardani¹³³ provided some quotes to another theme, relating to limited accessibility of their HV or GP. *"The health visiting team gave the pack out then it stops and you don't really, you don't necessarily see them until.... aged 4...are not getting any leaflets through the door...I think there's a relationship gap". "Moreover, participants did not want to visit their general practitioner because of 'the worry that it wasn't serious enough or that it was a waste of their time'."*

However as discussed previously, these are small quotes, rather than themes from the paper.

3.3.4.3 Views, attitudes, and perceptions of role

Fourteen studies reported data that related to PCPs views about behavioural sleep problems, perceptions of role or attitudes towards management. Studies indicate that PCPs report on both risk factors for poor sleep as well as impacts, and perceive management as part of their role, however attitudes (including confidence levels vary). These are described in detail below.

3.3.4.3.1 Views about behavioural sleep problems (or BI)

Five high methodological quality studies, four conducted in the US (one in Italy) reported on perceived risk factors for poor sleep. Three quantitative studies indicated that paediatricians had beliefs about risk factors for sleep problems which implied their awareness of their importance. Mindell and colleagues²²² (US) and Bruni and colleagues²¹¹ (Italy) reported that most paediatricians within each study reported 'parental attention and handling at bedtime' to affect child sleep habits (96.7% and 78.31%, respectively), followed by 'sharing a bed with the parent' (81.7% and 64.43%). 'Room sharing with siblings/other' (50% and 22.3%), whilst 'feeding before

bedtimes' (33% and 28%) appeared less important. Similarly, Faruqui and colleagues²¹⁷ (US) asked participants to rate 'rarely', 'sometimes' or 'usually', for 'perceived aetiology of sleep problems' for a range of statements relating to sleep hygiene practices. For electronic use, the highest percentages were for 'usually' (52%), followed by 'sometimes' (43%) and then rarely (3%). Similarly, two US qualitative studies reported that PCPs perceive poor sleep hygiene and routines to contribute to sleep problems. Sadler and colleagues⁷³ reported this within the theme 'barriers to healthy sleep' describing the perceived impact of screen use and family routines: *"Providers reported that screen use interfered with their patients' sleep... Providers acknowledged that parents who must balance school/college schedules with family needs and routines face many challenges regarding sleep"*. Williamson and colleagues²²⁹ reported the theme *"child versus family as major contributor to sleep problems"*.

Four studies, three quantitative and two qualitative, reported on the beliefs of PCPs about the impact of the sleep problems, usually (all but one) indicating an awareness of the impact on the child and family. Mindell and colleagues and Bruni and colleagues both reported the impact with the highest percentage of responses was 'impact on family happiness', 93.3% and 85.01%, respectively. For Mindell and colleagues', this was followed by 'marital satisfaction' (83.2%), 'parental depression' (77%) and 'work performance' (75.3%). Whereas for Bruni and colleagues, family happiness was followed by 'work performance' (49.76%), 'parental depression' (46.73%) and finally marital satisfaction (25.36%). These findings suggest that paediatricians have similar beliefs about impact of children's sleep problems (with the exception of the order of the impact on marital satisfaction and work performance), and that it impacts family happiness the most, though the percentages were slightly higher for Mindell and colleagues' study than those reported by Bruni and colleagues. Thomas and colleagues²²⁸ explored HVs' opinions of behavioural difficulties (described previously) also assessed the perceived impact of sleep problems for the family. Fifty-three participants rated their feelings on an 80mm bipolar scale for different statements regarding sleep problems. For the scale from "disruptive to everyday family life" to "not disruptive to everyday family life", the authors reported a mean of 60, and indicated that sleep problems were perceived as the most disruptive to family life, out of all the behaviour problems. However, the findings of this study must be interpreted with caution, because the sample was not representative, and it was not possible to determine three other MMAT criteria. Similarly, a US high quality qualitative study of PCPs reported perceived impact of child sleep problems. Williamson and colleagues²²⁹, in this high quality study, reported the theme *"sleep as critical for child wellbeing"*.

One study reported on other PCP beliefs about normality of sleep problems. Carter and Mason²¹² suggested that HVs had varied perceptions of what is considered 'normal' for a one-month old

waking throughout the night. A survey of 50 HVs on a range of behaviours indicated that most (85%) perceived twice a night as average, whereas 11.9% reported four times, approximately 50% said once and approximately 70% were reported three times. This study however scored a very low quality rating, due to a lack of reporting on methods in the paper, and therefore must be interpreted with caution.

3.3.4.3.2 Perceptions of role

Nine studies of mixed methodological qualities suggested that PCPs generally perceive treating behavioural sleep problems as part of their role. Out of 346 US paediatricians in Faruqi and colleagues' study ²¹⁷, 96% "agreed or strongly agreed" that it is part of their role to advise about sleep hygiene. In Wynter and colleagues' mixed methods survey ²³⁰, 280/ 343 Maternal and Child Health (MCH) nurses saw collecting information which included sleeping habits as essential to their role, when asked about providing advice to a mother of a six-month old who wakes frequently at night or is difficult to settle. On the other hand, 45.8% of school nurses in Paton and colleagues' ²²⁶ sample reported the perception that nurses should instead refer the problem on.

Although rated lower in quality due to issues with representativeness and unclear criteria, other studies suggested similar findings. Bonuck and colleagues ²¹⁰ suggested 100% and 90% of US head start staff participants reported that teaching parents about sleep hygiene and behavioural sleep problems, respectively, should be part of their training. Thomas and colleagues ²²⁸ indicated that HVs perceive sleep as something they should deal with themselves; 53 UK HVs rated their feelings about perceived responsibility on a 80mm bipolar scale from "responsibility of some other agency" to "responsible for dealing with myself" (mean 60mm). Similarly, Hewitt and colleagues ²¹⁹ also reported through polarised rating scales about perceived roles, with resulting scores from 0-9. HVs rated sleeping difficulties as 'appropriate' for them to treat (mean=9) both before and after a workshop about behavioural difficulties. This study, however, was also rated low in quality, particularly due to a small sample size and therefore is not generalisable.

Similarly, two high quality US qualitative studies, suggested that PCPs perceive sleep problems as their role. Sadler and colleagues described that "all providers were eager to help parents increase their knowledge and skills about sleep" and Williamson and colleagues quoted a participant citing that primary care was the most suitable place for parents to go to: "I do think that coming here [to primary care], especially for a lot of our family where it's easier to get here versus having to go to the [main hospital] sleep clinic, [it] would be easier for parents."

3.3.4.3.3 Attitudes towards management

Despite studies suggesting that PCPs perceive managing behavioural sleep problems as part of their role, PCP confidence ratings varied. Seven quantitative studies demonstrated this with Likert style / polarised rating questions. Three of these were medium to high quality. Faruqui and colleagues²¹⁷ asked paediatricians (n=346) to rate their confidence from one ('not confident') to five ('very confident') regarding advising about sleep hygiene. Ratings ranged from one through to five as 1%, 5%, 28%, 53% and 13%, respectively, suggesting that even though 96% of the same sample (as described previously) perceived advising on sleep hygiene as part of their role, the confidence ratings in doing so varied. Similarly, Australian school nurses in Paton and colleagues' sample²²⁶ rated their confidence and competence on a 4 point scale from not at all to very; mean ratings were approximately 'a little'. Both of these studies were rated highly on the MMAT. On the other hand, Cheng and colleagues²¹⁴, an Australian study of 88 community nurses, indicated that on a scale of not at all to extremely confident, 90% of participants reported they were very or extremely confident in giving advice about sleep and settling. This study was only rated of medium quality due to uncertainty for mixed-methods integration. The quantitative aspect was generally good with limited reporting of the target population.

The other four studies, though of lower quality, also reported varied confidence levels. In Bonuck and colleagues' study²¹⁰ (31 US 'HeadStart' staff) 60% were very comfortable and 40% somewhat for advising about bedtime routines. For methods to get children to fall and stay asleep, 50% were somewhat and 43% very comfortable. This study, however, was rated of low quality due to a small selected sample lacking representativeness. Nevertheless, Mindell and Owens¹³⁵, conducted a needs assessment survey of US paediatric nurse practitioners and asked them to rate their confidence in managing particular sleep disorders, from 1 to 5, with 5 also being 'very confident'). For 'insufficient sleep' (mean=3.3), 'Night-wakings' (mean = 3.8) and 'bedtime problems' (mean 3.7) the responses also indicate varied confidence by the PCPs, and were similar findings to those of Faruqui and colleagues. However, this study was rated low in quality because it was reported as part of a wider article lacking detail in the methods needed to determine some MMAT criteria ratings.

Thomas and colleagues²²⁸ and Hewitt and colleagues²¹⁹ reported on the confidence of UK HVs. For an 80mm scale of "feel able to cope adequately with this problem" to "do not feel able to adequately cope with this problem", the authors reported a mean score rating of 35 and reported that it was one of the behaviours they were least able to cope with. Ratings for "difficult to deal with" to "not difficult to deal with", also on an 80mm scale, were reported as 50 (and one of two of the most difficult behaviours). The sample of HVs in Hewitt's study reported that prior to their

behavioural workshop, sleeplessness was a behaviour which was difficult to deal with (mean score not provided). However, their training workshop significantly influenced their rating of being able to cope for all behaviours, which included sleeplessness. As discussed previously, the quality of both of these studies are low due to limitations in representativeness and generalisability to other HVs. In UK qualitative study, Abbott and Bryar²⁰⁹ evaluated a project to empower HVs and discussed their confidence. The authors described “The health visitor who ran the sleep clinic had evidence suggesting that other health visitors, not interviewed as part of the evaluation, were also feeling more confident in their practice” and illustrated this with “*I am definitely getting referrals for the more complex mothers and not [any more] for the bread and butter sleep management stuff So that is good*”. However, this is the only quote presented and the study itself was rated medium in quality due to lack of detail in reporting on the qualitative analysis.

Finally, other high-quality studies reported on attitudes about treatment. Bruni and colleagues²¹¹, indicated that Italian paediatricians preferred behavioural approaches (88.73%) and reported that treating problems initiating and maintaining sleep is usually most useful (92%). This suggests that the sample had a positive attitude towards behavioural strategies. Comments from Paton and colleagues about the sample of Australian school nurses suggested that the nurses endorse individualised management where possible: “Overall, ESNs reported that greater flexibility in delivering the sleep intervention, such as the timing of the components and communication options, could enhance the potential for benefits, as it would allow ESNs to adapt the intervention based on each family’s needs.” Williamson and colleagues²²⁹, a US qualitative study of PCPs reported on familial barriers to behavioural interventions with the theme “familial and contextual barriers to intervention components”.

3.3.4.4 Exploring relationships within and between studies

Papers included within this study were from different countries, whereby primary care systems for children differ. For example, the UK and Australia operate GP-based systems²³², whereas the US operates a system of paediatricians within paediatric primary care²³³. Italy and Canada appear to offer combined systems^{234,235}, though the only Canadian study included within this review discusses community clinicians (nurses). Turkey’s health service has been transitioning²⁰¹, though the study¹³⁷, included in this review, referred to paediatricians in the context of primary care. The Vietnamese study²²³ referred to HCPs within a primary care context.

3.3.4.4.1 Country and types of PCP

Ten studies, using various methodologies, were conducted in the US where primary care differs widely to the UK, and therefore most were focussed on paediatricians, and some paediatric nurses. Most were also of medium to high quality, except for Mindell and Owens (2003) where not enough information was reported in the paper to rate highly, and Bonuck and colleagues (2020) due to a selective sample. Using surveys or qualitative interview methods, five good to high quality studies suggested US PCPs knowledge varied. Medium to high quality studies suggested US PCPs endorse behavioural strategies and parent education, and would likely recommend graduated extinction, sleep hygiene components such as bedtime routines, and positive reinforcement. However, two US studies also suggested there is a lack of anticipatory guidance for bedtime routines. Nevertheless, high quality studies suggested PCPs perceive risk factors for and impacts of behavioural sleep problems and usually believe that the responsibility to manage these problems sits within their role. Studies of mixed qualities suggested confidence levels varied.

Nine studies were conducted in the UK and many were outdated (six published before 2000) and poor in quality, with only three medium to high quality studies being published since 2000. All UK studies explored outcomes for UK HVs (with minimal data on UK GPs). No recent UK studies included any quantitative findings, and there were minimal qualitative findings from UK HV participants. Therefore, findings must be treated with caution. Nevertheless, two high quality parent studies presented data which suggested the perceptions that UK PCPs lack training and advise cry-it-out. Medium quality studies suggested the perception that GPs and HVs had been helpful (however the paper was did not analyse this finding any further) and that HVs give out information packs. Other low quality outdated HV studies suggested HVs give behavioural advice such as bedtime routines and sleep hygiene, perceive poor sleep to have a negative impact, and perceive management as their role, but lack confidence in management.

Three studies, most of high quality (one medium) were conducted in Australia and focussed on school or community family nurses, with no data regarding GPs. Studies suggested that nurses had varied knowledge and wanted to learn more. Studies also suggested they endorse individualised behavioural strategies recommending many settling techniques to parents and perceive management as part of their role, but have little confidence.

Other countries included in the current review had only one study conducted within them and therefore are not necessarily generalisable. Nevertheless, a very good quality study Bruni and colleagues (2004), indicated that Italian paediatricians' knowledge was middling/moderate (57%), that paediatricians encourage bedtime routines the most (83.41%) and suggest ignoring the child

very little (2.23%) in comparison to graduated extinction (35.57%). Paediatricians were aware of various risks for poor sleep, as well as impacts. Ersu and colleagues (2017) in a good quality study, indicated the Turkish paediatricians' knowledge varied. On the other hand, one study of Vietnamese PCPs suggested that behavioural sleep problems are not often managed. Hall and colleagues (2019) suggested that Canadian community nurses perceived gaps in their knowledge, however the quality of the study was rated poor.

3.3.4.4.2 Differences between PCP and parent perspectives

Most studies reported on the perspective of the PCP in question whereas only four studies reported parent perspectives. PCP participants appeared to suggest themselves to have various levels of knowledge and to endorse behavioural management strategies (in particular sleep hygiene such as bedtime routines, and graduated extinction) and sometimes normalisation of sleep problems. PCP participants also suggested an awareness of the risks and impacts of poor sleep, and usually perceive management as part of their role, but have varied confidence in management.

Regarding the fewer studies which included parents as the population, two high quality UK studies presented some data which suggested parents perceived low knowledge of sleep problems in GPs and HVs, had had negative experiences of HVs being inflexible and recommending cry-it-out, and one of the studies suggested a lack of accessibility. Three medium quality quantitative studies of parent perspectives also suggested some usefulness of UK GPs/HVs for management, and recommendations within a US primary care clinic for cry-it-out and positive reinforcement, but a lack of anticipatory guidance regarding bedtime routines.

3.4 Discussion

3.4.1 Overview of findings

Nine studies^{73,133,137,211,214,218,222,225,226,229} reported on PCP knowledge/understanding. These medium to high methodological quality studies, mostly reported data from knowledge questionnaires or perceived PCP knowledge, suggest that PCPs' knowledge of children's behavioural sleep management and sleep hygiene appears to vary from low to moderate. However, the authors who created the knowledge questionnaires did not report a clear target for an adequate score, so it is difficult to draw conclusions.

Nineteen studies^{73,133,209,211,213-217,219-225,227,229,230} reported on PCP likely recommendations (medium to high qualities) or practice (mixed qualities). Many different behavioural strategies

were mentioned. The most common were bedtime routines and some other aspects of sleep hygiene, graduated extinction, parental education and positive reinforcement, though often these were reported as 'likely recommendations' rather than actual practice. Some studies^{209,213,214,217} lacked specific information on the nature of behavioural methods used which limits interpretation of the data. Some parent perspective studies suggested that parents were recommended cry-it-out. Some good to high quality studies suggested a lack of anticipatory guidance (US) or management due to inaccessibility of UK HVs.

Fourteen studies^{73,135,209-212,214,217,219,222,226,228-230} reported on PCP beliefs, role perceptions or attitudes. Five high quality studies^{73,211,217,222,229} (usually in the US) suggested PCPs appear to perceive risk factors for behavioural sleep problems such as electronic device use and unhelpful settling strategies. Five studies (mixed qualities) usually suggested PCPs believe there to be negative impacts of behavioural sleep problems, and mixed quality PCP research suggested they also perceive management as part of their role, but unfortunately have varied confidence levels.

Most identified studies were conducted in either the US, UK or Australia and there were some differences between countries in the above findings. US studies were mostly of high quality and focused on paediatricians and paediatric nurses. On the other hand, UK studies usually focused on HVs (with minimal data regarding GPs) and were outdated and low in quality; exceptions being recent qualitative research exploring parent perspectives which suggested a perceived lack of PCP knowledge. Similarly, Australian research also focussed on community nurses, with no data regarding GPs. Four studies reported on views of parents, rather than PCPs themselves. These findings usually differed from those of PCP participants, whereby UK PCP knowledge was perceived as limited (not just varied) and to recommend 'cry it out'. However, these are the perceptions of parents and may be biased by negative experience or assumptions.

3.4.2 Comparison to other reviews and research

Honaker and Meltzer's review¹³⁴ also included the questionnaire studies (up until 2014) on PCP knowledge about paediatric sleep in general and similarly to findings in this PhD thesis review, suggested that PCP knowledge is varied. Nevertheless, they suggested knowledge was highest for 'developmental' and 'sleep hygiene' in comparison to non-behavioural sleep problem subscales. Other studies which were relevant but not specifically eligible for the current review^{236,237} due to not including exclusively PCPs or assessment of behavioural sleep problems, also used similar questionnaires to assess knowledge scores and demonstrated varied knowledge of paediatric sleep problems. Similarly, in another study, 124 Canadian HCPs took also reported a lack of

knowledge through open-ended surveys²³⁸. Although these studies show similar findings, studies assessing UK PCPs knowledge is lacking.

Findings for PCP likely recommendations and practice from this PhD thesis review are promising because the effectiveness of these strategies are supported in the literature⁹⁷ and many are currently recommended for children with sleep problems in the US²³⁹. The strategies identified from this review are also similar to Honaker and Meltzer's review¹³⁴ who found PCPs report of management strategies favoured bedtime routines. However, Honaker and Meltzer also reported pharmacological management (mixed findings) which were not reported here. The findings of this PhD thesis review are similar to other studies which were relevant but not included, due to strict inclusion criteria of PCPs and behavioural sleep problems. For example, in Gruber and colleagues'²³⁶ and Richardson and colleagues'²³⁷ surveys of 97 Canadian HCPs and 39 Australian medical practitioners, 83% and 61% respectively would recommend graduated extinction at least half the time for night wakings. For bedtime resistance, percentages were 68.3% (for Gruber and colleagues, not reported in Richardson and colleagues) for positive reinforcement compared to 19% and 4% respectively for ignoring fears.

Findings on PCP beliefs, role perceptions or attitudes, awareness of impact and mixed confidence are similar to related studies^{236,237} which were not specifically eligible for this review, or for data within included studies which were not eligible due to not being specific to behavioural sleep problems^{135,217,225}.

Although in the current review there were few studies conducted in countries other than the US and the UK, studies have been conducted from other countries which are relevant, but not included in the current review due to strict eligibility criteria. For example, as noted previously, in Richardson and colleagues' study of Australian HCPs, other HCP types such as 'medical practitioners' were discussed, who likely included but were not exclusively PCPs, and were excluded from this review. Another difference to note between countries, is that PCP perspective research in the current review generally reported positive findings regarding behavioural management of behavioural sleep problems. The only study which suggested otherwise was a study of Vietnamese PCPs who did not mention behavioural interventions; all other studies were from western cultures. This echoes what is understood about cultural differences in parental sleep practices⁷⁹. This suggests that the findings of this review may be somewhat different had it identified more studies from other cultural backgrounds.

Much of the UK parent studies' (included within this review) findings such as main themes were not included in the data extraction process due to strict criteria. For example, themes were not exclusive to PCPs or behavioural sleep problems, but some illustrative quotes within referred to

HVs/behavioural sleep training. Nevertheless, data/themes within the parent perception studies but which was not eligible for the review suggested that parents generally had negative opinions of PCPs knowledge, attitudes and practice. For example, among other negative perceptions of HCPs, Cook and colleagues²¹⁵ reported that parents felt HCPs are inflexible for management strategies, and patronising towards parents seeking help for sleep problems. These findings all suggest a disjoint between PCP and parent perceptions of practice and attitudes/beliefs. PCP and parental differences are discussed more in Chapter Seven.

3.4.3 Strengths and limitations

This systematic review is the first to explore PCP knowledge, current practice and attitudes regarding management of chronic insomnia in children. Honaker and Meltzer's review¹³⁴ explored sleep problems in primary care in general but this current review is more detailed, up to date and specific to behaviourally based sleep problems. It is also more systematic and rigorous in methodology (e.g. the search terms were more sensitive and conducted on six different electronic databases, resulting in many more potential papers).

The difficulty in including papers with data exclusively focused on chronic insomnia or behavioural sleep and exclusively PCPs must be noted (further detail in section 3.2.4.3). A decision was made to only include papers or subgroup data within, if they were obviously describing behavioural problems, or were specifically named as 'behavioural insomnia' (or similar), and if they were all PCPs or the HCPs were obviously first port of call. Therefore, it was possible that some papers that did mean behavioural sleep problems / primary care, may have been missed. For example, Richardson and colleagues²³⁷ and Gruber and colleagues'²³⁶ studies, provided similar findings but the findings were not exclusive to PCPs. However, by applying these criteria strictly, it ensured rigour and certainty in the review ensuring that the data only related solely to behavioural sleep in primary care.

A systematic narrative synthesis used in this review allowed the review to be inclusive of a range of study designs, with widely varied types of outcome measures and subsequent data. Whilst, individual study findings cannot be directly compared with one another due to their heterogeneity, the general findings of each study have been discussed and systematically synthesised based on Popay and colleagues' guidelines¹⁹⁷. Popay and colleagues outlined key elements to include to reduce risk of bias and provide a methodological basis for narrative synthesis for reviews of wide ranging studies that cannot otherwise be synthesised (e.g. meta-analysis). Some studies provide relevant data as part of their main study, whereas others provide some relevant data as part of a similar study (e.g. relevant quotes within qualitative research),

suggesting that a systematic narrative synthesis was the most appropriate method of analysis in this review.

This review looks at PCP's current practice, views and knowledge regarding the management of chronic insomnia in children, it does not include training or pharmacological outcomes. This decision was taken to be able to focus on behavioural strategies but also due to the capacity and time frame available. Similarly, screening and including conference abstracts was not within the time constraints of this thesis. Nevertheless, the search strategies were extremely sensitive, resulting in the screening of approximately 5000 papers so it is likely that most relevant publications have been identified.

Whilst the MMAT ²⁰²⁻²⁰⁴ was useful to assess the quality of included studies of different designs it only includes five criteria for each study design so it is possible that other relevant aspects were overlooked. However, it is an appropriate tool to use to assess the quality of the included studies in the same level of detail for each design. Some papers rated low in quality failed to include sufficient detail in the methods, however due to time constraints and the dates of many of the papers lacking detail, it was not feasible to contact the authors for the necessary information and 'cannot tell' responses were recorded. The moderate quality of the included research data generally and lower quality in those focussed on UK HVs means conclusions regarding individual professional groups should be treated with caution.

A limitation of mixed-methods narrative systematic reviews is that a GRADE approach cannot be applied to assess the quality of the evidence base combined.

3.4.4 Implications

Further research is needed. In particular, UK research needs updating with better quality data exploring both GP and HV perspectives. Both qualitative and quantitative research would be beneficial, with research focussing on PCP knowledge and training and to get a range of views, from both the patient and PCP perspective. Research also appears to be lacking for other countries; with most research having been conducted in the US, the UK or Australia; few studies are reported elsewhere. However, given that this review only included English language versions of papers, it is possible that other studies could have already been conducted, but were not included.

If further high-quality research indicates a lack of knowledge/confidence, it may be beneficial to explore further support (e.g. support tools) for PCPs to increase the knowledge and understanding of paediatric chronic insomnia, along with their confidence in managing it.

3.4.5 Conclusion

This systematic review provides a detailed overview of the current evidence base for PCPs' understanding, knowledge, perceptions of their role and current practice regarding the management of chronic insomnia in children. Findings reveal varying knowledge and confidence in treating chronic insomnia in children, even though PCPs perceive their role to be important in management. Exploring options for further support (e.g. support tools) for PCPs to increase the knowledge and understanding of paediatric chronic insomnia, along with their confidence in managing it is likely to be beneficial. Further high quality, contemporary research is required.

Chapter 4 A Qualitative Exploration of Parents' Posts in Online Discussion Forums: Parents' Concerns about Sleep Problems, and Views about Sources of Support Online, in the Community and in Primary Care.

4.1 Overview

This chapter provides an overview of the second study of this thesis. This study specifically focussed on parental perspectives on the management of sleep problems in children in primary care and the community, by exploring what they post in public online forums. It builds on findings from the systematic review, by looking at parental perspectives within the UK context, through qualitative research.

4.2 Introduction

4.2.1 Background and rationale

Findings from the current evidence base about PCPs' knowledge and practice, were presented in the systematic review in Chapter Three. The findings must be interpreted with caution, due to limited data from studies of variable quality and in a range of settings. Moreover, much of the UK based research within the review focussed on HVs, was outdated and lacked in quality, indicating a need for more and higher quality UK research. Bearing this in mind, the evidence available suggested that PCPs vary in knowledge, though still recommend various behavioural strategies such as bedtime routines and controlled crying. The systematic review also suggests that PCPs perceive managing chronic insomnia to be part of their role, though confidence in doing so is variable. Most of the research within the review included PCPs as participants and therefore was largely based around the perspectives of PCPs themselves. However, it is equally, if not more important to consider the perspectives of parents. Throughout the rest of this chapter, parents and carers will be referred to as 'parents'.

Many people now seek advice or support for health problems online using websites such as online forums, social media sites, the National Health Service (NHS) choices website²⁴⁰ and many more. In a qualitative study of UK mothers, it was suggested that the internet is sometimes accessed for

advice on sleep when HCPs are not, though this was not discussed in detail¹³³. More generally, a literature review has discussed general parenting forums whereby parents and carers seek advice for problems or questions that arise regarding their children²⁴¹, which highlights the potential usefulness of online forums for parents. Examples of such forums are www.netmums.com. There are also sleep specific parenting information websites and online forums, for example www.babysleep.com.

It is therefore likely that parents seek advice on online forums for their children's sleep in general, or in relation to primary care management. Such online forums provide an opportunity to explore the topic of children's sleep management in primary care from parents' perspectives. It is important to consider parents' views and experiences of primary care management of their children's sleep problems and what resources they are aware of and are available to them in primary care and the community.

To date, there is no research analysing online forum discussions that parents have about how their children's sleep is managed in primary care. Exploring this topic by analysing such discussions in online forums will provide a more holistic evidence base by providing a unique insight into the views and experiences of parents. Online discussions are likely to differ from what parents discuss with their GP in consultation due to their anonymous nature which reduce chances of judgement from HCPs or people they know. There are also no boundaries, time limits or influences on the discussion from their PCP because the discussions take place at a suitable time for the parents and with other parents who are, or have been, in similar positions.

4.2.2 Aims and research questions

The following research questions were explored:

1. What do parents express in online forums regarding their concerns and expectations about their children's sleep problems.
2. What resources are parents of children with sleep problems aware of as available online, in the community and through primary care for parents and caregivers of children with sleep problems?
3. How do parents and families perceive that their children's sleep problems are currently addressed during GP consultations in primary care?

4.3 Methods

4.3.1 Ethics committee approval

The protocol and ethics form were peer reviewed and approved independently by two researchers within the school of Primary Care, Population Sciences and Medical Education. The study was then reviewed and approved by the University of Southampton, Faculty of Medicine Ethics Committee (ERGO II ID: 47681).

The University of Southampton guidelines for internet mediated research (2017²⁴²) and the British Psychological Society (BPS) guidelines for internet-mediated research 2017²⁴³ and 2021²⁴⁴ were adhered to. Specifically, the BPS states four ethical principles to internet-mediate research: (1) “autonomy, privacy and dignity of individuals and communities”, (2) “scientific integrity”, (3) “social responsibility” and (4) “maximising benefits and minimising harm”.

For example, the BPS discuss the importance of considering whether data from online sources are in the public or private domain and how this influences whether consent is needed from participants. Data within the current study were included from the public domain (whereby no login or cost was needed to access posts), so did not need consent from the users as participants. However, the BPS reiterates the importance of still ensuring anonymity and confidentiality. Therefore, to ensure that the data and posters could not be traced online; the online forums included in this study are not named, any potentially identifiable information from data were removed from the study reports and presentations, pseudonyms were used for users instead of their usernames, and quotes were paraphrased to retain meaning but reduce the likelihood of online identification.

4.3.2 Design

This was an exploratory qualitative study, analysing discussions in public discussion forums by parents, families or carers about sleep problems in children, and how these are managed in primary care and the community.

4.3.3 Setting

The setting was publicly available (where no cost or log in is needed for access to view forums) online discussion forums. The forums were chosen from scoping searches for relevant and eligible online discussion forums. Please see 4.3.5.1.1 for further detail.

4.3.4 Sample

Participants in this study were anonymous users of discussion threads selected in public online discussion forums (parent forums or sleep forums). Due to the exploratory nature of the study, an exact sample size was not known, however it was initially estimated that three of the most active, online forums would be included, and it was initially anticipated that approximately 300 of the first relevant discussion threads on the forums would be reviewed, with a search conducted on the forums for relevant data. Please see 4.3.5.2 for the final sample/data collection.

4.3.4.1 Eligibility criteria

Parents or carers who posted in the selected online forums about children's sleep problems were included in this study. Forums were excluded if they were not public (i.e. required a cost or a log in to view the posts).

4.3.5 Data collection and search strategy

Data for this study was collected from the most active and relevant public online forums. To see which forums were open access, most active and most relevant, scoping searches were conducted across search engines (please see 4.3.5.1.1 for details). After deciding which public online forums to search, further scoping searches were conducted within the selected forums to become familiarised with the forums and inform a search strategy that would enable collection of rich and relevant data (please see 4.3.5.1.2 for details). Data was then collected by running the final searches and systematically viewing and downloading relevant discussion threads. Please see below (4.3.5.2) for details of the final searches used.

4.3.5.1 Scoping searches and planning

4.3.5.1.1 Deciding which public online forums to include

To decide which public online forums to include, detailed scoping searches were conducted on two different search engines in September 2019. Eight different phrases were decided upon that included terms which could be used to identify forums : "child sleep", "sleep", "sleep forum", "how to get my child to sleep", "baby sleep", "toddler sleep", "bedtime problems" and "night waking". The same eight phrases were searched individually on each search engine and for each search the first 50 results were looked at. In an excel spreadsheet, the name of a new online forum was noted down each time it appeared. A total of 64 online forums, or websites with potential online forums, appeared from either one or both of the search engines' results.

When looking through the search results for each individual search, it was noted approximately how many times each forum appeared, so that it was clear which ones were most popular and active on the search engines. From this, the most common forums were checked, firstly to confirm they were public and secondly to confirm whether they were relevant enough to be considered for eligibility.

Out of 43 potentially eligible public forums, the type of forum and the number of approximate posts they had that could be relevant were considered. It was also considered whether they had many posts within the last 6 months which would be potentially eligible. Many of the sleep online discussion forums were specific to, or used for, sleep disordered breathing which was not the focus of this thesis. Therefore, it was most optimal to include two or three different general parenting forums from the list of eligible public forums.

When scoping search strategies at a later date within one of the forums, it became apparent that the forum was not posted in just by parents, and that it was also common for HCPs to comment. The forum was therefore excluded from the study. At this stage, it was clear there was more than enough data on the other two forums, so it was decided to review more threads for eligibility across two forums, rather than fewer threads across three. The study therefore includes two public online discussion forums.

4.3.5.1.2 Scoping searches to decide on search strategies within the forums

Scoping searches within the forums were conducted to become familiarised with them and identify the most efficient way to search for relevant data. These were conducted in September 2019 on one forum, and again in 2020 (with the other included forum) shortly before the data was collected. The scoping searches are described below.

To conduct the scoping searches on forum one, various combinations of searches (such as different search terms, topics searched in, and whether to search whole threads or individual messages) were trialled and the number of results were noted in a spreadsheet. The number of potentially relevant threads were also noted and were calculated as a percentage of the ones viewed within each scoping search result. Threads were considered relevant if the title or first post within the thread were eligible. The spreadsheet therefore identified which search combinations resulted in the most relevant data. Finally, it was also considered whether these numbers of potentially relevant threads were for threads which referred to children's behavioural sleep problems AND PCPs, or for threads which only needed to refer to children's behavioural sleep problems. It was decided to use the search terms that were more likely to include data

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about PCPs, but also allow for threads which discuss behavioural sleep problems generally to be included. Please see below for the final search strategy used.

It was aimed for the final search strategies from both forums to be as similar as possible to ensure a systematic methodology, so it was initially planned to match the second forum's search strategy as closely to the first forum's as possible. However, each online forum had individual ways of searching for posts, so the same searches on the first forum would not necessarily result in the most relevant data from the other. Therefore, scoping searches were also conducted on the second forum, using similar methods of scoping to the first whereby number of results and potentially relevant results were noted. The most efficient search strategy was chosen, taking into consideration similarities with forum one's search strategy.

4.3.5.2 Final data collection for each forum

Data were collected in summer 2020. Exact dates are not given to reduce likelihood of online identification.

4.3.5.2.1 Forum 1:

Varying terms for types of PCP were searched within the messages of a sleep category. Half of the searches were dated from before the UK March 2020 COVID-19 lockdown and the other half were dated afterwards. Initially it was planned to review the first 150 search results (listing as forums) for eligibility, however, after reviewing 150, it was clear that there would be unmanageable amounts of data. Including eligible threads from the first 100 results provided sufficient data. Potential effects of this decision on the data set is discussed in the study strengths and limitations in 4.5.3.

4.3.5.2.2 Forum 2:

Varying terms for types of PCP and sleep were searched within messages across the whole forum, within the previous year. Half of the search results reviewed were from before the COVID-19 UK lockdown and the other half were from after the lockdown was put in place. As with forum one, it was decided to review 100 search results (many of the threads were relevant and reviewing only 100 search results would still yield sufficient data on this forum).

For both forums, threads where the original poster discussed behavioural sleep problems in children were included for analysis. For threads which were included, the whole thread was downloaded into a word document.

4.3.6 Data analysis

Data was imported into NVivo software. It was initially planned to analyse the data based on reflexive thematic analysis^{182,188,189,199}, a pattern-based qualitative analysis flexible to different philosophical stances. Reflexive thematic analysis consists of six phases which can be moved through iteratively and reflexively: (1) “familiarisation with the data”, (2) “generating codes”, (3) “constructing themes”, (4) “reviewing themes”, (5) “defining and naming themes” and (6) “producing the report”. Reflexive thematic analysis can be approached inductively (data-drive) or deductively (theory driven), however as discussed in Chapter Two, it was to be applied inductively to this study.

With a pragmatic theoretical stance, reflexive thematic analysis was chosen as the most appropriate method for this study because it is theoretically flexible and can suit different research questions and methodologies. In particular, this study aimed to focus on exploration of what parents perceive the management of chronic insomnia to be. Discourse analysis, for example, was not chosen because it usually has a more relativist philosophical stance and focuses more on the interaction between language and social context in relation to the research question.

However, a large amount of data resulted from data collection and the primary goal of this study was to summarise how parents discuss their concerns and expectations, resources which they are aware of and how they perceived management within primary care. To pragmatically address the different research questions with a dataset of this size, a more descriptive qualitative analysis took place as described by Sandelowski (2000)¹⁹⁸. Sandelowski highlighted qualitative descriptive analyses as a suitable method when researchers are interested in describing a phenomenon in a more data-driven manner. Furthermore, Sandelowski highlighted that qualitative descriptive analyses are not necessarily underpinned by theoretical assumptions, and that the data and resulting findings can be presented in the best way that fits the data.

Therefore, to employ a qualitative descriptive analysis in this online forum study, topic summaries are presented as descriptive themes which answer the research questions, rather than as themes described by Braun and Clarke¹⁸⁹. Similarly, to Braun and Clarke’s methodology, the descriptive themes emerged from a series of iterative steps. The data were read and re-read. Relevant text to the research questions were coded and a coding schedule was created and revised accordingly throughout the coding process, and descriptive themes were developed from patterns within the data/codes. The coding schedule was discussed and developed further in individual meetings with IM, and then in subsequent meetings with IM, HE and CH to refine the themes and sub-themes. A final set of themes and sub-themes were decided upon (please see Appendix B.5 for the full coding manual) and written up.

4.3.7 PPIE

As noted in Chapter Two, the first PPI representative gave comments on the thesis plans through a telephone discussion/interview and was reimbursed for her time at PPIE rates. This took place before data collection for this study began. During the interview, she emphasised the importance of researching parent as well as PCP perspectives on the topic which confirmed the relevance and methodology of the study within this chapter. She commented that this study would be large and that there would be a lot of information, she had seen a lot of information passed between parents on online forums, and she perceived the advice to be from lay persons. This further highlighted the relevance of the study because it reiterated that parents use the online forums to seek advice for children's sleep. It also suggests they may not be receiving (or seeking) optimal advice elsewhere and that they may post valuable views about primary care. Regarding the study methods, she advised on possible online discussion forums which may be useful. These were considered when deciding on which online forums to choose, from the results of the search engine scoping searches detailed below. She also suggested that other form of social media may be a useful source of information, however due to confidentiality and ethical considerations, it was not feasible to incorporate it into this study.

PPI input was also sought for the emerging findings (emerging coding manual). She again confirmed the relevance of the study, as well as the relevance of the findings. She made useful suggestions about reorganisation of codes and renaming of some codes and sub-themes. Where feasible, her comments and suggested changes were included in the final set of themes and sub-themes.

4.4 Results

4.4.1 Sample

Ninety-three discussion threads in total were included (see Table five), and data seemed to reach saturation. Throughout these results, primary care refers collectively to both primary care delivered through general practice PCPs, and community PCPs such as HVs and nursery nurses. Where findings are specified to one type of primary care and not another, primary care from GPS/doctors are referred to as 'general practice', and primary care from community PCPs are referred to as community primary care, or simply HVs/ nursery nurses.

Table 5 Characteristics of the data

	Number of discussions	Pages of data
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Forum 1	56	Approximately 169
Forum 2	37	Approximately 133
Total	93	Approximately 302

4.4.2 Themes and subthemes

Five overarching themes with sub-themes were developed from the data (see table six) and are described below with example quotes. Please see Appendix B.2 for a detailed overview of themes, sub-themes and codes, and Appendix B.3 for the full coding manual with detailed descriptions and examples of themes and codes within.

Table 6 Overview of themes and subthemes

Over-arching theme	Sub-theme
1. Multiple concerns about children's sleep problems	1.1 Concerns about the child's sleep
	1.2 Information seeking
	1.3 The impact of sleep problems
	1.4 COVID-19 as a barrier or facilitator to support
	1.5 Management strategies
2. Parents experiences or advice online as a resource	2.1 Peer and emotional support
	2.2 Exchanging information
	2.3 Practical advice
	2.4 Sharing own routines
	2.5 Sharing views about healthcare practitioners and non-healthcare workers
3. Mixed experiences and perceptions of HVs and nursery nurses	3.1 Reiterating HV advice/action
	3.2 Mixed attitudes about community PCPs
	3.3 Experiences with nursery nurses

4. Limited experiences and perceptions of general practice	4.1 Reluctance to consult a GP for a behavioural sleep problem
	4.2 Consulting GPs for non-sleep problem or underlying cause of sleep problem
	4.3 Experiences of consulting GP for sleep problems
5. Other resources for supporting parents with child sleep problems	5.1 Tools and information resources online, through information sites, social media and apps
	5.2 Non-PCPs or non-healthcare workers
	5.3 Books or parenting/sleep expert authors

4.4.2.1 Theme 1: Multiple concerns about children's sleep problems

The forum discussions revealed that many parents appeared to have, and post in public online forums about, multiple different concerns about their children's sleep. These were not only directly about the sleep problems in the child themselves such as problems with bedtime or night-waking, but also related to factors surrounding the sleep problems (such as seeking information, concerns about the impact on both the child and family, social support, and about different management strategies). The subthemes identified are described below.

4.4.2.1.1 Sub-theme 1.1: Concerns about the child's sleep

Parents expressed different concerns directly regarding the sleep problems themselves, and different types of behavioural sleep problems were described. For example, many parents described problems with their child's waking throughout the night. They discussed the regularity of the waking, how long they felt they would get between wakes, and/or described specific circumstances with which the infant or child would need to go back to sleep. For example, one parent described concerns about consistent waking from 12am onwards: *"She will have a longer sleep at the beginning of the night, but then wake hourly (sometimes throughout the whole night) from around 12am...the night waking is so draining"*. Some parents also or instead described concerns about their infant or child waking too early in the morning. For example; *"My little one wakes early and I really need some help. At the moment she is up early every day by 5 o'clock, when her bedtime every day is around 7pm"*.

Moreover, many parents appeared to discuss problems with sleep associations and inability to self-settle to sleep either at the beginning of the night and/or during the night after wakings. They described troubles with babies needing to be held to get back to sleep, or for there to be particular circumstances which the babies/children would need to get back to sleep, which would need the parent present. E.g. *“Rocking or stroking can take ages...if I put him down he soon has a breakdown, or soon wakes up if I put him down after he’s asleep... Do any of your little one’s settle on their own?”*. Many parents appeared to describe sleep associations with feeding, whereby their infant needed to be breastfed or given a bottle of milk to be able to settle: *“I feed him and put him back to bed every time he wakes in the night. With just a dummy he will not settle back down and once I have fed and laid him down he will sleep in around 20 mins. It’s so draining”*. Some also described safety issues in relation to specific situations or positions that their infants/children needed to get to sleep. E.g. *“My daughter is a couple of months old and will not sleep in her cot. She will only sleep on me (day or night) which is really dangerous as well as impractical.”* Furthermore, some also described problems with implementing bedtime routines, such as conflict between parent and child in preparation for bedtime.

Other problems directly related to the sleep that parents seemed to be concerned about were whether the sleep problems were a reflection of an underlying medical problem such as reflux, allergies etc. Some parents described this in terms of last resort, e.g. they had tried multiple ways of improving the sleep and were *“starting to question whether something medical is going on”*.

Finally, some parents appeared to have concerns about whether the extent of the sleep problems they described were normal, i.e. whether they were actually problems that they could do anything about, whether they are problems to be expected, and whether it is something that the infant/child would grow out of naturally. For example, *“Is this regression normal? It’s happening every night”*.

4.4.2.1.2 Sub-theme 1.2: Information seeking

As well as expressing concerns about their children’s sleep problems, parents also appeared to be actively seeking information from other posters. Some parents seemed to seek information in relation to their concerns about what is ‘normal’. Some sought information about developmental phases like sleep regression, i.e. whether it is normal, how long it lasts and what to do (if anything) about it. For example: *“How did any of you find the sleep regression in the 4th month and how long did it go on for your babies? I’m wondering whether it will just phase out without doing anything, or whether I need to teach self-settling?”*. To note, sleep regression is a proposed developmental phase in infants when their sleep patterns change and they often wake in the night (however, literature suggests that sleep patterns are widely variable in the first year^{17,245})

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Throughout the posts in this study that refer to sleep regression, parents usually either asked questions such as those described here, or they simply referred to their child as going through the sleep regression phase, at around four months. Furthermore, some parents appeared to want age-specific guidance whereby they would often state the age of their infant/child and ask for information specific to that age, or to see whether their experiences at that age are normal. One parent even described that most information they had seen elsewhere was limited to babies, rather than older children. For example: *“All the information that I’ve read about seems to be more for the age of a baby or toddler. Do you know of any books out there for older children (such as 5 years), or would the strategies be the same with any age?”*

Some parents appeared to seek information about how much sleep their infants and babies should be having. They would often describe their own child’s sleep timing and ask whether it was enough, and/or compare it to sleep guidelines. For example: *“My baby is nearly 1 and has never really napped well, but slept for 12 hours from 6 weeks. Then a few months ago it all went wrong. She doesn’t nap anymore (has around a quarter of an hour total in the daytime) and now wakes throughout the night and just sits there playing for 1-2+ hours and is up around 6 o clock. Is this normal at this stage and has anyone experienced this? She doesn’t get the amount of sleep in a day which everything seems to recommend”*

Many parents sought advice and tips from other parents in relation to actively managing the sleep problems. They appeared to be welcoming of different types of advice, such as looking for advice/tips specific to different management strategies, or looking generally for any advice that parents could offer, such as routines that had worked for other people, e.g. *“does anyone have and advice to improve things?”*. Some parents seemed to be asking advice in anticipation of future sleep problems, either for planning of having more children, in anticipation of current strategies not working, or future sleep problems as children develop: *“We are going to be having another baby this summer. I want to know if there’s anything different that I should do to reduce the chances my next baby will have sleep problems.”*

Finally, some parents were asking about whether they should seek support from a HCP such as a GP. These parents seem to describe their situation as desperate, before asking about this and sometimes also mention that they are thinking of asking them about pharmacological approaches. For example, *“I’ve thought about asking the doctor for [medication]...has anyone done this?”*. This suggests that parents may think of the doctor as a last resort option.

4.4.2.1.3 Sub-theme 1.3: The impact of sleep problems

Many parents expressed concerns about the impact of their child's sleep problems. Parents discussed the direct impact on the family, such as day to day routines, impact on work and on siblings. Some also discussed that the sleep problems have worried them about their plans to have more children. For example, *"I'm a first-time mum and this is so difficult. I'm scared that I won't want any more children"*. Sometimes, parents also appeared concerned about the impact that lack of sleep may have on their children's health and development in the future, physiologically and/or psychologically; *"I'm concerned that my little one won't grow or develop properly because of this"*. Many parents expressed concerns that were related to their own mental health because of the sleep problems. For example, parents described themselves as feeling low, desperate, alone, and or/ that the problem was never ending. Some described that they felt manipulated. Some of the posts suggested extremely low mental health; e.g. *"I have regular feelings that I can't do this anymore"* and *"I'm desperate for some help, please. I usually deal with things really well but this is breaking me mentally"*.

4.4.2.1.4 Sub-theme 1.4: COVID-19 as a barrier or facilitator to support

Some parents discussed their concerns about the impact the COVID-19 pandemic on social support due to lockdown. In some cases, there was increased support (e.g. with a partner working from home) but posters were worried about what would happen once they were back at work. Some parents, not impacted by this, expressed concerns for others who were lacking support in lockdown.

4.4.2.1.5 Sub-theme 1.5: Management strategies

Many parents expressed concerns about different management strategies. In particular, there were many posts that suggested parents were concerned about co-sleeping and/or extinction-based techniques such as controlled crying. Regarding co-sleeping for example, many parents expressed that they were concerned either for safety reasons, or for creating bad habits. For example; *"It really scares me to think about co-sleeping – I'm so frightened of SIDS [sudden infant death syndrome]"*. Nevertheless, there were also many parents who did not mind co-sleeping and discussed the use of adherence to safety guidelines. Regarding extinction-based strategies (cry-it-out, controlled crying, or sleep training in general), many parents either felt that these particular strategies were wrong and feared negative effects on their child or that they could not tolerate the crying, or they wanted to try these techniques but were concerned how to do it correctly. Some described that though they are personally against the technique, they understood why others try them. For example; *"I understand why some parents try 'cry it out' in certain*

situations, but I personally don't agree with it and don't think it's right...I'm not sure whether it's true that it doesn't cause any damage – we don't and probably won't ever know if cry it out has done any harm.". Nevertheless, as with co-sleeping, there were also parents who were not against these techniques and recommended them. These findings indicate that there are multiple different views about different techniques and highlight the personal differences between individual families.

Furthermore, many parents seemed to have tried different strategies and seemed to be frustrated if they had not worked. They often explained this for practical or emotional reasons. For example, in order to provide context when asking for advice, many explained multiple things that they had tried to improve the sleep problems but which had not worked, or they appeared to be expressing frustration about failed methods. Some parents even appeared to feel a sense of failure by describing concerns that they had been doing the wrong thing to try to manage the sleep problems, or they had the concern that they may even have caused the problems by doing the wrong thing. For example, *"I just feel like I have done all the wrong things regarding getting my little boy to sleep"*.

4.4.2.2 Theme 2: Parents experiences or sharing advice online as a resource

The largest resource that parents appeared to use in relation to the management of their children's sleep problems, was each other. Their support for each other seemed to be present in multiple ways, such as peer and emotional support, for the exchange of information, for practical advice to one another, to share their own routines, and to give each other advice about consulting with professionals. The sub-themes identified are described below.

4.4.2.2.1 Sub-theme 2.1: Peer and emotional support

Primarily, most parents seemed to be a source of peer and emotional support for one another. For example, there were many responses to posters whereby parents described that they had been or were currently in similar situations, many even if they had no practical advice to give. This appeared to be for various reasons such as letting the parent know that they were not alone, that their concerns were normal or even simply emotional support by letting them know that they had sympathy. For example: *"Firstly, you are not alone with this struggle. I went through exactly the same thing with my little boy! It was dreadful"*. Some also described that they were in the same situation looking for advice from other responders.

Parents also appeared to often normalise the problems (i.e. that some children simply have sleep problems), normalise the concerns of other parents, or reassure and encourage one another that they are doing the right thing or that things will get better over time. For example, *"It will get*

better. Keep going". Similarly, some appeared to manage one another's' expectations around the sleep problems or promote their acceptance: *"Your baby's sleep will gradually improve, whether you do anything or not. With my little girl, I found that acceptance really helped and I actually felt less stressed when I realised that my night times were going to be different to what I was used to."*

On the other hand, some parents responded to other parents negatively, or some parents perceived that responses from other posters were negative. For example, they appeared to feel judged by some parents, or were criticised: *"Just letting you know, reading your reply really hurt me. I only wanted a bit of advice..."*. However, throughout the discussions, positive support was much more common than negative responses.

4.4.2.2 Sub-theme 2.2: Exchanging information

Further to emotional support, many parents appeared to act as an information resource. In particular, parents appeared to give age-specific guidance, such as advising on what age they would recommend other parents try different strategies (e.g. *"A little baby can't just be left alone crying. It may be the sleep regression, but she is too little for sleep training"*) or they would try to give an explanation for the child's sleep problems (e.g. *"It's the way you settle a baby that causes both night-waking and quick naps"*). The explanations could be for different purposes such as why something is normal, information on what to change to help the situation, or as potential non-sleep factors to consider which they believed may be causing the problems.

Some parents gave information to one another by relaying what they remembered they had been told from professionals (whether primary care or non-PCPs). This appeared to also be for different reasons such as to back up their own advice, simply pass on advice, or to share feelings about professionals. For example, one parent appeared to describe unhelpful information from a professional: *"I had the same thing with my daughter, so I remember this! Our [HCP] said to ensure we weren't feeding her to sleep which we weren't doing. She also said to make sure we were feeding more in the day, which is just not possible when a baby who is breastfed isn't hungry."* Participants also relayed or directed other parents' to their own sources of advice such as websites they had used or social media platforms they followed (see section 4.4.2.5 for further information about the sources specifically).

4.4.2.3 Sub-theme 2.3: Practical advice

In many cases, parents provided practical advice to one another which came in many different forms. In particular, parents advised about different management strategies, whether they were positive or negative comments. Management strategies included co-sleeping, practical/behavioural strategies, or variations of sleep training techniques. There were varied

opinions on each type of strategy, and different parents gave different levels of advice, such as simply advising someone to try a strategy, or advising them of how to implement it. For example:

“You can try many different forms of sleep training that don’t mean leaving your baby to cry. Some don’t involve any crying. I get frustrated that when someone mentions that they sleep train, people assume they just leave their baby to cry until they sleep, which is completely incorrect and not how many sleep training techniques work”

Many parents also appeared to recommend practical tools, either recommending them directly or by stating which tools had been useful for themselves. Again, there were recommendations for many different types, such as tools to help soothe children (songs, dummies, comforters), tools for co-sleeping (bedside sleepers etc), sleeping/baby apps, and tools to enhance children’s understanding such as a Gro clock (a clock which displays the sun and moon, to help children learn when it is time to stay in bed or wake up). Some parents advised on tools that they had tried but did not work. Many parents made practical suggestions about changing the child’s sleep environment. For example, lighting, temperature, location and surroundings in the bedroom. One parent described that *“making the room really dark”* really helped their child sleep.

Other types of practical advice included recommending that parents increase their practical and emotional support from others (such as increasing role sharing between partners: *“Can your partner take your little one out in the car or for a walk while you have some sleep?”*), or for parents to simply do whichever strategy works for them to be able to get some sleep (i.e. self-care too): *“Do whatever it takes to get through it in this short period”*.

4.4.2.2.4 Sub-theme 2.4: Sharing own routines

The majority of parents on the forums shared their own routines, to either recommend different management strategies, to back up what had worked for their child’s sleeping problems and/or to provide a context to their request for advice. They also shared routines which they had tried but were not successful. The shared routines varied in nature, types of routines, and level of detail. For example, one parent described the routine they implemented which helped their child:

“My daughter is only 5 months old and does her routine of feed, wash and bedtime around 7pm where she settles herself. She has a nappy change and some milk later in the evening and will take a full bottle, but then will sleep the rest of the night until a small stir around 6am before waking an hour later. People have told me I shouldn’t be feeding late in the evening, but it really

helped us, because otherwise she would wake in the middle of the night for it.

I'd rather do it at 11pm than 3am."

4.4.2.2.5 Sub-theme 2.5: Sharing views about healthcare practitioners and non-healthcare workers

Some parents expressed their views about HCP and non-healthcare workers in relation to managing sleep problems and encouraged others to consult with someone to help manage their children's sleep problems. Those recommended were PCPS (most commonly HVs) or non-primary or non-healthcare workers such as 'sleep consultants'. Sleep consultants mentioned by parents in these discussions were usually not specified any further (e.g. as a medical practitioner or as a non-HCP), however some parents mentioned them in the context of finding them on social media/paying for private sleep advice and less frequently, two recommended hospital-based sleep consultants. E.g. *"I advise seeing a [sleep professional]. Invaluable."* For other things related to the sleep problem, (e.g. parental mental health, or beliefs around other potential causes of sleep problems), GPs and/or HVs were recommended. E.g. *"If controlled crying isn't successful, alternatives are...sleep specialist...doctor to see if something else is causing the problem."* A small number of parents discouraged consulting some types of PCP/non-PCP or encouraged consulting with one person over another: *"A GP isn't going to help really. You could be recommended to a sleep consultant through a health visitor, or a health visitor might be able to give information"*.

A small number of parents commented on consultation advice (either advice given to themselves, or advice that other parents had mentioned they had been given from consultations), and their views of the PCP or non-PCP. The comments were mixed with both positive and negative posts. For example: *"We went to a [sleep professional] for some advice. If you use their recommendations, it really helps"* and *"I wouldn't bother following their advice. For me, weening at that age was a tough time for sleep"*.

4.4.2.3 Theme 3: Mixed experiences and perceptions of HVs and nursery nurses

In comparison to the amount of data for the themes 'concerns about children's sleep problems' and 'parents experiences or advice sharing online as a resource', there were fewer data in relation to the management of behavioural sleep problems within primary care. For example, it was common for there to be long discussion threads about the sleep problems, parents concerns and about parents sharing experiences with sleep problems, own routines, and personal advice. However, mentions of primary care (particularly in reference to behavioural sleep problems) were often mentioned briefly within discussions, rather than being the focus of a discussion. Nevertheless, there were some interesting themes from this data. When PCPs were mentioned,

this was often in relation to community-based PCPs such as HVs, and experiences and views seemed to be mixed. Three sub-themes resulted within; (1) reiteration of HV advice and action, (2) mixed attitudes towards community PCPs and (3) experiences with nursery nurses. All are described below.

4.4.2.3.1 Sub-theme 3.1: Reiterating HV advice/action

Of the posts regarding community-based PCPs, many parents appeared to reiterate different advice and actions that they had experienced with HVs. This often seemed to be related to their views of their HVs' beliefs about the potential causes or explanation of their child's sleep problems and what they should change to improve them. This was often in regard to feeding (e.g. *"Our health visitor said to ensure we weren't feeding her to sleep (we weren't)"*), but there were also mentions of toileting and COVID-19 pandemic isolation causing sleep problems.

In posts about specific sleep training strategies (e.g. extinction-based strategies) and HVs, parents frequently described the advice received from their HV. The strategies described suggested their HVs generally were in favour of general sleep training, or variations of the cry-it-out method such as controlled crying or gradual retreat. For example, *"My health visitor thought gradual retreat was the strategy we should try and it really helped."* Parents' perceptions of HV advice about the cry-it-out method seemed to be mixed; whereby some parents said that HVs do not recommend it, whereas others did. Some posts mentioned HVs' advice in relation to different ages, e.g. not recommending extinction approaches below a certain age. The different terms for extinction-based approaches were often used interchangeably, and so it was not always clear what parents were referring to.

Some parents discussed their experiences of HVs' advice regarding co-sleeping. The advice and experiences appeared to be mixed in terms of favouring or against co-sleeping, but HVs also appeared to discuss the safety around co-sleeping: *"I sent my health visitor away the first time because she told me off in my house, and I felt I had to pretend many times (about sleeping methods, feeding methods etc). Nowadays, my recent health visitor supports me and I feel I can do it my way"*.

Some parents discussed other advice which they were given by their HVs, or action which their HVs took. These included practical suggestions or changes to sleep environment (e.g. *"Our health visitor suggested we try sleeping separately in different rooms so that he has his own"*), or signposting to information online. Other action included referrals to nursery nurses or sleep specialists/clinics within the HV team for sleep problems (e.g. *"I've been recommended to a sleep specialist health visitor, through my health visitor"*), or to GPs for related parts of the problem

such as parental mental health (*"I spoke with my health visitor about this for a long time when she came over and she recommended I see the doctor for my mental health, but I think it was just exhaustion instead"*).

Some parents described the feeling that their HVs were not concerned about the sleep problems, and may even have normalised them by suggesting that they would grow out of it, or that some children do just struggle to sleep: *"Our health visitor didn't look like she was worried about it. She said that some children just don't need as much sleep."*

4.4.2.3.2 Sub-theme 3.2: Mixed attitudes about community PCPs

Parents appeared to have mixed attitudes towards community PCPs; some specific to sleep management, and others towards PCPs generally or for other issues. For example, some parents described HVs positively in terms of their helpfulness, knowledge and understanding: *"I know that my Health visitors have a sleep training service where the best have trained them. It's fantastic"*.

On the other hand, some others described HVs negatively, reporting feelings of being misunderstood, that they were unhelpful or they disagreed with their advice. For example, *"Our health visitor didn't understand – she told me that I should be giving my little one extra food in the day. She's not waking because she's hungry, she wants comfort!"* A small number of parents described holding back from telling their HVs the truth (or going against their advice) such as perceiving advice on social media as more useful. Moreover, two parents described that they felt their HVs had been inaccessible: *"I feel that I've been left alone with this. I've been unable to get hold of my HV for the whole week"*. One poster related this inaccessibility to the coronavirus pandemic.

4.4.2.3.3 Sub-theme 3.3: Experiences with nursery nurses

A few parents reported experiences with nursery nurses. One described that they had tried a nursery nurse among other community PCPs, with no success. Others described that they had been referred to a nursery nurse through a HV, for which one had successful outcomes and the other was still awaiting consultation. For example: *"We found a nursery nurse who was fantastic and helped with both eating and sleep training with our little boy. We were put in touch through our health visitor"*.

4.4.2.4 Theme 4: Limited experiences and perceptions of general practice

A small number of parents mentioned experiences, or lack of experiences, with the management of children's behavioural sleep problems in relation to consulting in general practice.

Nevertheless, the findings in relation to general practice are still important to note. Data

identification methods included conducting an equal number of searches in the forums for general practice PCPs and for HVs, so this suggests that parents may consult (or discuss consulting in discussion forums) with HVs more than GPs/doctors about their sleep problems. This theme has three sub-themes: (1) consulting GPs for non-sleep problems or underlying causes of sleep problems, (2) experiences consulting for sleep problems, and (3) reluctance to consult for a behavioural sleep problem. All are discussed below.

4.4.2.4.1 Sub-theme 4.1: Consulting GPs for non-sleep problem or underlying cause of sleep problem

There were a small proportion of posts about experiences consulting with GPs for the behavioural sleep problem itself. However, parents more often described consulting a GP, an intention to consult a GP, or a recommendation to consult a GP about either a non-sleep problem, parts of the sleep problem that were not seen as the sleep issue itself (e.g. parental mental health), or to check for anything else going on that may be causing the sleep issue. For example: *“It might be something else like an infection. Have you seen the doctor to rule anything like that out?”*. These posts were still a small proportion of the overall threads. This is interesting considering the forum searches were conducted for PCPs and sleep problems. Some posts described that they had consulted their GP about the sleep problem but were informed that it may be due to underlying reasons such as reflux and were given a prescription for that. One parent seemed to have delayed going to the GP in a consultation, because they did not mention it throughout the thread, until other physical symptoms arose: *“I’ve made an appointment to see the GP now because since we last spoke, she’s had problems toileting and it’s a different colour”*.

4.4.2.4.2 Sub-theme 4.2: Experiences consulting GP for sleep problems

In parents who did mention consulting a GP specifically about their children’s sleep problems, it appeared that they may consult about the sleep problem if they were already consulting about something else or as a last resort. This could be to ask for medication, after trying other health practitioners, or after trying many things at home. For example: *“The only thing left that I could try is complete cry it out, but I don’t want to do that. I’ve tried lots of HVs, nursery nurses etc...its now the time to try my GP”*.

Regarding advice given by GPs, only a small number of participants mentioned any advice specific to the sleep issues; one had been recommended a pharmacological approach, whereas the other had been recommended controlled crying. Some parents mentioned (or recommended parents to) consult with their GP for a referral to either HVs or secondary care paediatric departments.

E.g. *“[Didn’t say much [GP], just said that everything else was ok and recommended I ask the health visitor”.*

Finally, a small number of parents described unhelpful reactions from their doctor when they consulted about their children’s sleep problems. For example, one described the feeling of being misunderstood and another described the feeling that they were not taken seriously: *“I’m at the end of my tether. When I say that my little girl never sleeps, the doctors never take it seriously. I don’t think that this has been normal, but they think that because I’m a first time mum I must just need to get used to it.”*

4.4.2.4.3 Sub-theme 4.3: Reluctance to consult a GP for a behavioural sleep problem

A small number of parents appeared to be reluctant to consult a GP for behavioural sleep problems and anticipated negative responses. For example, one appeared embarrassed to see a doctor (*“We did hesitate about going to see our GP because we felt a bit silly saying that our little boy won’t sleep “*) whereas another appeared to be worried about how a GP would react (*“I’m concerned that because our baby is so young, the GP would just laugh at me if I went”*).

4.4.2.5 Theme 5: Other resources for supporting parents with child sleep problems

Whilst there were limited mentions of primary care in relation to the management of children’s sleep problems, parents did appear to access, or be aware of other types of resources. These were tools and online information resources, through non-PCPs or non-health workers, and in particular from books or parenting/sleep expert authors. Subthemes are discussed below.

4.4.2.5.1 Sub-theme 5.1: Tools and information resources online, through information sites, social media and apps

Parents appeared to be aware of and use (or recommend) online resources for both information and/or for tools in the management of their children’s sleep problems. For example, Information resources online that were mentioned included search engines, specific websites, online forums, social media platforms, and apps. For example: *“[app] is really good at explaining the reason for it (makes you realise you’re not crazy), saying whether it’s a phase, telling you what you can expect and how you can manage it”*. However, it was not clear which of the resources were formal evidence-based resources (such as NHS information sites), even though some were described as evidence-based. Nevertheless, parents appeared to use these resources to gain information and learn more about topics such as sleep stages and management strategies.

On the other hand, online resources that were used as tools in the management of children’s sleep problems included apps and video resources. For example, some apps were referred to as

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helpful in tracking children's sleep, whereas others were useful apps for helping children to sleep (e.g. they had specific sound to soothe children). Different types of apps were most often described to have been useful or were recommended to other parents. For example: *"It used to take ages to get my little boy to nap and he'd always cry when I it was that time. The app is fantastic"*. As with other resources, the accuracy and evidence-base for the apps mentioned by parents is uncertain.

4.4.2.5.2 Sub-theme 5.2: Non PCPs or non-healthcare workers

Often, parents described the use of sleep consultants or sleep specialists, rather than specifying using the NHS. In most cases it was not certain whether they were referring to NHS consultants, or privately paid sleep consultants who do not work in healthcare (and therefore roles, background and qualifications are unclear). However, in other posts, often parents referred to the sleep consultants/specialists as being sought out through social media accounts or within the context of private payment, or it seemed that they were not discussed in the context of a NHS HCP. Parents appeared to have had mixed experiences with them. For example, one parent described that a sleep consultant did not offer any strategies that they had not already tried (*"I tried speaking to a sleep consultant, but I had already given many of their suggestions a go"*) whereas another described a successful experience (*"Using advice from a sleep consultant, we sleep trained our little girl early. I understand it's not what everyone would want to do, however it helped our little one"*). Two parents recommended parents seek a sleep consultant through hospitals and a small number of parents described the use of secondary care professionals such as midwives or secondary care mental health services.

4.4.2.5.3 Sub-theme 5.3: Books or parenting/sleep expert authors

Many parents described the use of books or information from parenting/sleep expert authors, or they recommended them to other parents. The resources were used to gain information about children's sleep and about different management strategies. For example, *"I feel like much of the information around is incorrect or not clear, so I bought [book] and I'm so happy that I got it. It gives information for every worry that I had and it has lots of detail. I'd really recommend getting it if possible as it has so much sleep info"*. Some parents actively sought information on which books other parents would recommend.

4.5 Discussion

4.5.1 Summary of findings

This study explored parents' posts on public online discussion forums about their concerns about, and management of, sleep problems in children with a focus on sources of community, primary care and online support and resources. The results suggest that parents express multiple concerns regarding their children's sleep problems in online discussion forums where they seek a variety of informational, practical, and emotional support from other parents. They also share information regarding the use of other resources such as sleep or parenting books, apps, online information and sleep 'consultants' and describe experiences of seeking information from PCPs such as HVs with mixed results. When mentioned, consulting GPs was usually seen as a 'last resort' or for excluding underlying medical problems that may contribute to the sleep problem. This study addressed three research questions. Each are discussed below.

4.5.1.1 Parents have many different concerns about children's sleep problems

The first research question was to explore what parents express in online forums regarding their concerns and expectations about their children's sleep problems. Within the findings, the many concerns surrounding not only the sleep problems themselves, but also related broader factors (such as the impact of the sleep problems, concerns about management strategies and questions around seeking professional support) highlight the importance of addressing the problem, from both a health service and a community perspective. The number and range of concerns that parents expressed on the forums suggested there may be an unmet need of easy access to, or an unawareness of, HCPs and formal evidence-based resources for these problems. For example, an interview study which explored UK parents' thoughts of advice for children's sleep problems suggested parents often sought information online in response to limited advice from other sources, which included professionals.¹³³ Furthermore, it seemed that many of the concerns that parents had were related to a question of normal development; whether their infants sleep problems were normal, what the normal amount of sleep is that their child should have, whether particular phases were normal and for what age. This suggests a potential need for further resources or parental education such as anticipatory guidance.

Parents also appeared to have many different concerns about different management strategies, questions regarding whether different strategies should be used and/or how to correctly implement them. There were contrasting views on extinction-based methods such as cry-it-out or controlled crying, and likewise for co-sleeping. For example, many parents expressed concerns regarding the consequences of extinction-based techniques, and this is in line with previous

literature which explored reasons why parents often oppose these techniques^{71,114}. On the other hand, other parents described the effectiveness of such techniques to alleviate sleep problems, which is also in line with previous literature^{96,97,154}. Some parents appeared to understand the benefits of a method or understand other parents reasons for opposing views but were still personally against trying them. These findings further highlight the theoretical debates regarding extinction-based techniques discussed in Chapter Two and indicate the importance of an individualised, flexible and tailored approach to management from HCPs, accounting for families' preferences, experiences and circumstances. Such approaches are illustrated by Whittall and colleagues' theory¹⁵⁷ of a stepped-care approach to extinction-based methods for BI, and Blunden and colleagues' application of Bronfenbrenner's ecological systems approach to sleep education^{158,159}, both discussed in Chapter Two.

4.5.1.2 Awareness of resources, and perceptions of management online, in the community and in primary care

The second and third research questions were to explore what resources parents of children with sleep problems are aware of as available online, in the community and in primary care, and to explore how parents perceive that their children's sleep problems are currently managed during GP consultations in primary care.

Firstly, despite the many concerns that parents expressed, they appeared to act as an important online resource for one another, sharing both practical information, emotional support and at times information about consulting with PCPs / non-PCPs. These findings are as expected for online forums, and similar to those of other online forum research for management of other health problems, highlighting the usefulness of practical information and emotional support in online forums²⁴⁶. Online discussion forums therefore generally appear to be an easily accessible, supportive and positive environment for parents to discuss sleep problems. However, due to wide ranging types of information shared in the current study, the accuracy of such information is not always clear and some information/resources shared between parents may be inappropriate or inaccurate. This is a concern that is shared in other research exploring the management of other health problems through online forums²⁴⁶ and warrants further investigation of advice shared in the online forums and other sources of advice.

In comparison to discussing their concerns and sharing their own experiences and advice, mentions of primary care, in particular general practice for the behavioural sleep problem, were less frequent. Nevertheless, when parents did talk about their views or experiences within primary care, they seemed to be mixed. As with other problems, some parents did discuss consulting with their HVs about the sleep problems, or recommend this to other parents, but

experiences and views varied. For example, parents reported differing opinions from their HVs regarding co-sleeping, although there was more consistency about variations of the cry-it-out technique such as controlled crying. Some parents reported their HVs normalised the sleep problem, and attitudes towards their experiences with HVs were mixed, with some referring to their experiences as positive, others as negative. This suggests that parents are experiencing differing practice from their HVs in relation to the management of children's sleep problems, but also further highlights individual needs of the families. Similar advice given by different HVs may be perceived or interpreted differently by different families. The negative perceptions and experiences of PCPs in this study are similar to findings in other UK parent research^{133,215} whereby some parents perceive HCPs negatively and to be inflexible for different family's situations and preferences (illustrative quotes referred to HVs). This suggests that some parents' perceptions of HCP practice may be somewhat different to theories and ideas supporting an individualised approach from HCPs.^{157,158}

In the current study, experiences with doctors or GPs were described less often and differently to HVs. When consulting for sleep problems, it appeared that parents may see a consultation with a doctor as a 'last resort' or only appropriate in conjunction with other problems, or specifically to check whether there were other underlying physical causes of the sleep problems. Parents' posts on GP recommendations were more limited, although some parents were reassured that there wasn't an underlying serious medical condition and/or received prescription of medication or referral to either HVs or secondary care. Some parents suggested that they were reluctant to consult for a sleep problem due to anticipation (or experiences) of negative reactions, such as fear of embarrassment or of being judged negatively by the PCP. This is in line with UK research which explored parents' barriers to seeking help from HCPs about sleep problems and suggested that parents may perceive or experience negative consequences from consulting HCPs (such as perceptions that HCPs will have negative attitudes and judgements towards them and that it might be a waste of both parent and HCP time)²¹⁵. Further research is needed to explore parents' perceptions of consultations with GPs.

Although there are some findings regarding parents' views of the management of their children's sleep problems within primary care, the infrequency of data on online forums is important to note. There could be a number of reasons including that parents are either not usually consulting about this issue, or that they infrequently discuss it in online discussion forums. The limited data in this study, combined with other research findings that suggest parents have negative perceptions of HCPs^{133,215}, suggests that parents may not think to consult in primary care and particularly general practice. Thus, improving PCP knowledge and practice (see findings in chapters five and six regarding PCP knowledge) and increasing awareness amongst parents that

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behavioural sleep problems can be consulted about in primary care may be beneficial. This also highlights that further research into the role of primary care in insomnia management is necessary.

Aside from resources within primary care, parents appeared to use other resources such as online tools and information resources, sleep 'consultants' and/or parent books and authors.

Interestingly, few existing formal evidence-based resources (such as NHS information websites) were described and it is not clear how accurate the information was which the parents had accessed. Existing evidence-based resources may not be being accessed or may not be having an impact. Additionally it is uncertain if parents are directing each other to reliable information. Relying on other parents' sources of advice may lead to use of inaccurate advice if they are not from evidence-based sources. Signposting of evidence-based resources within GP primary care, and access to existing evidence-based resources is further explored in Chapters five and six of this thesis. Parents use of private sleep consultants also requires further research. They are not a regulated profession in the UK unlike HCPs, and parents appeared to have had mixed experiences of their contact with them.

4.5.2 Implications

Parents have unanswered concerns regarding their children's sleep problems and exploring ways to improve this both in research and practice would be beneficial.

Further research into the management of children's sleep problems within primary healthcare services is necessary. Primary care is a common point of first contact with health services for parents and children and this online forum research highlights a potential lack of awareness from parents of the role of primary care could have to support them. Current evidence-based resources for children's sleep problems exist but did not seem to be discussed often on the online forums. Parents' use of apps and online platforms also suggest ways in which further evidence-based information could be created and presented in a more impactful way. Thus, there appears to be opportunities to improve parental support and the management of sleep problems in children through signposting parents to accessible evidence-based resources and support. However, more in-depth exploration e.g. through qualitative interviews from the parent perspective is needed to further examine and expand these findings. Because this study's findings regarding parents' experiences with PCPs are mixed, more insight into the management of children's sleep problems within primary care would help because it would also highlight current practice, and direct future research and changes in practice to address any areas for improvement.

4.5.3 Strengths and limitations

This is the first known study to explore parents' discussions in online parenting forums about how they perceive the management of their children's behavioural sleep problems. The natural environment of observations of parents' discussions online provides a perspective free from the influence of a research environment which may not necessarily have been evident in a more controlled study such as qualitative interviews with parents. The study included a large amount of data (approximately 300 pages), from two UK parenting forums. However, due to this study design, it was not possible to probe participants for further data regarding primary care which was limited in this study. Nevertheless, the exploratory nature of qualitative research treats all data with equal importance and focusses more on transferability of the findings instead of generalisability ¹⁸⁴.

Data to be included from each forum was limited to eligible threads from the first 100 search results, rather than the initial 150 planned (see section 4.3.5.2.1) due to the volume of data and time available. Including further forums may have highlighted other findings but data saturation seemed to be reached thus more threads would probably still have included a small proportion of similar data regarding primary care.

A possible disadvantage to online forum research, is the over-representation of parents with negative experiences ²⁴⁷ (i.e. they may be more likely to post about their concerns and negative healthcare experiences than those who have not experienced problems), or that perspectives may be biased by excluding parents who do not use or have access to the online forums. Further, it is not possible to purposely select participants based on participant characteristics, because they are anonymous users who can disclose as little or as much information about themselves as they wish. Nevertheless, the study included a large amount of threads across two currently active parenting forums with a wide variety of parent views and experiences. Furthermore, this study was conducted in a highly systematic way using current best practice ^{243,244}, from scoping searches, to resulting data collection and analysis.

A challenge that arose during the analysis was that it was not possible to distinguish between the different types of extinction-based interventions for participants. Therefore, there may be some uncertainty in parents' reports of extinction-based strategies recommended by their PCP. For example, a parent who referred to 'cry it out' may have actually meant 'controlled crying'.

4.5.4 Conclusions

This study found that parents post about many different concerns and potential unmet needs regarding children's sleep problems. Online they frequently act as a resource for each other, giving emotional and practical support and sharing personal experiences. They mention use of many other resources, such as apps, websites and privately paid sleep consultants, however the accuracy and evidence-base for these resources are uncertain. Parents appear to have mixed experiences and views of community-based PCPs, and limited experiences of discussing sleep problems with GPs. There appears to be opportunities to improve parental support and the management of sleep problems in children through improved awareness of the role of primary care and signposting parents to accessible evidence-based resources and support. Further research is needed to specifically explore the management of children's sleep problems within primary care.

Chapter 5 An Online Survey of Primary Care Providers' Views, Understanding and Current Practice Regarding the Management of Paediatric Chronic Insomnia in Primary Care

5.1 Overview

This chapter presents the quantitative part of the third study within this thesis; a mixed-methods study which consisted of online surveys and qualitative interviews of UK-practicing PCPs regarding the management of paediatric chronic insomnia. Presented here are the results of the online survey, in which 355 PCPs took part. Findings from the qualitative interviews and the mixed-methods analysis will be presented in Chapter Six.

5.2 Introduction

5.2.1 Background and rationale

Honaker and Meltzer¹³⁴ suggested in their narrative review that discussions of sleep in primary care consultations and PCPs' confidence on the topic are lacking. They also suggested that PCP formal professional education on the topic was minimal. However, their study review was not specific to the management of chronic insomnia in children and it was a narrative, rather than systematic review.

These limitations were addressed in the systematic review reported in Chapter Three, which more specifically and systematically explored the current literature on PCP views, understanding and current practice regarding the management of chronic insomnia in children. Some findings of the review also indicated that PCPs' knowledge about chronic insomnia may vary, that PCPs would likely recommend behavioural strategies (in particular bedtime routines), and that PCPs may perceive managing chronic insomnia as their role, though their confidence in management varies. However, interpretation of these findings was limited by mixed study quality, restricted geographical representation and primary care settings that differed to the UK. Specifically, (1) minimal data explored GPs, (2) most of the PCPs in good quality studies explored paediatricians in other countries, where primary care differs to the UK, (3) many UK studies explored UK HVs but most were of poor quality and outdated, and the good quality studies presented conflicting

perspectives, and (4) no studies within the systematic review explored UK nurses. Findings therefore indicated that UK based primary care research in this area was lacking and needed updating with higher quality research.

Chapter Four reported on the perspective of parents via a qualitative analysis of parents' discussions about their children's sleep problems in online forums (pending publication). Specifically, it explored what they express in the forums regarding concerns and expectations about their children's sleep problems, what resources they are aware of (in primary care, online or the community), and how they perceive that their children's sleep problems were currently addressed during consultations in primary care. Findings indicated that parents express multiple concerns about their children's sleep problems, that they often act as a resource for each other by sharing experiences and emotional support, and that they use other resources such as books, sleep consultants and apps. However, the advice and recommendations that parents gave one another were wide ranging or based on personal opinion and may not have been accurate or evidence based. Furthermore, there were limited mentions of primary care, mostly relating to community primary care (e.g. HVs), with mixed views and experiences of them, rather than general practice. The infrequency of mentions of primary care suggest the value of increased awareness that help can be provided by or signposted to in primary care. The study in Chapter Four therefore highlighted the importance of addressing the concerns of parents, but also the importance of further research on PCP perspectives of the topic.

The study presented in this chapter explored UK-based PCPs' views, understanding and current practice regarding the management of chronic insomnia in children up to and including the age of five. A mixed-methods approach enabled triangulation of a rich qualitative and quantitative data set²⁴⁸ and the study provided a more holistic perspective of the topic, by reporting on the perspective of PCPs to complement the parent perspective. Specifically, it provided insight into what UK PCPs currently understand, believe and practice regarding the management of children's sleep problems to inform further research to improve management.

5.2.2 Aims and research questions

1. To explore PCP views about chronic insomnia in children (up to the age of five).
2. To understand what PCPs currently know about chronic insomnia in children, and how much formal education they have received on the topic during/since training.
3. To explore PCPs' current practice regarding management of children's chronic insomnia.
4. To explore perceived PCP unmet needs regarding managing children's chronic insomnia.

5. To find out whether there are any particular types of support tool that PCPs would like, to manage children's chronic insomnia.

5.3 Methods

5.3.1 Design and sample

Mixed-methods were used to explore the research questions above. Specifically, an online survey, and in-depth qualitative interviews with a subset of survey participants, were conducted. This chapter reports only on the online survey. Chapter Six reports the methods and findings of the qualitative interviews.

5.3.2 Ethics approval

This study was reviewed and approved both by the University of Southampton Research Governance Office (RGO ref 53955), and by the Health Research Authority (HRA, IRAS ref 277619). A research passport and letter of access was also acquired where required.

5.3.3 Study setting

This study was advertised in primary care organisations, through the Clinical Research Network (CRN) and in an NHS Trust (through a HV manager), by distribution of an email containing the survey link. The survey was also advertised in the community (e.g. social media and via non-NHS organisations). The study explored views/practices within a primary care setting (which included community primary care such as health visiting and nursery nursing). Participants were able to choose when and where they completed the survey, however the survey needed to be completed in one go.

5.3.4 Sample and recruitment

5.3.4.1 Eligibility criteria

5.3.4.1.1 Inclusion

Any UK practicing PCP (or HCP based in the community) such as UK GPs, HVs, advanced practice nurses, practice nurses, nurse practitioners, nursery nurses, and/or any other PCP / HCP based in the community could take part.

5.3.4.1.2 Exclusion

PCPs (or HCPs based in the community) who do not practice in the UK could not take part.

5.3.4.2 Sample size and technique

The exact number of survey participants needed was unknown because it was an exploratory study. However, it was estimated that there would need to be at least 100 survey participants to achieve an adequate range of views. A confidence interval approach was used to determine a target sample size for the survey based on the key response outcome “If you had the chance now, would you like to access further sleep teaching opportunities about chronic insomnia in children?”. The most conservative sample size is given by assuming that 50% of participants would choose each response. Based on a 95% confidence interval +/-10%, a minimum of 97 participants would be needed. Therefore, the lower target for the survey was 100 participants and upper target 300.

Survey data collection started in September 2020 and the sample size was monitored throughout the study. Recruitment was slow initially, likely with the busy nature of the target population’s workload which was likely heightened during the Coronavirus pandemic. It was planned to recruit only through one CRN region, however after two link circulations within the region, less than 50% of the lower target had been achieved (completed surveys) and it was decided to expand the survey to other regions in the UK (see further details below in 5.3.4.3.1). The sample achieved approximately 100 completed responses towards the end of January 2021 after six more regions circulated the survey link. At this point, recruitment rates had increased, some other invited regions were still yet to circulate the link, and the study was still limited by most of the participants being GPs rather than practice nurses or other staff. Therefore, the survey was kept open until the last of the regional survey link circulations had been completed, to achieve as close a sample size to 300 as possible. In February to March 2021, recruitment rates increased even further taking the sample size to over 200 completed participants. As the study approached 300 completed participants, a survey closure date was set in March 2021 to allow for any last participants to be recruited from the last regional link circulation which took place in Mid-February 2021.

5.3.4.3 Recruitment

5.3.4.3.1 CRN

Recruitment was planned initially by asking the CRN for their advice on how to recruit PCPs from GP practices for this study. The CRN suggested that this project would be eligible for CRN support

following an application, and that they would be able to circulate an email on the researcher's behalf, to research active practices, containing the survey link. The application for CRN portfolio support was approved in February 2020. The lead CRN distributed an email containing a link to the survey, to staff in research active practices in their region in September 2020. The recipients could then disseminate to other eligible staff within their practice so that eligible PCPs could decide if they would like to take part.

Due to trouble recruiting in the covid-19 pandemic, recruitment was expanded to other local CRN (LCRN) regions. The lead CRN circulated an expression of interest email to other LCRNs around the country, who could then contact SH if they were interested in disseminating the survey link within their region also. 12 LCRN regions contacted SH to express interest, and after various meetings with individual LCRNs, sending study documentation and arranging set up of the link circulation within each region, 9 more regions in total circulated the survey link to their research active practice staff (between November 2020 and February 2021).

A total of 10 LCRN regions therefore circulated the link (from within the north, west, south, and east of England, including the midlands and London). Some of the regions re-circulated the link to advertise the study again at later points in time. Some LCRN regions also provided their own financial incentives to GP practices, to help recruitment.

Recruitment took place in various proportions across the country. Approximate percentages of the sample for each LCRN region (of complete respondents for which LCRN region is known, n=284, and including NHS Trust recruitment, described below) were 11.27% (Wessex), 1.41% (South London), 1.76% (Thames Valley and South Midlands), 2.11% (North Thames), 6.7% (Kent, Surrey and Sussex), 1.41% (West Midlands), 16.2% (North-West London), 41.2% (East of England), 14.44% (North West Coast) and 3.17% (East Midlands).

5.3.4.3.2 NHS Trust

To plan recruitment of HVs and nursery nurses, a locality manager within an NHS Trust along with the head of research within their Research and Development (R&D) department were contacted (separately) during the study design. Both agreed to be involved with the study. During a face-to-face meeting, the HV managers and an R&D contact suggested some minor changes to the survey (to shorten it to 15 minutes and to also provide it as a paper copy which can be handed out in team meetings). The survey was amended prior to the start of data collection; however, the paper copies were no longer necessary due to the covid-19 pandemic and remote working.

Following the delay in study set up due to the covid-19 pandemic Trust R&D approvals were put in place and the HV manager circulated an email containing a link to the survey to eligible staff with

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the HV team, to decide individually if they would like to take part. The HV manager also recirculated the link again later to give staff a second opportunity to take part.

Attempts were made to contact another NHS Trust to expand the HV participant base but no other trusts were ultimately involved in the study.

5.3.4.3.3 Community recruitment

Due to trouble recruiting in the Covid-19 pandemic, an amendment (see Appendix C.2) was made to include community advertisement. The survey link was then advertised on social media and through other non-NHS organisations such as the NIHR School for Primary Care Research.

Attempts were made to contact a non-NHS HV organisation to see if they would be interested in circulating the link to members, however this was unsuccessful. Snowballing recruitment was also included in the amendment, so it was possible for participants to pass on details of the study to others who they thought might want to take part.

5.3.4.3.4 Consent

Survey participants read a detailed participant information sheet on page 1 (appendix C.3.1) and also needed to complete the consent form (appendix C.3.2) at the beginning of the survey, before they could proceed to the survey questions.

5.3.5 Data collection

Survey data collection started in September 2020 and finished in March 2021.

The online survey was developed based on existing literature (including some questions and adaptations from survey questions in the existing literature (Mindell and colleagues 1994²²², Owens 2001²²⁵, Mindell and Owens 2003¹³⁵, Bruni and colleagues 2004²¹¹, Faruqi and colleagues 2011²¹⁷) and detailed discussions in supervisory meetings. This was also pilot tested with a HV, a school nurse and two GPs before data collection began. Survey development was also informed by PPI input (please see 5.3.7 for PPI comments) whereby suggestions for questions were made. See Appendix C.3.3 for the final HRA approved version. Participants completed the survey online via the University of Southampton's online survey website 'iSurvey'.

The survey included mostly quantitative questions (closed questions and Likert scale questions). Likert scale response options were from one to five, to align with and enable comparison with questions/findings from similar paediatric sleep research studies using questionnaires (including studies from which the questions in the current study were used/adapted) ^{217,222,225}. The survey also included free text boxes throughout where participants could expand on answers or give

further detail. The free text boxes will be explored and analysed prior to publication, however, they are beyond the scope of this thesis and therefore no formal analysis of the free text qualitative responses are presented in this thesis. The survey also included demographic questions after the main survey questions.

The end of the survey asked if participants would be interested in proceeding to an interview. This section provided researcher contact details and encouraged them to email/phone to express an interest or gave them the option to enter their email address to be contacted (see Chapter Six). Participants were also asked to provide an email address if they wished to be entered into a draw for a £100 gift voucher. The final page of the survey provided participants with a debrief statement (appendix C.3.3).

5.3.6 Data analysis

Questions were analysed with descriptive statistics, specifically numbers, frequencies, mean, median, mode, lower and upper quartiles and standard deviations as appropriate to variable type and distribution were reported. Analyses were presented with histograms and bar charts.

Likert-style questions were analysed by presenting the number and percentage of respondents for each response option, but by also calculating the number and percentage of respondents choosing the options on the higher or lower ends of the scale. For example, on a scale of one (no impact) to five (major impact) on a question about the perceived impact of chronic insomnia, the number and percentage of participants who rated either a high or major impact (four or five) was reported. This enabled comparison with similar research using Likert style data^{135,217,225}.

5.3.7 PPIE

The first PPI contact for this research expressed a preference for a focus on PCPs rather than parents, prior to the design of the study documentation. She also suggested some questions for the surveys/interviews that she thought would be important, such as asking what a PCP would say if a family came to them with sleep problems, how seriously they would take it and how much action they would think needs to be taken. These questions were considered early in the design stage of the current study and confirmed and refined the research plan which had been driven by supervisors' expert knowledge and reading around the current literature. Where possible, her suggestions were included in the surveys and/or interview, prior to piloting. She described her negative experiences, and that she felt that PCPs should have a particular process to follow, such as a flow chart with options for referral and different severities. Based on these comments, a question was included to ask if any PCPs have a particular process that they follow/use.

5.4 Results

316 participants completed the survey. Some additional participants started the survey and stopped part-way through or missed some questions due to the questions not being mandatory. However, it was decided to count someone as a participant still if they answered the first question (in order to include as much data as possible) which meant there were a total of 355 participants. Therefore, not all participants answered all of the questions throughout the survey, and the total number of participants for each question differs throughout. In particular, due to the demographic questions being at the end of the survey, the sample characteristics below are for most, but not all participants, so percentages for each demographics question do not necessarily add up to 100% of the sample. The number of participants for each demographics question are stated in the table. Where each aspect of the findings are discussed afterwards, the number of responders are listed for each particular question.

5.4.1 Sample characteristics

Approximately two thirds of participants reported their gender as female (200/308). Participants' age ranged from 24-75 years (mean = 46.3, SD=9.54). The sample consisted mostly of GP practice staff (n=305 / 314, 97.13%). Most participants were GPs (n=244 / 319, 76.49%), and others included practice nurses and nurse practitioners etc (see table 7). A small number of participants were community practitioners such as HVs or nursery nurses (n=8 / 314, 2.55%). Participants practiced in a range of regions within England, had been practicing as a HCP for one to 50 years (mean=20.1, SD = 10.48), and in primary care for one to 41 years (mean=14.3, SD = 9.12). Most participants had personal experience caring for children aged five or under, however this question enabled participants to answer with free text, some of the answers are somewhat subjective or left blank. Nevertheless, most participants (n=267, 75.21%) indicated "yes" (or a variation of yes) or described that they had their own children.

Age, gender and ethnicity characteristics for GP practice staff are broadly similar to available data on the March 2021 demographics of general practice staff working in the NHS²⁴⁹, which reports there are more female nurses and female GPs, and broadly similar age (GPs and nurses) and ethnicity data.

Table 7. Survey participant demographics

			N (%) or mean (SD)	Median	Range
Age (n=311)			46.3 (9.54)	46	24-75
Gender (n=308)		Male	108 (35.06)		
		Female	200 (64.94)		
Ethnicity (n=307)	Black or Black British	Caribbean	1 (0.33)		
		African	2 (0.65)		
		Other	0		
	White	British	207 (67.43)		
		Irish	2 (0.65)		
		American	0		
		Other	14 (4.56)		
	Asian or Asian British	Indian	53 (17.26)		
		Pakistani	4 (1.3)		
		Bangladeshi	1 (0.33)		
		Other	4 (1.3)		
	Mixed	White and Black Caribbean	0		
		White and Black African	0		
		White and Asian	5 (1.63)		
		White and Hispanic	1 (0.33)		
		Other	5 (1.63)		
	Other ethnic groups	Chinese	3 (0.98)		
		Japanese	0		
Hispanic		0			
Other		5 (1.63)			
Setting (n=314)		GP Practice	305 (97.13)		
		Community	8 (2.55)		
		Both	1 (0.32)		
PCP (n=319)		GP	244 (76.49)		
		Advanced nurse practitioner	17 (5.33)		
		Practice nurse	31 (9.71)		
		Nursery nurse	2 (0.63)		

		N (%) or mean (SD)	Median	Range
	HV	7 (2.19)		
	Other	19 (5.96)		
	Pharmacist	3 (0.94)		
	GP Trainee	3 (0.94)		
	Non-clinical	5 (1.57)		
	Healthcare assistant	1 (0.31)		
	Nursing assistant / associate	2 (0.63)		
	Other	2 (0.63)		
Years since qualified (n=314)		20.1 (10.48)	20	1-50
Years in primary care/community (n=302)		14.53 (9.12)	13	1-41
Personal experience of caring for children aged 5 or under	yes (or mention of having own children/ grandchildren)	267 (75.21)		
	No	36 (10.14)		
	Other response / answer not clear	4 (1.13)		

5.4.2 Views and beliefs

5.4.2.1 Beliefs about the impact of chronic insomnia

Participants rated how much they thought chronic insomnia in children has an impact on various domains, using a 5-point Likert scale from 1 ('no impact') to 5 ('major impact'); see Table 8. In general, respondents believed chronic insomnia to have an impact on all domains; average ratings for the statements ranged between 3.4 and 4.7. Ratings of 'no impact' occurred in less than 3% of the respondents for each statement, and in particular, no participants indicated that they thought chronic insomnia has 'no impact' on 'social health' or 'parental stress'.

Nevertheless, there appeared to be some differences in the levels of perceived impact for different domains. 65.1%, 51.6% and 76.6% of participants believed that chronic insomnia has a major impact (rated five) on 'mood and behaviour', 'learning ability' and 'parental stress', respectively, with very few participants reporting 'no impact' (0.3%, 0.6% and 0%, respectively). Furthermore, over 80% of respondents rated the impact as a large or major impact (rated four or

five) for 'mood and behaviour', 'learning ability', 'social health' and 'parental stress'. Interestingly, the ratings were slightly lower for the domains of 'general physical health', 'weight gain' and 'accidental injury', whereby 64.8%, 51% and 48% respectively, rated the perceived impact as large or major. Please see the bar charts below (Figures 7-13) which illustrate the differences in data distribution for each domain.

Table 8. Ratings of the impact of chronic insomnia in children. Questions from / adapted from Owens²²⁵, Faruqui and colleagues²¹⁷, Mindell and colleagues²²² and Mindell and Owens¹³⁵

	1 (No impact) n (%)	2 n (%)	3 n (%)	4 n (%)	5 (major impact) n (%)	% who rated 4 or 5	Mean (SD)	Mode
Mood and behaviour (n=355)	1 (0.3)	4 (1.1)	29 (8.2)	90 (25.4)	231 (65.1)	90.5	4.54 (0.72)	5
Learning ability (n=353)	2 (0.6)	9 (2.5)	42 (11.9)	118 (33.4)	182 (51.6)	85	4.33 (0.83)	5
General physical health (n=352)	1 (0.3)	29 (8.2)	94 (26.7)	126 (35.8)	102 (29)	64.8	3.85 (0.94)	4
Social health (peer and family relations) (n=349)	0 (0)	13 (3.7)	51 (14.6)	142 (40.7)	143 (41)	81.7	4.19 (0.82)	5
Weight gain (n=349)	10 (2.9)	52 (14.9)	109 (31.2)	116 (33.2)	62 (17.8)	51	3.48 (1.03)	4
Accidental Injury (n=348)	7 (2)	60 (17.2)	114 (32.8)	110 (31.6)	57 (16.4)	48	3.43 (1.02)	3
Parental stress (n=354)	0 (0)	3 (0.8)	17 (4.8)	63 (17.8)	271 (76.6)	94.4	4.7 (0.6)	5

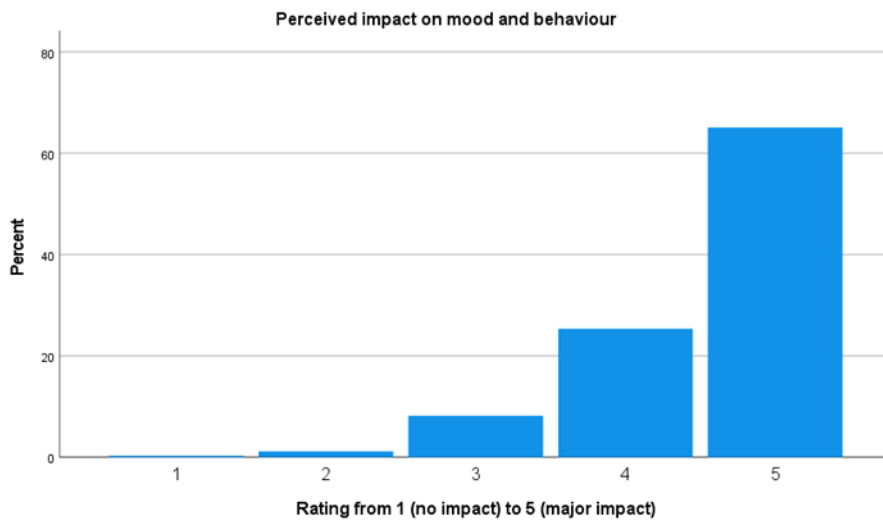


Figure 7. Bar chart for the perceived impact of chronic insomnia on mood and behaviour

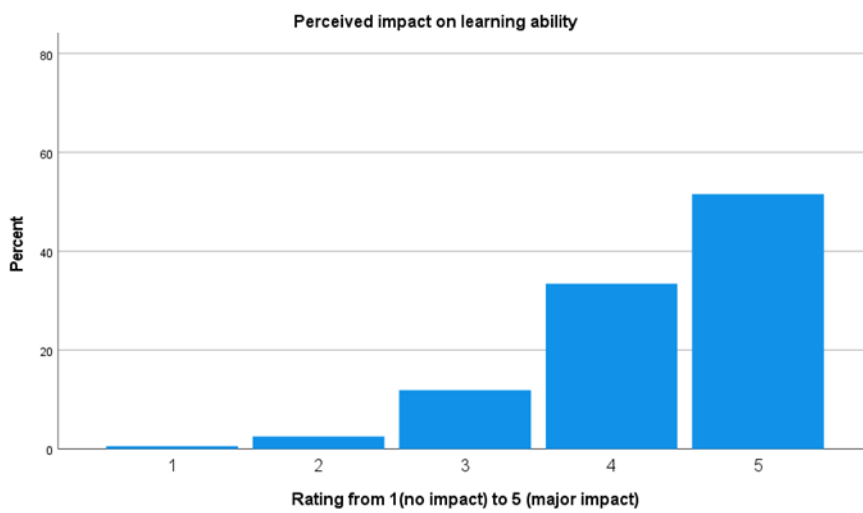


Figure 8. Bar chart for the perceived impact of chronic insomnia on learning ability

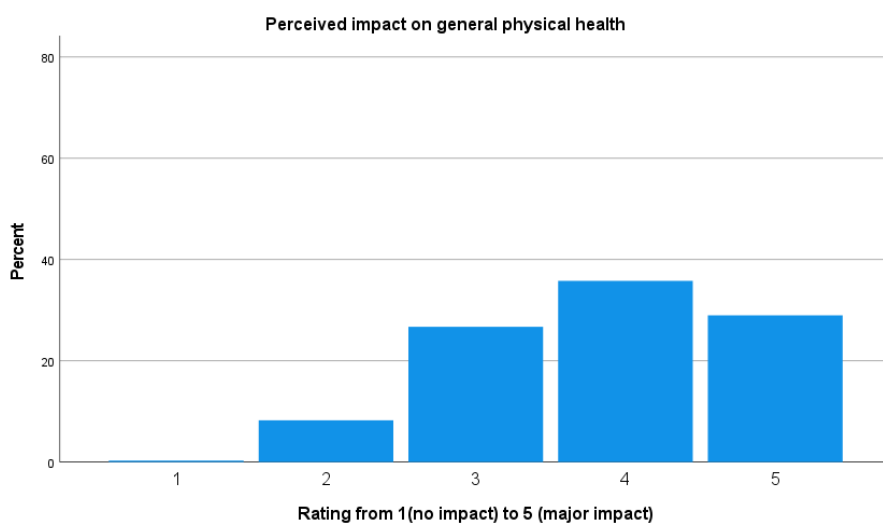


Figure 9. Bar chart for the perceived impact of chronic insomnia on general physical health

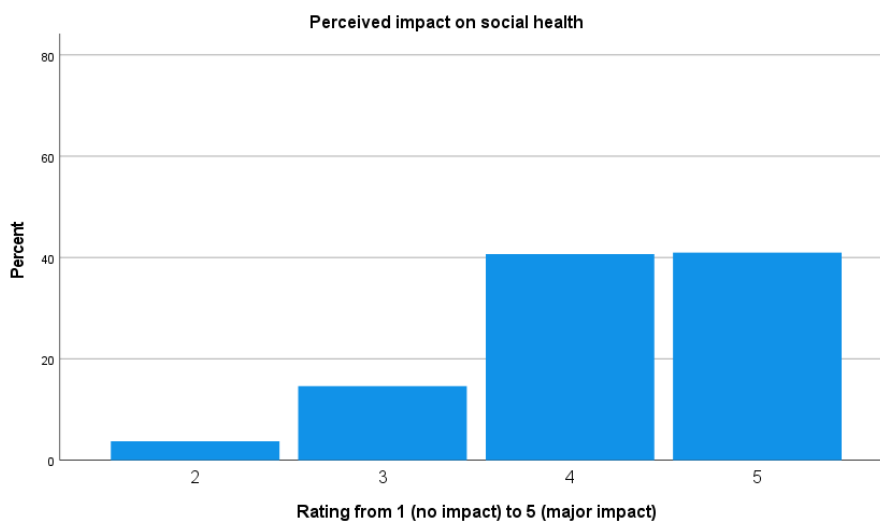


Figure 10. Bar chart for the perceived impact of chronic insomnia on social health

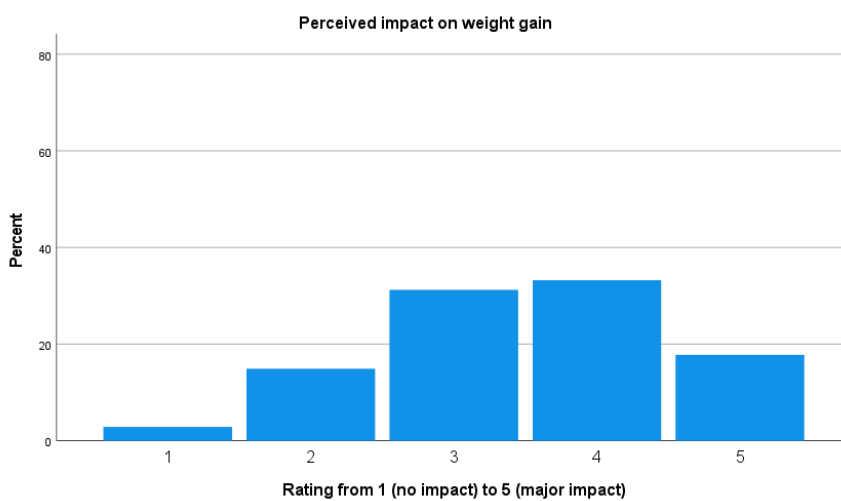


Figure 11. Bar chart for the perceived impact of chronic insomnia on weight gain

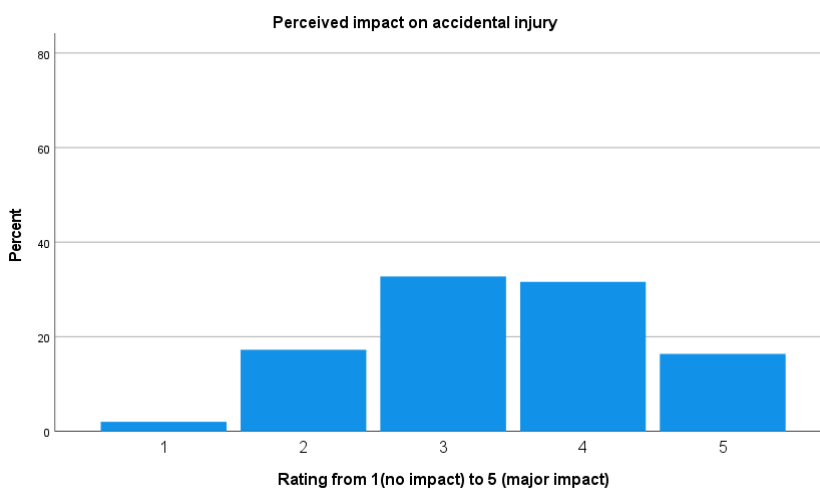


Figure 12. Bar chart for the perceived impact of chronic insomnia on accidental injury

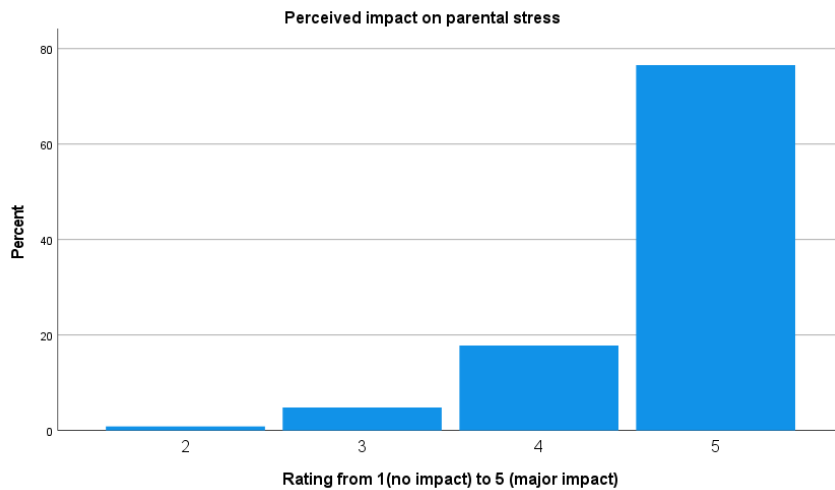


Figure 13. Bar chart for the perceived impact of chronic insomnia on parental stress

Participants also rated how much they agreed or disagreed with statements about chronic insomnia affecting the child and family (see Table Nine and figures 14-15). 86.7% agreed or ‘strongly agreed’ that chronic insomnia affects the child and 97.4% agreed or strongly agreed that it affects the family. This indicated strong beliefs about the impact on everyone involved. In particular, almost all participants agreed or strongly agreed that chronic insomnia impacts on the family.

Table 9. Beliefs about the effect of chronic insomnia

	1 (strongly disagree) n (%)	2 n (%)	3 n (%)	4 n (%)	5 (strongly agree) n (%)	% who rated 4 or 5	Mean (SD)	Mode
“Chronic insomnia affects the children experiencing it” (n=354)	1 (0.3)	9 (2.5)	37 (10.5)	106 (29.9)	201 (56.8)	86.7	4.4 (0.8)	5
“Chronic insomnia in children impacts the family” (n=349)	0 (0)	1 (0.3)	8 (2.3)	89 (25.5)	251 (71.9)	97.4	4.69 (0.53)	5

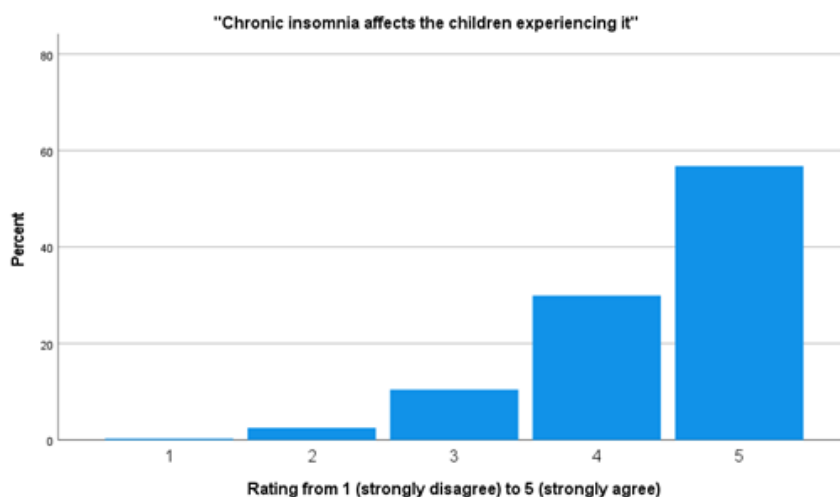


Figure 14. Bar chart for the perceived impact on the children

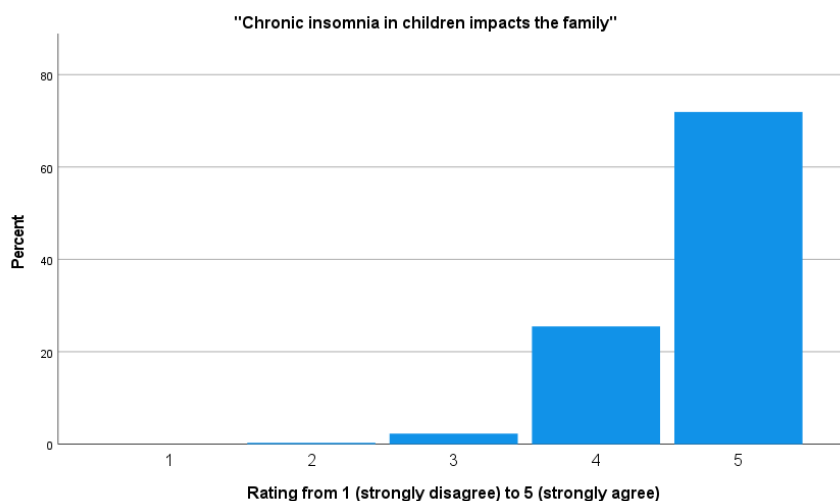


Figure 15. Bar chart for the perceived impact on the family

5.4.2.2 Beliefs about the management of Chronic insomnia

Participants also rated various statements about chronic insomnia management, using a 5-point Likert scale from 1 (strongly disagree) to 5 (strongly agree); see Table 10.

80.3% agreed or 'strongly agreed' that it is important for health services to manage children's chronic insomnia, and 67.7% agreed or strongly agreed that it is important for primary care to manage children's chronic insomnia. 90.7% participants agreed that it is important to manage paediatric chronic insomnia with behavioural approaches (mode = 5), in comparison to only 21.5% who agreed or strongly agreed that it is important to manage with pharmacological approaches (mode = 2): please see figures 16-17 for bar charts which illustrate the differences between beliefs about pharmacological and behavioural management.

Table 10. Ratings about the management of chronic insomnia

	1 (strongly disagree) n (%)	2 n (%)	3 n (%)	4 n (%)	5 (strongly agree) n (%)	% who rated 4 or 5	Mean (SD)	Mode
“It is important for health services to manage / advise about children’s chronic insomnia” (n=356)	2 (0.6)	5 (1.4)	63 (17.7)	136 (38.2)	150 (42.1)	80.3	4.2 (0.82)	5
“It is important to manage /advise about children’s chronic insomnia in primary care” (n=354)	6 (1.7)	25 (7.1)	83 (23.4)	140 (39.5)	100 (28.2)	67.7	3.86 (0.97)	4
“It is important to manage /or advise about children’s chronic insomnia in my practice.” (n=352)	5 (1.4)	33 (9.4)	99 (28.1)	126 (35.8)	89 (25.3)	61.1	3.74 (0.99)	4
“It is important to manage / advise about children’s chronic insomnia using behavioural interventions” (n=348)	0 (0)	2 (0.6)	30 (8.6)	123 (35.3)	193 (55.5)	90.8	4.46 (0.68)	5
“It is important to manage / advise about children’s	76 (21.5)	111 (31.4)	90 (25.5)	41 (11.6)	35 (9.9)	21.5	2.57 (1.23)	2

	1 (strongly disagree) n (%)	2 n (%)	3 n (%)	4 n (%)	5 (strongly agree) n (%)	% who rated 4 or 5	Mean (SD)	Mode
chronic insomnia with pharmacological approaches" (n=353)								

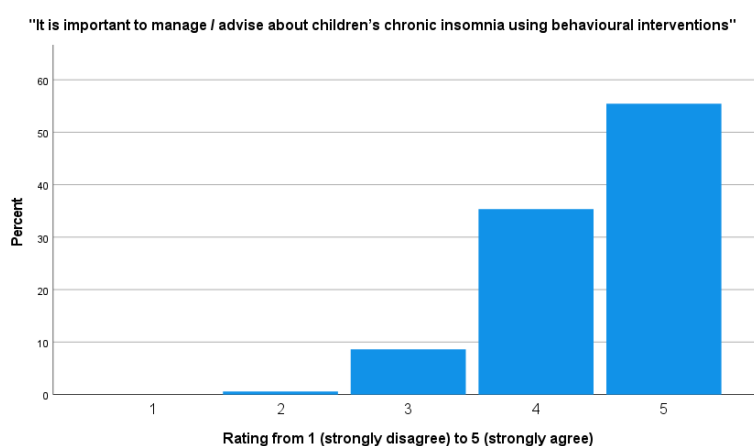


Figure 16. Bar chart for the belief about behavioural management of chronic insomnia in children

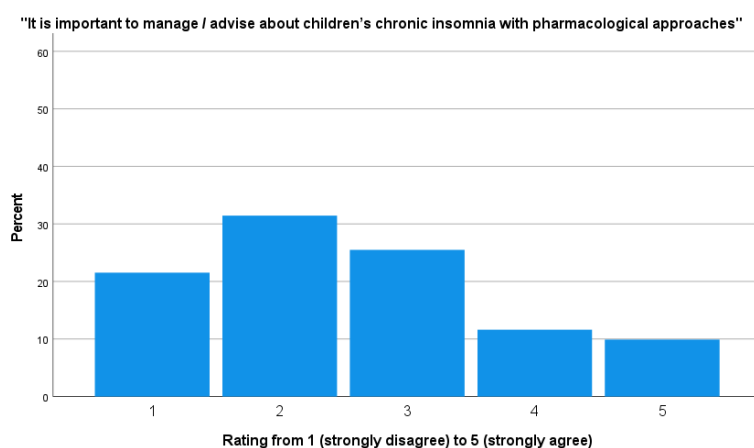


Figure 17. Bar chart for the belief about pharmacological management of chronic insomnia in children

A question within the survey also asked participants to rank who they believed was most important in managing childhood chronic insomnia. From a list of 6 items (four different PCPs, an item named 'parents' and an item named 'other'), participants were asked to rank the order of importance from one (least important) to six (most important). Table 11 presents the number and percentage of participants choosing each rank for each item in the list. Figures 18-19 present the

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percentage of participants for each item who ranked a higher importance and a lesser importance, respectively.

The item most often chosen as the most important (a rank of six) was 'parents' with 147 participants (42.4%) who ranked parents choosing this option. The most commonly chosen rank for the HV team was the second most important (a rank of five). However, 52.2% and 51.9% of participants who ranked the HV team and parents, respectively, ranked them as the most or second most important (see figure 16). For all other items, ranks of importance were more varied. The most commonly chosen rank for GPs, nursery nurses and GP practice nurses were 4, 4 and 2 respectively.

Table 11 Ratings of importance for who should manage children's chronic insomnia

	N (%) answering each response						% who ranked 5 or 6	Mean	Mode
	1 (Least important)	2	3	4	5	6 (Most important)			
HV team (n=349)	20 (5.7)	86 (24.6)	34 (9.7)	27 (7.7)	136 (39)	46 (13.2)	52.2	3.89	5
GPs (n=351)	21 (6)	48 (13.7)	103 (29.3)	122 (34.8)	48 (13.7)	9 (2.6)	16.3	3.44	4
Nursery nurses (n=346)	12 (3.5)	65 (18.8)	107 (30.9)	115 (33.2)	41 (11.8)	6 (1.7)	13.5	3.36	4
GP practice nurses (n=343)	40 (11.7)	115 (33.5)	54 (15.7)	48 (14)	74 (21.6)	12 (3.5)	25.1	3.11	2
Parents (n=347)	103 (29.7)	15 (4.3)	31 (8.9)	18 (5.2)	33 (9.5)	147 (42.4)	51.9	3.88	6
Other (n=201)	98 (48.8)	11 (5.5)	12 (6)	8 (4)	9 (4.5)	63 (31.3)	35.8	3.04	1

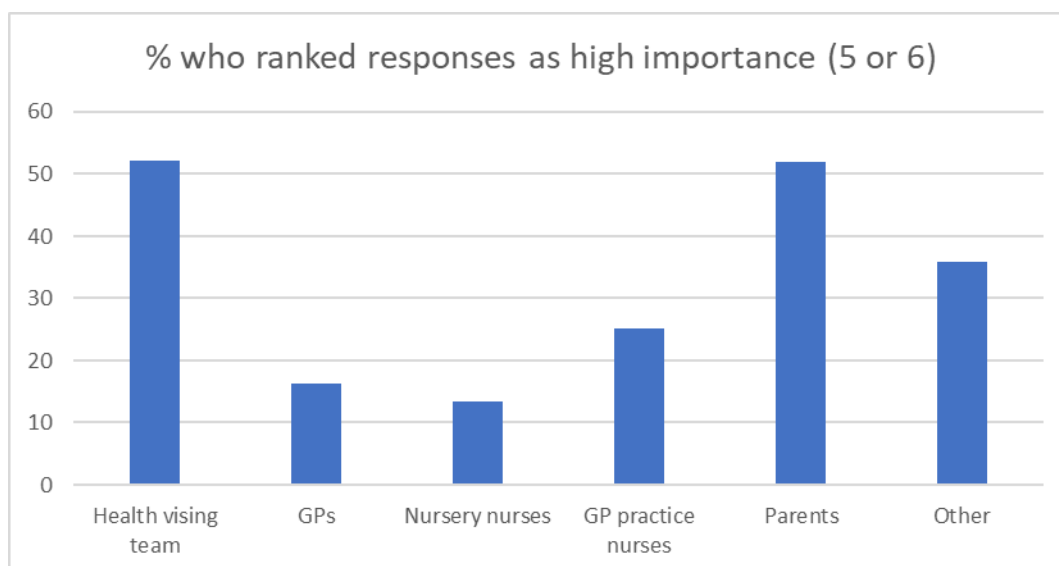


Figure 18 The percentage of participants who ranked each type of PCP of higher importance (a rank of 5 or 6) for managing chronic insomnia in children

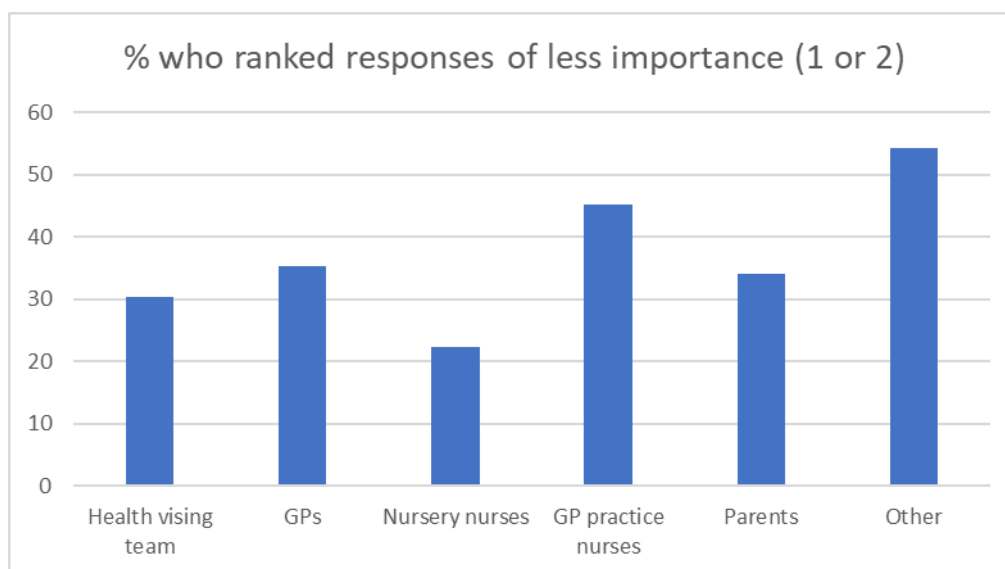


Figure 19 The percentage of participants who ranked each type of PCP of lesser importance (a rank of 1 or 2) for managing chronic insomnia in children

An unexpected finding was that for the 'parent' response, whilst more than 50% of participants ranked them most or second most important, 103 participants (29.3%) ranked parents as the least important. Similarly, whilst 52.2% of participants who ranked the HV team ranked them as very or the most important (a rank of five or six), 25% ranked them as two (the second least important). It may be that some participants believed parents and HVs as less important in managing chronic insomnia. This was surprising given (1) all participants in the Chapter Six interviews thought parents and HVs are important in the management, (2) literature suggests that parents are the ones to implement behavioural sleep interventions / bedtime routines and (3) health visitors are the first point of contact for children of this age in the UK^{250,251}. It was initially suspected that the

scale for this question may have at times been misread (i.e. as 'one' meaning the most important rather than the least important, and 'six' as least important rather than most important'), however it is not possible to know this and these findings need further exploration.

5.4.3 Management/Practice

5.4.3.1 Consultations

One question asked participants "how often do you discuss children's chronic insomnia with parents during consultations?" (see Table 12). The most frequent response was 'sometimes' (42.5%) followed by 'rarely' (40.6%). This is interesting considering that behavioural sleep problems in childhood are common. Because Chapter Four suggested that parents have many concerns about their children's sleep problems, a possible reason for a rare/sometimes frequency of consultation may be that parents do not consult about their child's sleep problems. This may emphasise the need to encourage parents and PCPs to discuss chronic insomnia, but needs further exploration first.

Table 12. Frequency of discussion about chronic insomnia in children

N=320		
	N	%
Never	23	7.2
Rarely	130	40.6
Sometimes	136	42.5
Frequently	27	8.4
Very frequently	4	1.3

Furthermore, participants were asked to rate who most often brings up the issue of chronic insomnia in three different age ranges of children (see table 13). For all infants and children up to and including age 5, only 1.6% to 10.2% of PCPs said they bring up sleep problems themselves in comparison to 58.6% to 80.2% who said the families bring it up. The percentage for 'both' were in between. Furthermore, the percentage of participants who said they bring the topic up themselves decreased as the age range became older and increased for the family. These findings may offer a possible explanation as to why it is rarely the focus of consultation; many families may

not think of bringing sleep problems to primary care, and because the PCPS do not bring it up either, sleep problems may not get recognised within primary care.

Table 13. Who brings up the discussion about chronic insomnia in children?

	Myself (PCP) (N, %)	The Family (N, %)	Both (N, %)
Up to 6 months old (n=314)	32 (10.2)	184 (58.6)	98 (31.2)
6 months to 12 months old (n=313)	13 (4.2)	229 (73.2)	71 (22.7)
12 months to 5 years (n=313)	5 (1.6)	251 (80.2)	57 (18.2)

5.4.3.2 Approach and decision making

Participants were also asked whether they follow a particular thought process or approach when a parent comes to them about problems with child chronic insomnia. Out of 313 participants who answered this question, nearly half answered 'yes' (n=145, 46.3%). 53 (16.9%) answered 'no' and 115 (36.7%) answered 'somewhat'. Because only a small number answered 'no' the data suggests that many PCPs do use an approach, though it may not necessarily be completely structured.

Participants also indicated which of the following they would use to aid their decision making (see table 14). Participants were able to choose more than one option, so the exact N for the overall question is not certain. Percentages for this question refer to the percentage of total number of 355 survey participants who selected each response, rather than the percentage of participants who responded to this overall question. 258/355 participants (72.1%) indicated they would have a general discussion about the child's sleep history. The second most common aid was personal experience (n=174, 49%), followed by sleep diary (n=145, 40.9%). A small number of participants indicated that they would not use anything specific.

Table 14. Decision making aids

	N (% of 355 total survey participants)
Existing literature	79 (22.3)
Personal experience	174 (49)
Sleep diary	145 (40.9)

General discussion about the child's sleep history	258 (72.1)
Do not use anything specific	47 (13.2)
Other	13 (3.7)

5.4.3.3 Likelihood of recommendations

Participants rated their likelihood of making different recommendations in relation to three different age ranges: 'Up to 6 months old', '6 months to 12 months' and '12 months up to and including 5 years'. The questions were adapted from Mindell and colleagues (1994)²²², Owens (2001)²²⁵, Bruni and colleagues (2004)²¹¹ and Ersu and colleagues (2017)¹³⁷ to be specific to chronic insomnia in children and to include other interventions. After piloting of the survey whereby all infants and children were included within the same set of questions, a further adaptation was made for the questions to be specific to the three different age ranges of children. Participants rated their likelihood on a 5-point Likert scale from 1 (never) to 5 (every time). Likelihood of recommendations varied, however there seemed to be some distinct preferences, described below.

5.4.3.3.1 'Up to 6 months old' age range

Positive bedtime routines were the most commonly chosen recommendation, with 86.7% of participants indicating they would likely recommend it most or 'every time' (a rating of 4 or 5). Ratings also became less frequent with response options of lesser frequency, with only 1.3% of participants reporting they would never recommend positive bedtime routines (a rating of one). This pattern however was the opposite for 'ignore the child', 'delayed bedtime' and 'pharmacological recommendation', with only 8.3%, 7.1% and 1.6% who indicated they would likely recommend them most or 'every time', respectively. Please see table 15 and Figures 20-30 (bar charts below) which illustrate the differences in data distribution of likely recommendations for children up to six months old.

The second most commonly chosen recommendation was suggested to be 'advise that the problem will resolve over time' with nearly half of the sample (46.9%) indicating they would recommend it most of the time or 'every time'. Other recommendations such as graduated extinction, extinction with parental presence, scheduled awakenings and make a referral were more varied in likelihood, with only 19.4%, 28.7% and 13.3% respectively indicating most of the time or 'every time'.

Regarding extinction-based techniques specifically, 'ignore the child' appeared less preferred than graduated extinction which was less likely than 'extinction with parental presence' (8.3%, 19.4% and 28.7% respectively, indicating most or 'every time'). This indicates that the participants generally preferred a gentler extinction-based approach over an unmodified one.

Table 15. Likelihood of making individual recommendations for the 'up to six months' age range

Recommendation	1 (Never) n (%)	2 n (%)	3 n (%)	4 n (%)	5 (Every time)	% who rated 4 or 5	Mean (SD)	Mode
Ignore the child / Cry it out / Extinction (n=313)	165 (52.7)	74 (23.6)	48 (15.3)	23 (7.3)	3 (1)	8.3	1.8 (1.01)	1
Controlled crying / graduated extinction / Ferber method (n=314)	94 (29.9)	74 (23.6)	85 (27.1)	55 (17.5)	6 (1.9)	19.4	2.38 (1.14)	1
Extinction with parental presence / gradual retreat (n=310)	63 (20.3)	49 (15.8)	109 (35.2)	76 (24.5)	13 (4.2)	28.7	2.76 (1.15)	3
Positive bedtime routine (n=317)	4 (1.3)	7 (2.2)	31 (9.8)	66 (20.8)	209 (65.9)	86.7	4.48 (0.86)	5
Scheduled awakenings (n=311)	114 (36.7)	56 (18)	63 (20.3)	36 (11.6)	42 (13.5)	25.1	2.47 (1.43)	1
Delayed bedtime (n=308)	148 (48.1)	78 (25.3)	60 (19.5)	16 (5.2)	6 (1.9)	7.1	1.88 (1.02)	1
Pharmacological recommendations (n=311)	235 (75.6)	50 (16.1)	21 (6.8)	5 (1.6)	0 (0)	1.6	1.34 (0.68)	1

Referral (n=309)	83 (26.9)	101 (32.7)	84 (27.2)	32 (10.4)	9 (2.9)	13.3	2.3 (1.06)	2
Advise that the problems will resolve over time (n=307)	23 (7.5)	45 (14.7)	95 (30.9)	102 (33.2)	42 (13.7)	46.9	3.31 (1.11)	4
No recommendation (n=279)	195 (69.9)	36 (12.9)	37 (13.3)	10 (3.6)	1 (0.4)	4	1.52 (0.88)	1
Other (n=184)	133 (72.3)	9 (4.9)	26 (14.1)	6 (3.3)	10 (5.4)	8.7	1.65 (1.17)	1

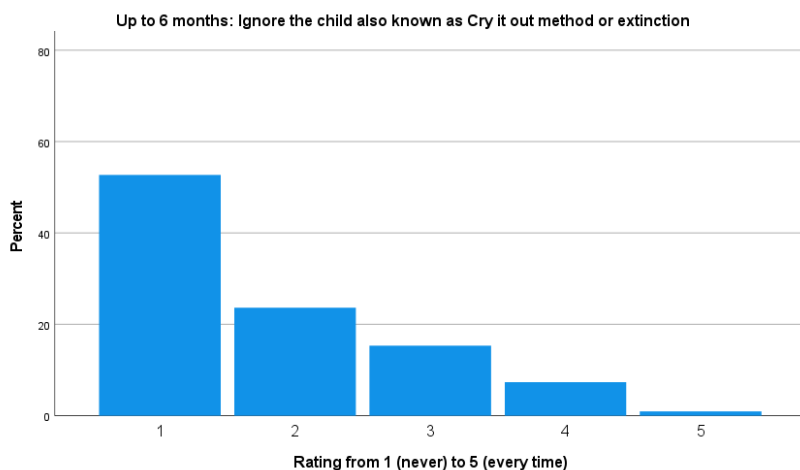


Figure 20. Bar chart for the likelihood of recommending the cry it out method for the 'up to six months' age group

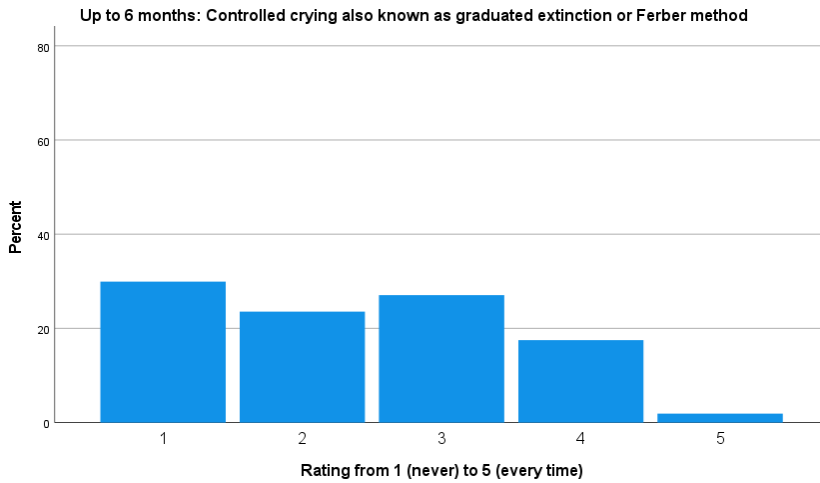


Figure 21. Bar chart for the likelihood of recommending graduated extinction for the ‘up to six months’ age range

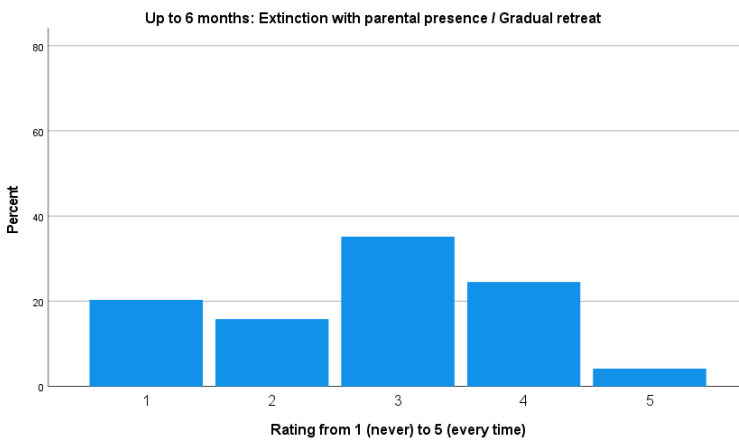


Figure 22. Bar chart for the likelihood of recommending extinction with parental presence for the ‘up to six months’ age range

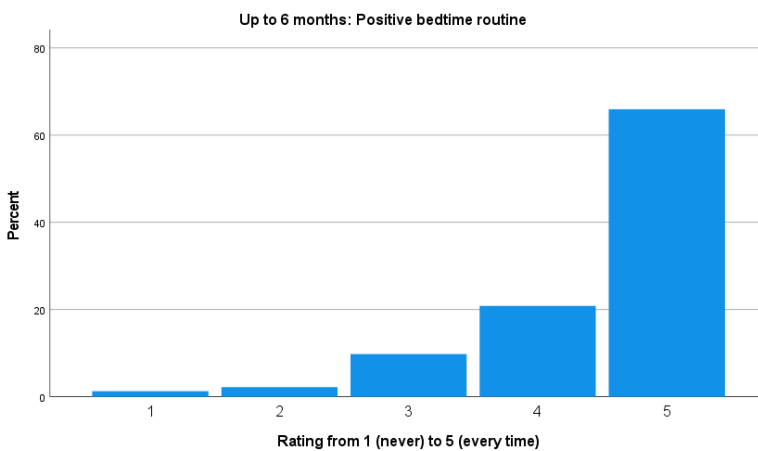


Figure 23. Bar chart for the likelihood of recommending positive bedtime routines for the ‘up to six months’ age range

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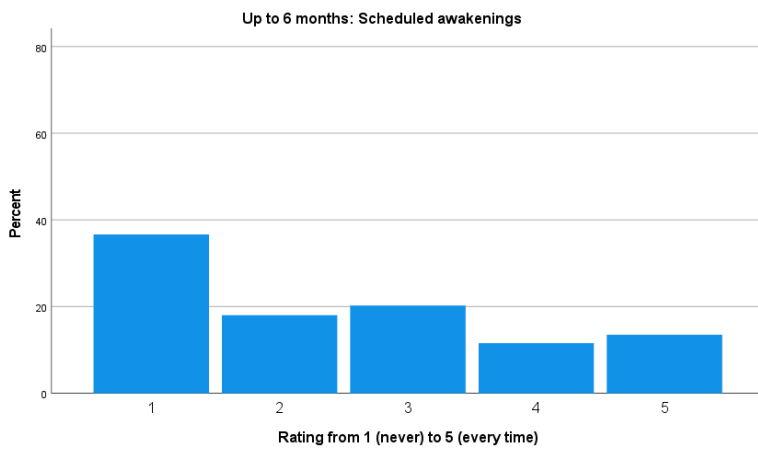


Figure 24. Bar chart for the likelihood of recommending scheduled awakenings for the 'up to six months' age range

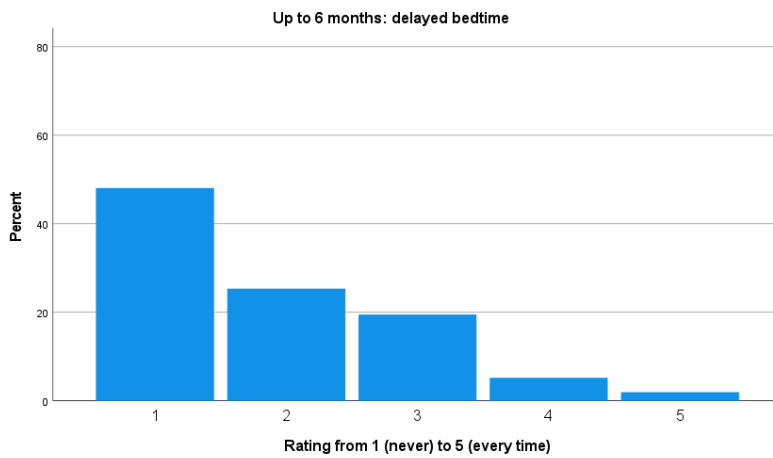


Figure 25. Bar chart for the likelihood of recommending a delayed bedtime for the 'up to six months' age range

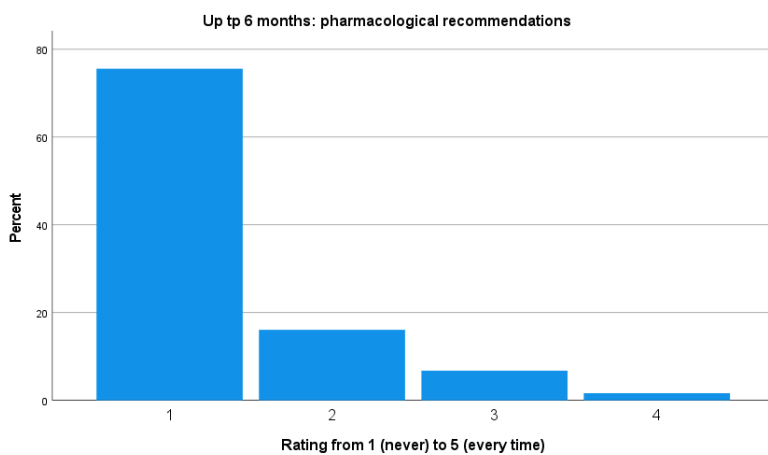


Figure 26. Bar chart for the likelihood of making a pharmacological recommendation for the 'up to six months' age range

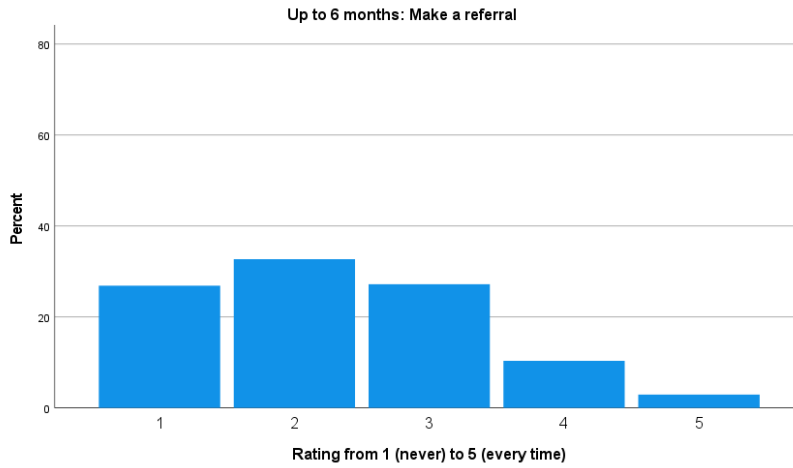


Figure 27. Bar chart for the likelihood of making a referral for the ‘up to six months’ age range



Figure 28. Bar chart for the likelihood of advising that the problems will resolve over time, for the ‘up to six months’ age range

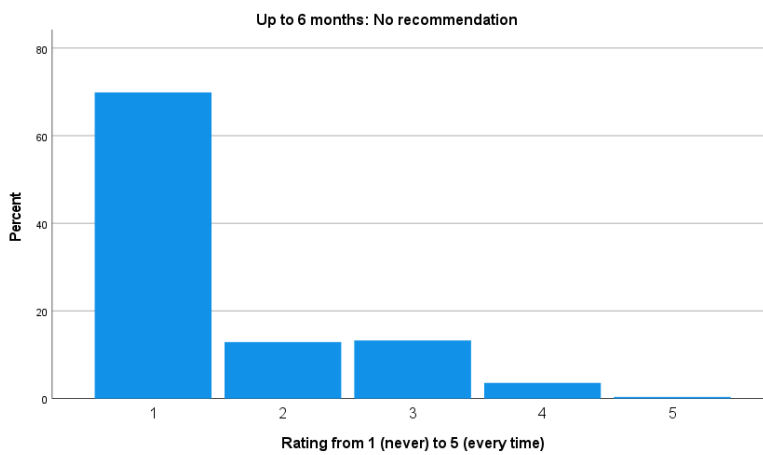


Figure 29. Bar chart for the likelihood of making no recommendation for the ‘up to six months’ age range

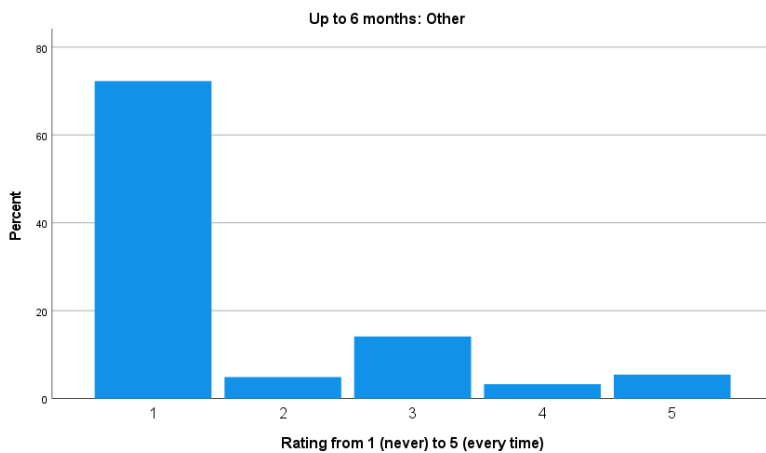


Figure 30. Bar chart for the likelihood of making another recommendation for the 'up to six months' age range

5.4.3.3.2 '6 months to 12 months' age group

Results in this age range followed a similar pattern to the likely frequency of recommendations in the up to six months age range. Positive bedtime routines were again most commonly chosen as a likely recommendation, with 87.4% of participants indicating they would recommend it most or all of the time, whereas only 1.6% of participants indicated they would never recommend it.

'Ignore the child', 'delayed bedtime', 'scheduled awakenings' and 'pharmacological recommendations' had the opposite pattern, whereby only a small percentage of participants rated the likely frequency of recommendations as most or all of the time (9%, 8.8%, 26.2% and 2.2% respectively) in comparison to 53.1%, 40.8%, 38.8% and 72.6%, respectively, who rated that they would never recommend them. Please see table 16 and Figures 31-41 (bar charts below) which illustrate the differences in data distribution for the six to 12 months age range.

The second most likely recommendation remained as 'advise that the problem will resolve over time', however the percentage of participants rating this as most or all of the time was slightly lower than the previous age range, at 37.7%. Other recommendations such as controlled crying, 'extinction with parental presence' and make a referral were more varied, with 23.6%, 34.7% and 15.5% rating indicating they would recommend them most or all of the time, respectively.

Regarding extinction techniques specifically, ignore the child was again much less likely to be recommended than controlled crying, which appeared less likely than extinction with parental presence (9%, 23.6% and 34.7%, respectively, indicated they would recommend them most or all of the time).

Table 16 Likelihood of making individual recommendations for the 'six months to 12 months' age range

Recommendation	1 (Never) n (%)	2 n (%)	3 n (%)	4 n (%)	5 (Every time) n (%)	% who rated 4 or 5	Mean (SD)	Mode
Ignore the child / Cry it out / Extinction (n=311)	165 (53.1)	71 (22.8)	47 (15.1)	23 (7.4)	5 (1.6)	9	1.82 (1.05)	1
Controlled crying / graduated extinction / Ferber method (n=309)	79 (25.6)	69 (22.3)	88 (28.5)	64 (20.7)	9 (2.9)	23.6	2.53 (1.16)	3
Extinction with parental presence / gradual retreat (n=306)	38 (12.4)	60 (19.6)	102 (33.3)	89 (29.1)	17 (5.6)	34.7	2.96 (1.1)	3
Positive bedtime routine (n=311)	5 (1.6)	2 (0.6)	32 (10.3)	66 (21.2)	206 (66.2)	87.4	4.5 (0.83)	5
Scheduled awakenings (n=309)	120 (38.8)	55 (17.8)	53 (17.2)	40 (12.9)	41 (13.3)	26.2	2.44 (1.44)	1
Delayed bedtime (n=306)	125 (40.8)	93 (30.4)	61 (19.9)	22 (7.2)	5 (1.6)	8.8	1.98 (1.02)	1
Pharmacological recommendations (n=307)	223 (72.6)	52 (16.9)	26 (8.5)	6 (2)	0 (0)	2	1.4 (0.73)	1
Referral (n=303)	83 (27.4)	83 (27.4)	90 (29.7)	38 (12.5)	9 (3)	15.5	2.36 (1.1)	3

Recommendation	1 (Never) n (%)	2 n (%)	3 n (%)	4 n (%)	5 (Every time) n (%)	% who rated 4 or 5	Mean (SD)	Mode
Advise that the problems will resolve over time (n=308)	29 (9.4)	54 (17.5)	109 (35.4)	81 (26.3)	35 (11.4)	37.7	3.13 (1.12)	3
No recommendation (n=268)	193 (72)	37 (13.8)	36 (13.4)	2 (0.7)	0 (0)	0.7	1.43 (0.75)	1
Other (n=172)	126 (73.3)	13 (7.6)	22 (12.8)	5 (2.9)	6 (3.5)	6.4	1.56 (1.05)	1

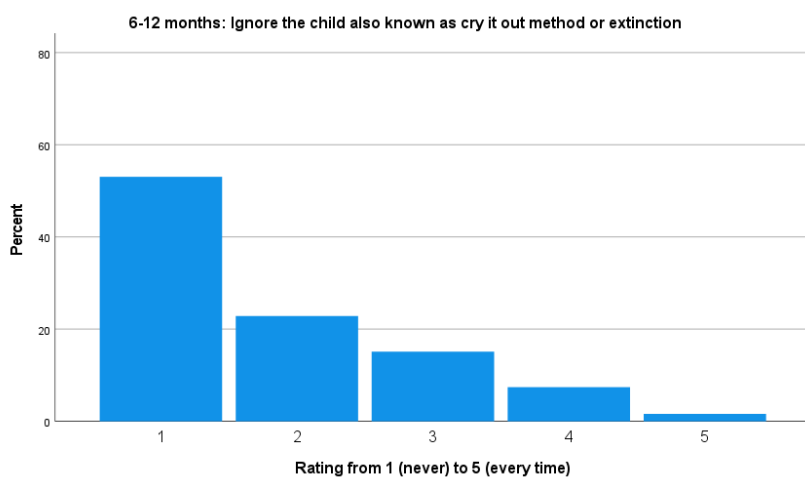


Figure 31. Bar chart for the likelihood of recommending cry it out for the 'six to 12 months' age range.

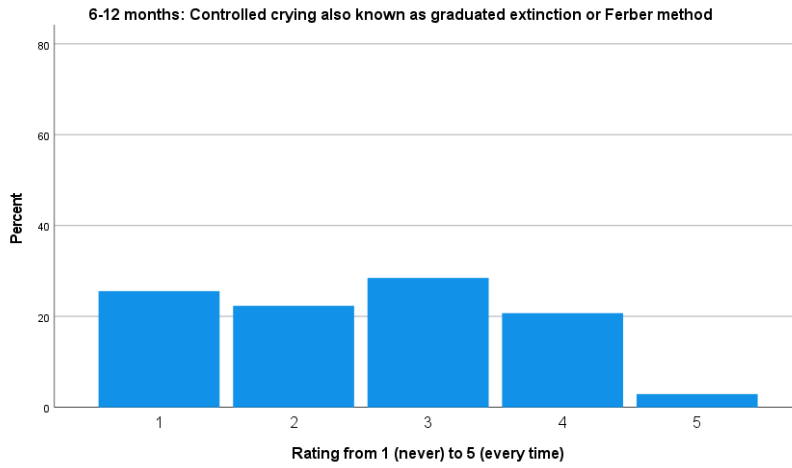


Figure 32. Bar chart for the likelihood of recommending graduated extinction for the ‘six to 12 months age range’.

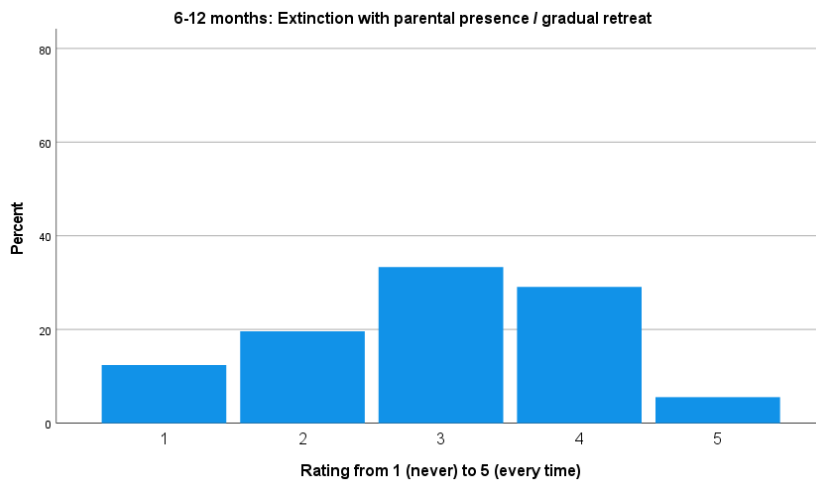


Figure 33. Bar chart for the likelihood of recommending extinction with parental presence for the ‘six to 12 months’ age range.

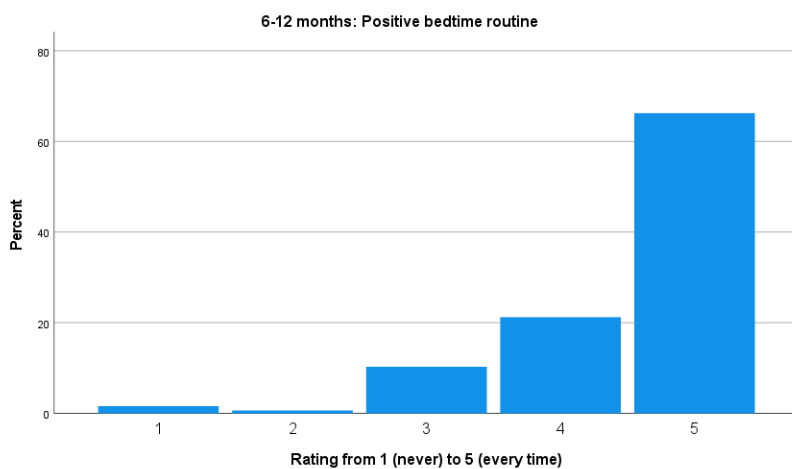


Figure 34. Bar chart for the likelihood of recommending positive bedtime routines for the ‘six to 12 months’ age range.

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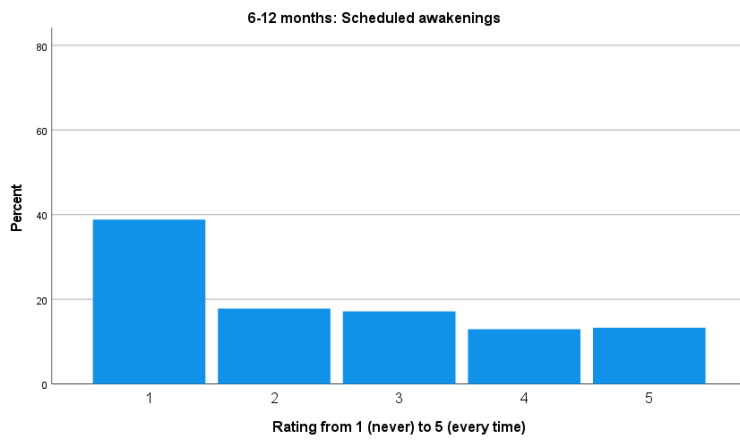


Figure 35. Bar chart for the likelihood of recommending scheduled awakenings for the 'six to 12 months' age range.



Figure 36. Bar chart for the likelihood of recommending a delayed bedtime for the 'six to 12 months age range'.

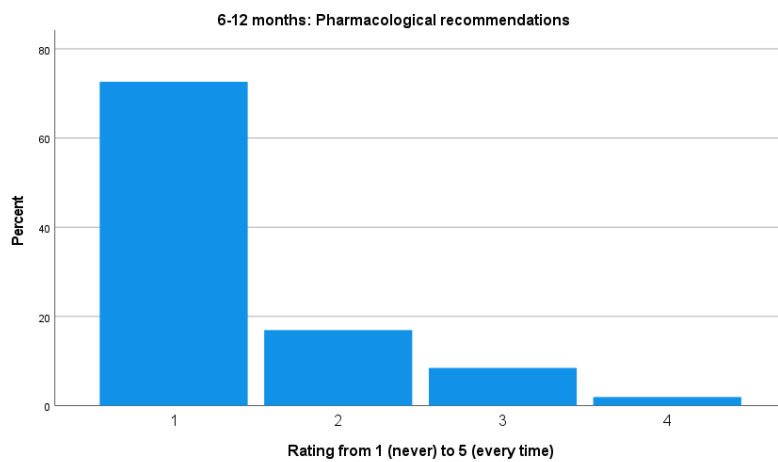


Figure 37. Bar chart for the likelihood of making a pharmacological recommendation for the 'six to 12 months' age range.

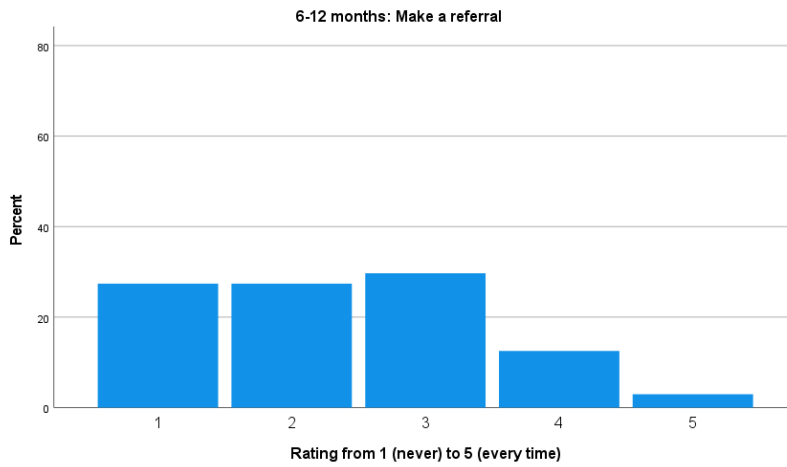


Figure 38. Bar chart for the likelihood of making a referral for the 'six to 12 months' age range.



Figure 39. Bar chart for the likelihood of advising that the problems will resolve over time, for the 'six to 12 months' age range.

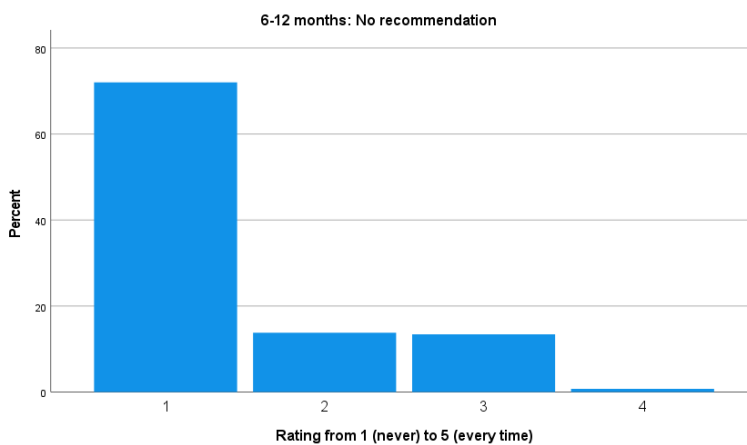


Figure 40. Bar chart for the likelihood of making no recommendations for the 'six to 12 months' age range.

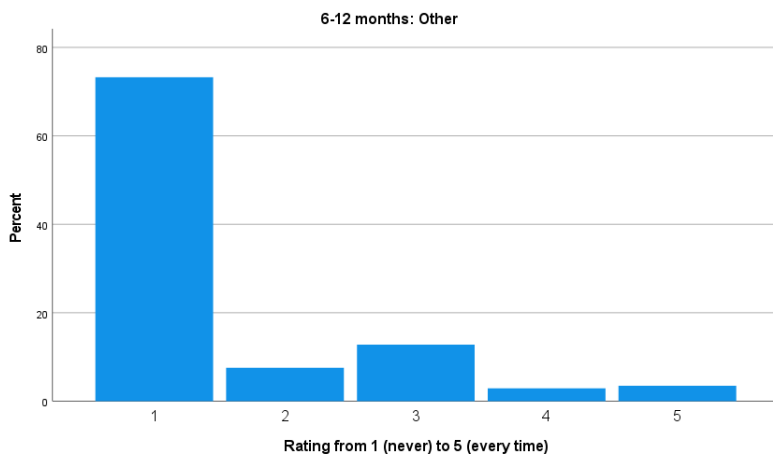


Figure 41. Bar chart for the likelihood of making another recommendation for the 'six to 12 months' age range.

5.4.3.3.3 '12 months to 5 years' age group

Positive routines again appeared the most likely recommendation, with 89.1% indicating they would likely recommend it most or all of the time, and with only 1.6% indicating they would never recommend it. The opposite pattern occurred for 'ignore the child', 'delayed bedtime' and pharmacological recommendations', with only 8.8%, 15% and 4.2% respectively indicating they would recommend them most or all of the time, but with higher percentages rating them as never. Controlled crying also followed the opposite pattern, but the percentage of ratings at the ends of the scales were not as extreme. Please see table 17 and Figures 42-52 (bar charts below) which illustrate the differences in data distribution for the one to five years age range.

The second most likely recommendation was 'extinction with parental presence', however the percentage of participants indicating they would recommend it most or all of the time was the same as 6-12 months (34.7%). Rather, the percentage of participants who indicated most or all of the time for 'advise that the problems will resolve over time' was this time lower than extinction with parental presence, at 26.9% (instead of slightly higher as in the previous age range).

Likelihood of other recommendations, such as scheduled awakening and referral also varied more (with 31.6% and 26.9% indicating they would recommend them most or all of the time, respectively).

Regarding extinction-based techniques, ignore the child remained less likely than controlled crying, which was less likely than extinction with parental presence, with 8.8%, 22.4% and 34.7% indicating they would recommend them most or all of the time, respectively.

Table 17. Likelihood of making individual recommendations for the '12 months to five years' age range

Recommendation	1 (Never) n(%)	2 n (%)	3 n (%)	4 n (%)	5 (Every time) n (%)	% who rated 4 or 5	Mean (SD)	Mode
Ignore the child / Cry it out / Extinction (n=308)	157 (51)	73 (23.7)	51 (16.6)	24 (7.8)	3 (1)	8.8	1.84 (1.03)	1
Controlled crying / graduated extinction / Ferber method (n=308)	87 (28.2)	78 (25.3)	74 (24)	57 (18.5)	12 (3.9)	22.4	2.44 (1.19)	1
Extinction with parental presence / gradual retreat (n=309)	42 (13.6)	64 (20.7)	96 (31.1)	83 (26.9)	24 (7.8)	34.7	2.94 (1.15)	3
Positive bedtime routine (n=310)	5 (1.6)	2 (0.6)	27 (8.7)	51 (16.5)	225 (72.6)	89.1	4.58 (0.81)	5
Scheduled awakenings (n=307)	112 (36.5)	44 (14.3)	54 (17.6)	41 (13.4)	56 (18.2)	31.6	2.63 (1.53)	1
Delayed bedtime (n=307)	106 (34.5)	78 (25.4)	77 (25.1)	39 (12.7)	7 (2.3)	15	2.23 (1.12)	1
Pharmacological recommendations (n=306)	166 (54.2)	84 (27.5)	43 (14.1)	12 (3.9)	1 (0.3)	4.2	1.69 (0.88)	1
Referral (n=305)	41 (13.4)	76 (24.9)	106 (34.8)	70 (23)	12 (3.9)	26.9	2.79 (1.07)	3
Advise that the problems will resolve over time (n=305)	48 (15.7)	74 (24.3)	101 (33.1)	56 (18.4)	26 (8.5)	26.9	2.8 (1.17)	3
No recommendation (n=261)	194 (74.3)	30 (11.5)	32 (12.3)	2 (0.8)	3 (1.1)	1.9	1.43 (0.82)	1

Recommendation	1 (Never) n(%)	2 n (%)	3 n (%)	4 n (%)	5 (Every time) n (%)	% who rated 4 or 5	Mean (SD)	Mode
Other (n=164)	123 (75)	8 (4.9)	23 (14)	5 (3)	5 (3)	6	1.54 (1.04)	1

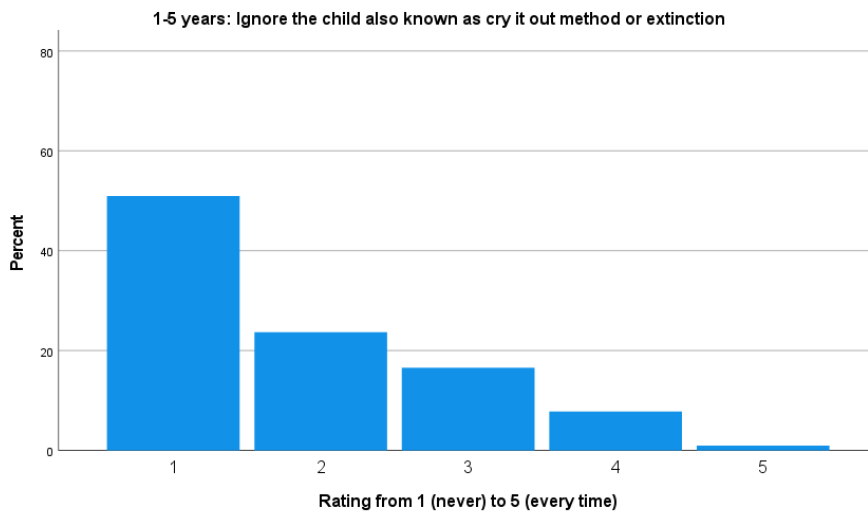


Figure 42. Bar chart for the likelihood of recommending cry it out for the '12 months to 5 years' age range.

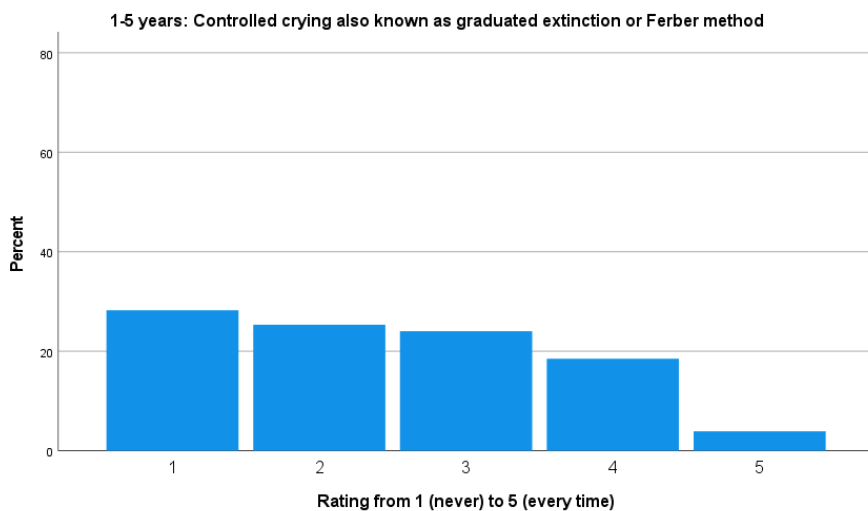


Figure 43. Bar chart for the likelihood of recommending graduated extinction for the '12 months to 5 years' age range.

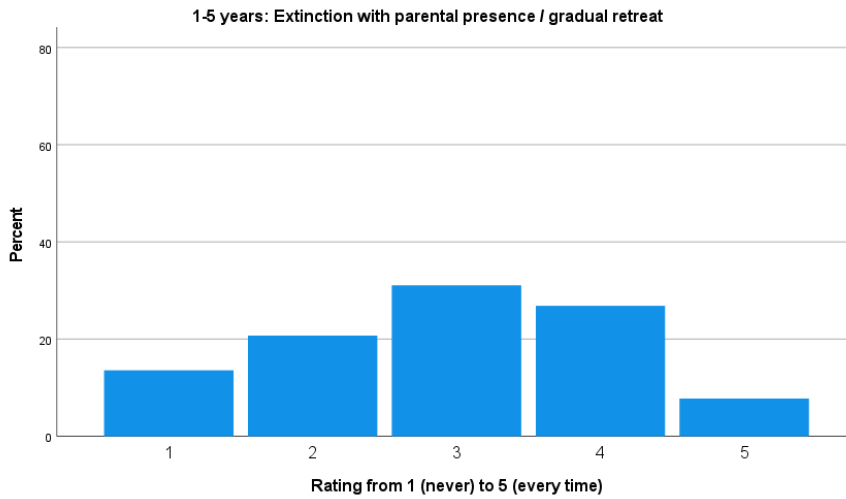


Figure 44. Bar chart for the likelihood of recommending extinction with parental presence for the '12 months to 5 years' age range.

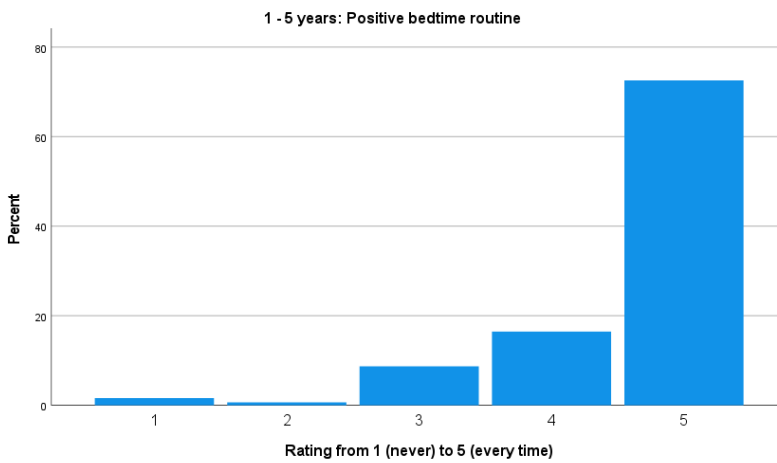


Figure 45. Bar chart for the likelihood of recommending positive bedtime routines for the '12 months to 5 years' age range

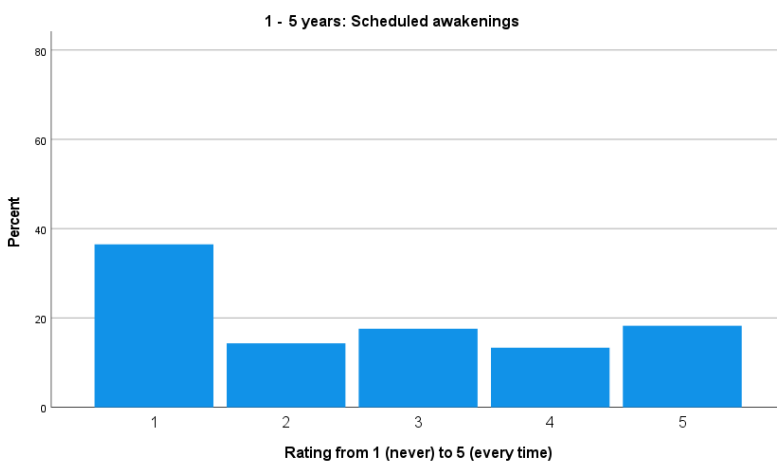


Figure 46. Bar chart for the likelihood of recommending scheduled awakenings for the '12 months to 5 years' age range.

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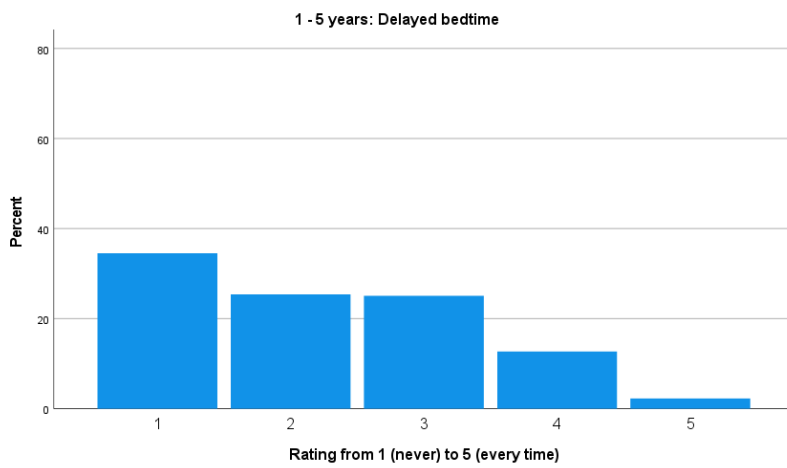


Figure 47. Bar chart for the likelihood of recommending a delayed bedtime for the '12 months to 5 years' age range.

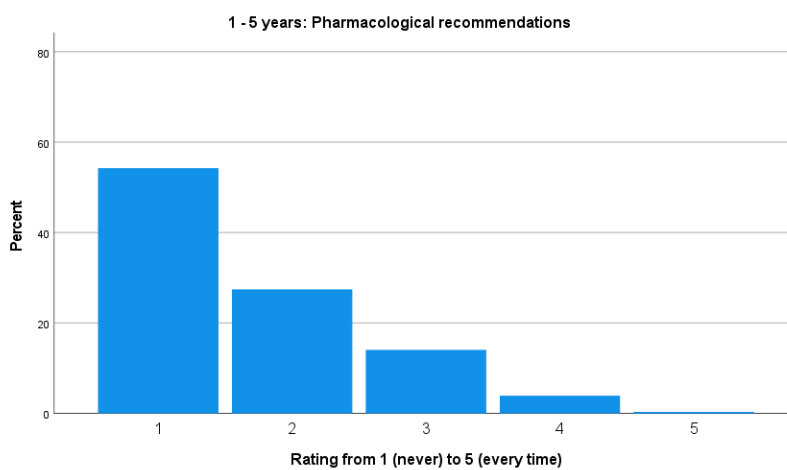


Figure 48. Bar chart for the likelihood of making a pharmacological recommendation for the '12 months to 5 years' age range.

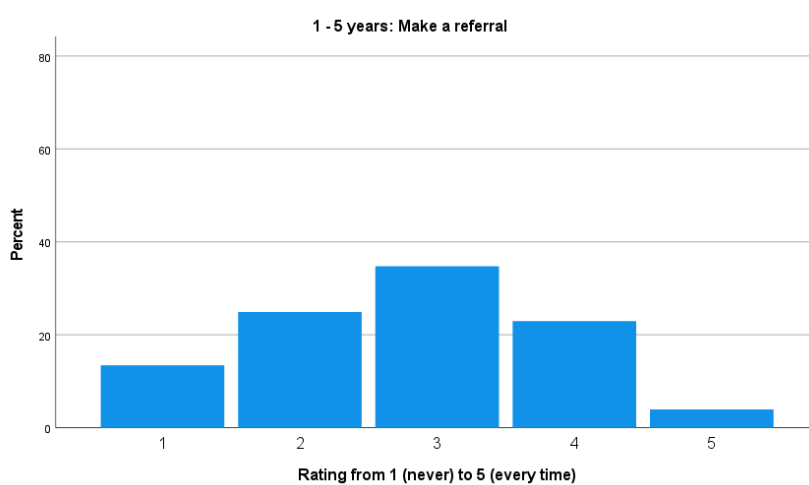


Figure 49. Bar chart for the likelihood of making a referral for the '12 months to 5 years' age range.

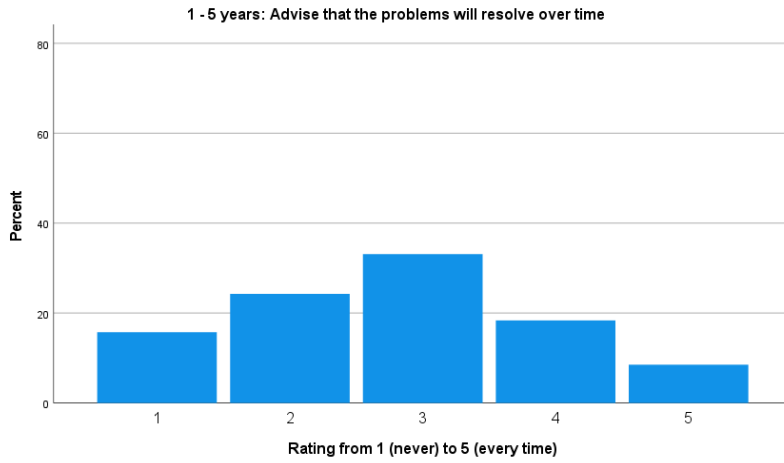


Figure 50. Bar chart for the likelihood of advising that the problems will resolve over time, for the '12 months to 5 years' age range.

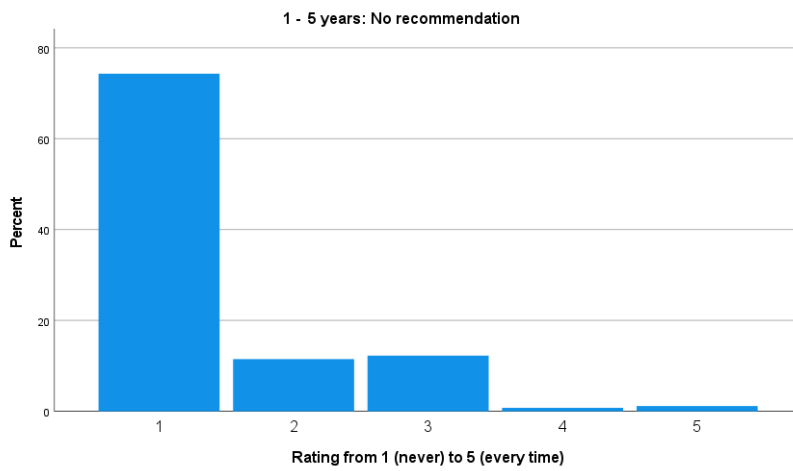


Figure 51. Bar chart for the likelihood of making no recommendation for the '12 months to 5 years' age range

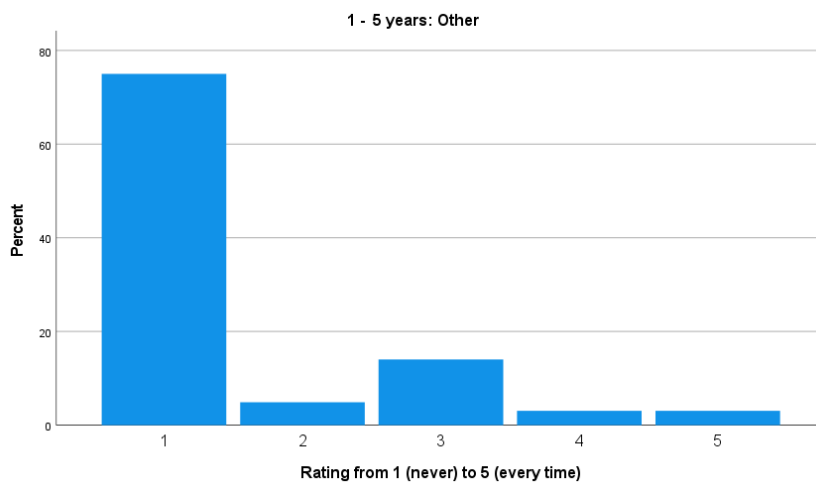


Figure 52. Bar chart for the likelihood of making another recommendation for the '12 months to 5 years' age range.

5.4.3.3.4 Similarities and differences between recommendations across age ranges

See Figure 53 for an illustration of the percentage of participants indicating they would make each recommendation most or all of the time, for each age group. However, it must be noted that although there are slight differences in percentages, they have not been tested for significance. In all age ranges the most popular recommendation was positive bedtime routines, with over 85% of participants indicating that they would make the recommendation most or all of the time (see Figure 48). On the other hand, for each other recommendation, less than 50% of participants indicated they would make the recommendation most of the time or every time.

Nearly half of the participants (46.9%) indicated that for the up to 6 months age group most of the time or every time, they would advise that the problems would resolve over time. This percentage was slightly lower as the age group became older (37.7% for 6-12 months, 26.9% for 1-5 years). This may be expected in view that it is considered normal for new-born and infants to wake frequently throughout the night (see Chapter One). It must be noted, however that despite the decrease, the percentage of participants who indicated they would advise this most or all of the time remained higher than for many other recommendations, even in the 6-12 months and 1-5 years age groups. Exceptions were for the 1-5 year age group, whereby the percentage of participants reporting most or all of the time for 'advise that the problems will resolve over time' (26.9%), became slightly lower than for extinction with parental presence (34.7%), and the same as 'make a referral' (26.9%).

Other recommendations such as controlled crying, extinction with parental presence, scheduled awakenings and referral slightly varied across age with 19.4% to 22.4%, 28.7% to 34.7%, 25.1% to 31.6% and 13.3% to 26.9% of participants respectively, indicating they would recommend them most or all of the time. The percentage of participants reporting most or all of the time for making a referral, scheduled awakenings and delayed bedtime also increased slightly with older age groups.

In each age group, pharmacological recommendations, 'no intervention', and 'cry it out' were consistently the least likely to be recommended with less than 10% indicating they would make the recommendation most or 'all of the time'. Because many participants indicated that they would 'never' give no recommendation across all ages, the data suggests that PCPs usually give a recommendation to help the parent.

Although extinction-based recommendations were much less likely recommended than positive bedtime routines, there were some differences between types of extinction technique. For all age ranges, a higher percentage of participants indicated they would likely recommend 'extinction

with parental presence' most or all of the time, than for controlled crying. Similarly, across all age ranges a higher percentage of participants indicated they would likely recommend controlled crying most or all of the time, than participants did for 'cry it out'. This suggests that 'extinction with parental presence' was more popular than 'controlled crying' which was more popular than 'cry it out', suggesting that participants preferred gentler extinction approaches.

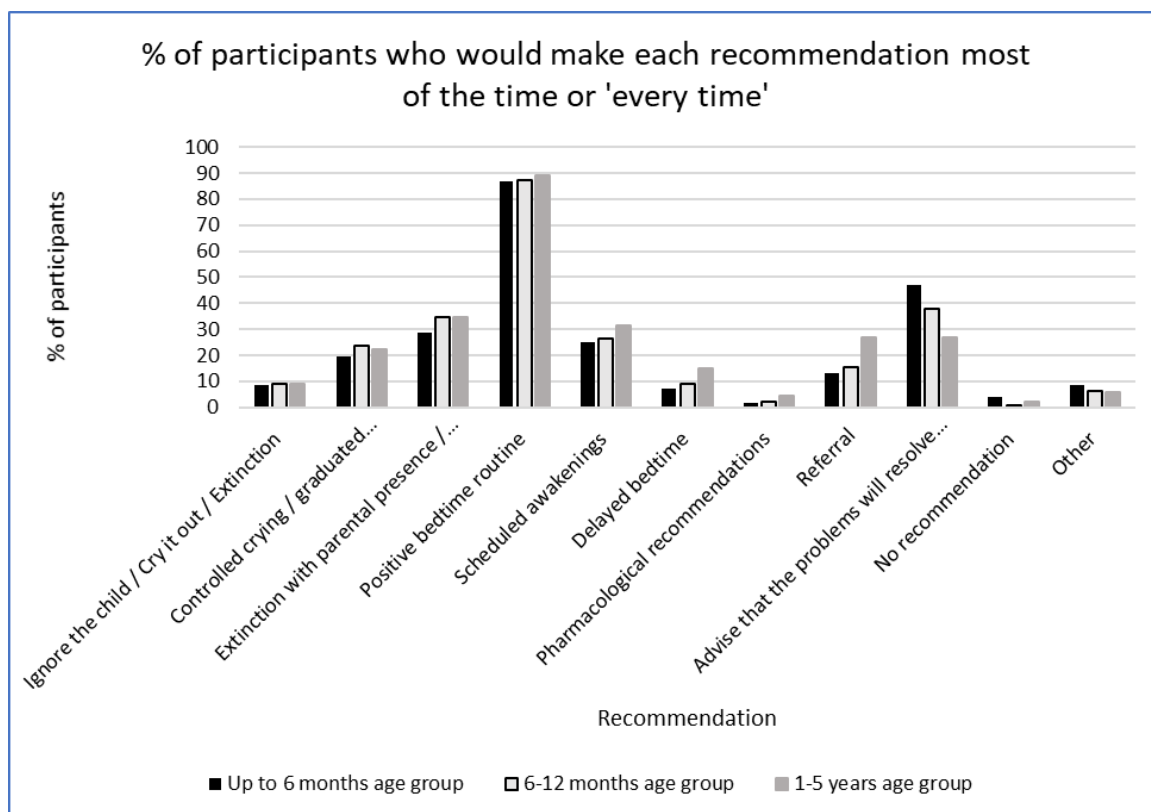


Figure 53. Percentage of participants who indicated they would likely make each recommendation most or all of the time, for each age group

5.4.3.4 Awareness of other resources

Participants were asked whether they were aware of any resources or sources of support/information for parents of children with chronic insomnia. Out of 309 responding participants, 96 (31.18%) said 'yes' and 213 (68.9%) said 'no'. It is concerning that nearly 70% of PCPs filling in this survey were not aware of other resources. Signposting to other resources could be a relatively simple way of managing this issue. Out of 95 of those who said 'yes', participants reported how often they would typically use the resources (please see Table 18). The most common responses were 'most of the time' (n=45, 47.48%) and 'in particular circumstances' (n=36, 37.9%).

Table 18. Frequency of the use of resources in discussion

N=95		
	N	%
All of the time	9	9.5
Most of the time	45	47.4
In particular circumstances	36	37.9
Rarely	4	4.2
N/A	1	1.1

5.4.3.5 Confidence in management

Using questions from a previous survey (Faruqui and colleagues 2011²¹⁷), participants were asked to rate their confidence levels about management, using a 5-point Likert scale from one (not confident) to five (very confident). Similar to previous research in other countries, the confidence levels varied. In this survey, average confidence levels were highest for advice about sleep hygiene (mean=3.36, SD = 1.07) which was still only just over a neutral score, with all other statements' average scores being below 3. The most common score for each statement was 3, indicating that many participants were neither confident nor unconfident, highlighting potential for improvement. Furthermore, confidence levels appeared to be higher for advising about sleep hygiene than the other management domains.

Table 19. PCP's confidence ratings for statements relating to the management of chronic insomnia in children. Statements from or adapted from Faruqui and colleagues (2011) ²¹⁷

	1 (not confident) n (%)	2	3	4	5 (very confident)	% who rated 4 or 5	Mean (SD)	Mode
Your ability to advise children (or their guardian)	20 (6.3)	41 (12.9)	108 (34)	104 (32.7)	45 (14.2)	46.9	3.36 (1.07)	3

about sleep hygiene (n=318)								
Your ability to motivate children to change their sleep behaviours (n=317)	52 (16.4)	101 (31.9)	113 (35.6)	41 (12.9)	10 (3.2)	16.1	2.55 (1.01)	3
Your ability to manage and refer children with chronic insomnia (n=316)	36 (11.4)	75 (23.7)	133 (42.1)	65 (20.6)	7 (2.2)	22.8	2.78 (0.97)	3
Your ability to conduct follow-up of the children's chronic insomnia (n=314)	48 (15.3)	89 (28.3)	115 (36.6)	57 (18.2)	5 (1.6)	19.8	2.62 (1.001)	3

5.4.4 Knowledge and training

5.4.4.1 Beliefs about professional teaching specific to paediatric chronic insomnia

Participants were asked whether they had received any professional teaching specific to chronic insomnia in children. 85% reported that they had not received any teaching during their medical education/ training and 79.6% reported having not been given an opportunity to receive teaching about this since their professional training. However, interestingly just over half of those who had received an opportunity for training since becoming a HCP, had not attended.

Just over half of the participants (52.9%) felt that they should have had sleep teaching (or more sleep teaching) specific to chronic insomnia, and 80.3% of participants said that given the chance to access sleep teaching opportunities, they would like to do so.

Table 20. Questions about professional teaching about chronic insomnia in children

	Yes – n (%)	No – n (%)	Not sure (somewhat) – n (%)
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During your medical education/ training to become a health professional, did you receive formal teaching specific to chronic insomnia in children? (n=316)	17 (5.4)	268 (84.8)	31 (9.8)
Since you completed training to become a health professional, have you had the opportunity to receive any teaching specific to paediatric chronic insomnia? (n=315)	43 (13.7)	249 (79)	23 (7.3)
Have you attended any of the opportunities? (n= 41)	14 (34.1)	21 (51.2)	6 (14.6)
Do you feel that you should have had any (or more) sleep teaching specific to chronic insomnia, when training to be a health professional? (n=314)	166 (52.9)	56 (17.8)	Somewhat: 92 (29.3)
If you had the chance now, would you like to access further sleep teaching opportunities about chronic insomnia in children? (n=315)	253 (80.3)	62 (19.7)	-

5.4.4.2 Sleep knowledge questions

Lastly, participants were given a series of statements relating to children's behavioural sleep and were asked to rate whether they thought they were True, False or that they did not know. These questions were taken from two previous validated surveys, sleep hygiene sub-scale within Mindell and colleagues' 'sleep survey' knowledge questionnaire²²² and related questions from Owen's PSS²²⁵, and therefore are presented within two separate tables below. Average scores were not calculated because it was felt to be more meaningful to focus on differences between questions.

Regarding the sleep hygiene questions (table 21), the percentage of participants scoring correctly for individual questions ranged from 26.5% to 75%, indicating that knowledge for the different statements varied. The questions which participants most often scored incorrectly or did not know the answer to were about letting an infant cry themselves to sleep and about rocking an infant back to sleep. The question most often answered correctly was about not allowing a child to sleep later in the morning, when they are having troubles sleeping at night.

Table 21. Sleep hygiene questions from Mindell and colleagues' 'Sleep Survey'²²²

Statement (correct answer whereby T=true and F=false)	Correct – N (%)	Incorrect – N (%)	Don't know – N (%)
Depriving a child of his/ her nap is effective in helping children to sleep at night (F) n=319	188 (58.9)	68 (21.3)	63 (19.7)
Sleep resistance and frequent night wakings in children are often highly amenable to behavioural techniques (T) n=317	217 (68.5)	39 (12.3)	61 (19.2)
Rocking an infant to sleep before placing him/her in the crib is likely to be an effective strategy to improve sleep (F) n=320	126 (39.4)	117 (36.6)	77 (24.1)
In general, infants should be allowed to cry themselves back to sleep (T) n=317	84 (26.5)	153 (48.3)	80 (25.2)
A child who regularly has trouble getting to sleep at night should be allowed to sleep later in the morning (F) n=320	240 (75)	19 (5.9)	61 (19.1)

Regarding the specific questions from Owens PSS, the percentage of participants scoring correctly ranged from 24.3% to 77%, again indicating that knowledge for the different statements varied. The question which appeared most difficult was about a establishing a temporary delayed bedtime.

Table 22. Relevant questions from Owens' PSS²²⁵

Statement (correct answer whereby T=true and F=false)	Correct – N (%)	Incorrect – N (%)	Don't know – N (%)
It is normal for school-aged children to take naps up to several times a week (F) n = 319	204 (63.9)	79 (24.8)	36 (11.3)
Breast fed babies usually sleep through the night at an earlier age than bottle-fed babies (F) n=318	206 (64.8)	36 (11.3)	76 (23.9)
Healthcare providers should not recommend temporary establishment of a later bedtime as an	77 (24.3)	136 (42.9)	104 (32.8)

intervention for a child with difficulty falling asleep (F) n=317			
It is normal for young children to awaken briefly during the night at the end of a sleep cycle (every 60-90 minutes) (T) n=318	245 (77)	25 (7.9)	48 (15.1)
“Learned hunger” resulting from frequent night feedings can lead to increased nocturnal awakenings in infants (T) n=319	201 (63)	36 (11.3)	82 (25.7)

5.5 Discussion

5.5.1 Summary of findings

This survey of 355 UK PCPs (primarily GPs) was the quantitative part of a mixed methods study, and explored PCPs views, understanding, training and current practice regarding the management of chronic insomnia in children aged five and under in primary healthcare. It also explored whether the PCPs have any unmet needs and interest in any types of support tool, for the management of chronic insomnia in children. It addressed five research questions and highlighted potential areas for further research within this field, but also suggestions for changes in practice. Each research aim and their findings are discussed in detail below.

5.5.1.1 Beliefs

The first research aim was to explore PCP views about chronic insomnia in children. Results suggested PCPs believe chronic insomnia to have an impact on all domains listed. In particular, percentages were high for psychosocial domains, with over 80% of participants reporting a large or major perceived impact, and the highest percentage being for ‘parental stress’ (94.4%). Percentages for other domains such as ‘general physical health’, ‘weight gain’ and ‘accidental injury’ were slightly lower (64.8%, 51% and 48%, respectively). These findings suggest that PCPs recognise that chronic insomnia impacts on multiple domains, but with stronger beliefs about impact on family and psychosocial domains. Statistical significance tests were not conducted within the scope of this thesis due to the exploratory nature of the survey and time focussed on qualitative analysis of the interviews. However, significance tests would be of value before publication.

These findings are similar to those of Owens²²⁵ and Faruqui and colleagues²¹⁷ who (although not specific to chronic insomnia) reported that US paediatricians perceived an impact on all domains,

with a slightly higher perceived impact for the psychosocial over general health/injury domains. Similarly, Mindell and colleagues (1994, US paediatricians)²²² and Bruni and colleagues (2004, Italian paediatricians)²¹¹ who used different questions also reported perceived impacts of insomnia on factors such as 'family happiness' (93.3% and 85.1%), 'parental depression' (77% and 46.73%) and 'parental work' (75.3% and 49.76%). Furthermore, these findings are in line with other research using similar rating scales for impacts of sleep problems (not specific to behavioural sleep problems/chronic insomnia) in Canadian and Australian HCPs (not specific to PCPs)^{236,237}.

80.3%, 67.7% and 61.1% of the PCPs in the current study agreed or strongly agreed that it is important to manage chronic insomnia in health care, in primary care, and in 'their practice', respectively. Although, the percentages differ slightly, they still suggested the PCPs believed that it should be managed in primary care. Furthermore, the personal definitions of 'primary care' and 'my practice' may have differed between participants, because this was not given in the survey. For example, some participants may not have considered HVs as part of primary care. Nevertheless, findings from the question asking participants to rank PCPs in terms of importance for the management of chronic insomnia in children suggested that the HV team were more often ranked of higher importance than GPs, GP practice nurses and nursery nurses. Differences between general practice and health visiting are explored in a qualitative analysis of interviews reported in Chapter Six.

A higher percentage of participants in the current study agreed or strongly agreed that chronic insomnia (described as behavioural in the beginning of the survey) should be managed with behavioural treatment (90.8%) than with pharmacological treatment (21.5%). This is in line with international guidelines that promote first-line behavioural treatment¹⁰¹ for chronic insomnia. In other research, views about pharmacological approaches seem to differ. Though not specific to chronic insomnia in children, 14.8% of Mindell and colleagues' sample of 183 US paediatricians²²² reported likely pharmacological recommendations whereas the percentage in Bruni and colleagues' sample of Italian paediatricians²¹¹ was 58.54% (most frequently antihistamines in Bruni and colleagues' study). Nevertheless, similar to this current study, a much higher percentage in Bruni and colleagues' sample of paediatricians (83.41%) reported recommendations for bedtime routines, suggesting a preference of behavioural management over pharmacological. However, the fact that 21.5% of participants in the current study agreed that it is important to use pharmacological approaches for chronic insomnia is worth further exploration as this does not align with the British National Formulary for Children (BNFC) which suggests that child settling problems should be managed with behavioural strategies, (unless the children have co-morbid conditions such as autism, behavioural measures are unsuccessful, and they are prescribed in

secondary care)^{100,102}. Potentially it could reflect different definitions of chronic insomnia and/or of the case mix seen by the PCPs in this survey. Further detail on what specific pharmacological treatments PCPs recommend, and under what circumstances would be valuable.

It is important to explore PCP beliefs about the management of chronic insomnia in children, because beliefs ultimately influence management. For example, the TPB^{166,167}, discussed in Chapter Two, suggests that attitudes are one of three factors which influence behaviour. Positive attitudes (underpinned by PCP beliefs about the impact of chronic insomnia, effectiveness of behavioural sleep interventions and the role of primary care in managing chronic insomnia) is likely to influence PCP's management.

5.5.1.2 Management

The third research aim was to explore PCPs' current practice regarding the management of children's chronic insomnia. Firstly, the current survey suggested that this issue is not commonly discussed in consultation, with 40.6% and 42.5% of participants reporting that it is discussed 'rarely' and 'sometimes', respectively. Honaker and Meltzer's narrative review of paediatric sleep problems (not specific to insomnia)¹³⁴ suggested that sleep is not often addressed in paediatric primary care. Considering the high prevalence of chronic insomnia / behavioural sleep problems in children, and potential unmet needs for parents (as discussed in Chapter Four), it would be beneficial to encourage PCPs to ask more about this issue. It must be noted, however, that the majority of participants in the current study were based in general practice (GPs, practice nurses etc) and the responses might have differed had there been a higher percentage of HVs or nursery nurses within the sample. This is explored in further detail within the interview findings in Chapter Six.

The current survey suggested that 'positive bedtime routines' is consistently the most preferred recommendation, with more than 85% of participants likely to recommend them most or all of the time, compared to under 50% of participants for any of the alternatives most or all of the time. It is important to note that other aspects of sleep hygiene were not included within the response options (see 5.5.3 for explanation and further discussion). Results also suggest that the PCPs were least likely to make pharmacological recommendations, no recommendation, or unmodified extinction with less than 10% indicating them most or all of the time. The questions for likely recommendations were adapted from similar research (format options from Owens²²⁵ and some response options from Mindell and colleagues²²²), so cannot be directly compared. Nevertheless, Mindell and colleagues²²² and Bruni and colleagues²¹¹ also reported that amongst US and Italian paediatricians the commonest recommendations were bedtime routines (95.1% and 83.4%, respectively), compared to cry it out (18.1% and 2.23%) and no intervention (3.3% and

6.7%). These findings echo parental dislike / uncertainty of extinction-based interventions ^{114,215}. Cook and colleagues ²¹⁵ reported that it was uncertain which techniques specifically parents disliked, but illustrative quotes from parents described 'cry it out' in a negative way.

Other recommendations in the current survey while individually recommended by fewer than 50% of respondents as most or all of the time, appeared more varied. Regarding extinction-based recommendations specifically, percentages were slightly higher for gradual retreat over graduated extinction, and slightly higher for graduated over unmodified extinction, suggesting that the PCPs preferred gentler extinction approaches. However, there would need to be further analysis to see whether the differences are statistically significant. This is consistent with other research whereby percentages of likelihood are higher for gentler extinction ^{211,222}. There appear to be cross-cultural differences in how physicians respond to these questions. For example, more US paediatricians would like recommended graduated extinction in Mindell and colleagues' study ²²² (84.6%) compared to only 35.57% of Italian paediatricians in Bruni and colleagues' study ²¹¹. Owens ²²⁵ also reported that in a 14-month-old with night waking, US paediatricians would likely recommend graduated extinction over other recommendations. No other research included gradual retreat as a response option. Gruber and colleagues ²³⁶ (97 Canadian HCPs) and Richardson and colleagues ²³⁷, (39 medical practitioners) though not specific to PCPs, also suggested preferences for graduated extinction (both studies) and in the case of the Gruber and colleagues study for 'positive reinforcement'.

The recommendation 'advise that the problem will resolve over time' appeared to differ by developmental stage. In the up to six months age group, nearly half of the participants (46.9%) said they would likely recommend this most or all of the time, followed by 37.7% for six to 12 months, and 26.9% for one to five years. As discussed in Chapter One, more variable sleep patterns are expected in younger infants and there are developmental changes in sleep/wake cycles in the first five years, so this decrease with age may be appropriate. However, the survey findings would need further testing to see if they are statistically significant. These findings are similar to previous studies. For example nearly 50% of US paediatricians in Mindell and colleagues' study ²²² would usually or always say the children would outgrow the problem. 77.89% of Italian paediatricians in Bruni and colleagues' study ²¹¹ also reported 'usually' or 'always'. Natural development of chronic insomnia in children is discussed more in Chapter Seven.

Nearly 70% of PCPs reported that they were not aware of other resources or sources of support for parents of children with chronic insomnia. There are many existing evidence-based resources online such as NHS (e.g. NHS Choices ²⁵²⁻²⁵⁴, and 0-18 Healthier Together ^{255,256}) and non-NHS websites (from evidence-based organisations such as babysleep.com ²⁵⁷ and Cry-sis ²⁵⁸).

Signposting to resources such as these could be an effective and straightforward option for PCPs who are time-limited in consultations. The lack of awareness and signposting to these resources is of concern and should be a priority in future research and training. These findings are different to a US qualitative study⁷³ which suggested that US PCPs recommend various resources to parents, such as educational materials. Resources seemed to be both formal and informal resources.

Finally, participants reported on their confidence levels for managing chronic insomnia. On a rating from one (not confident) to five (very confident), the commonest response was three, for all aspects of management, with some other ratings above and below. This suggests that participants were usually neither unconfident nor confident, and that confidence also varied. Similarly, Faruqui and colleagues²¹⁷, who created the confidence statements used in this survey, reported that less than 15% of their sample of US paediatricians were very confident on any statement, although some of the confidence statements in Faruqui's study were not specific to chronic insomnia. Mindell and Owens (2003)¹³⁵ surveyed US paediatric nurse practitioners and reported that average confidence ratings for managing night wakings, bedtime problems and insufficient sleep (with the same rating options), were 3.8, 3.7 and 3.3 respectively. Confidence was also reported as low in other studies with different questions (not specific to chronic insomnia), whereby less than 10% of Turkish paediatricians¹³⁷ and only 25% of US paediatricians²²⁵ reported they were confident to manage sleep problems. All of these findings suggest that PCP's confidence levels could be improved. As self-efficacy theory (described in Chapter Two) suggests, improving PCP confidence would improve their self-efficacy which would influence their management of chronic insomnia in consultations.

5.5.1.3 Training/knowledge

The second research aim was to understand what PCPs currently know about childhood chronic insomnia and how much formal education they have received. The fourth and fifth research aims were to explore perceived PCP unmet needs regarding managing children's chronic insomnia, and whether there are any types of support tool that PCPs would find helpful. Results suggested that 84.8% and 79% had received no formal teaching during, or training opportunities since HCP training, respectively. 80.3% of participants reported that given the chance, they would like further access to teaching opportunities. This suggested that PCPs may have unmet training needs regarding the management of chronic insomnia in children, however types of training need further exploration. This is discussed more in the interview findings in Chapter Six.

These findings are similar to those of other research reporting PCP training deficits in this field. Mindell and Owens (2003)¹³⁵ reported that 67% of US paediatric nurse practitioners reported no teaching about paediatric sleep disorders, but that 92% were interested in further teaching. Ersu

and colleagues¹³⁷ reported that 80 to 82% of Turkish paediatricians sampled had received no training on sleep problems in children. Neither of these studies were specific to chronic insomnia in children, rather related more broadly to sleep problems but, given the high prevalence of chronic insomnia amongst children's sleep problems, it is likely that the findings also imply a lack of training in chronic insomnia.

Finally, participants were asked a series of relevant true/false/don't know questions from Mindell and colleagues' 'Sleep Survey' knowledge questionnaire²²² and Owens' PSS²²⁵. Percentages of PCPs who scored correctly varied for each question ranging from 24.3% to 77%. Problematic questions related to infants' being able to cry themselves to sleep, rocking an infant to sleep and temporary delayed bedtime. Although average scores were not calculated, the findings support previous research that suggests PCP knowledge varies. Rocking to sleep was also a problematic question in Bruni and colleagues' study, and these survey findings are similar to those in Ersu and colleagues' study¹³⁷, where the percentage of Turkish paediatricians scoring correctly ranged from 40% to 66%. Although not directly comparable with current findings, Bruni and colleagues and Mindell and colleagues, who used the same sleep hygiene subscale suggested varying PCP knowledge with average scores of 73.5% for US paediatricians (Mindell and colleagues) and 57.89% for Italian paediatricians (Bruni and colleagues).

Reports of varied knowledge scores, minimal professional training about chronic insomnia in children, and an interest in future training opportunities all suggest that further training opportunities and increase of knowledge about this issue would be beneficial. According to self-efficacy theory discussed in Chapter Two, this would also increase their PCPs 'capability' in management thereby influencing their self-efficacy / confidence which influence their behaviour.

5.5.2 Implications

This research study has several implications for both further research and practice. Firstly, there is a need to develop and offer training opportunities or resources for PCPs. Suitable training opportunities/resources could be brief e-modules which PCPs can complete at a time and place suitable to them, or training resources which can be given to PCPs to also update them on the latest evidence and guidelines. Moreover, PCPs' awareness of existing evidence-based resources for parents need to be increased so that they can signpost to them confidently. It is interesting that nearly 70% of participants were not aware of other resources, particularly because the sampling method meant that these PCPs would have chosen to take part in this survey and perhaps had a higher interest in this topic. To increase this awareness of resources, they could be

included in subsequent training opportunities for PCPs, or further research can be undertaken to increase the awareness and accessibility of resources alone.

Further, because chronic insomnia is common in children, but rarely presents to GPs, an increased awareness for both PCPs and parents that chronic insomnia can be consulted about in primary care, even if this is just for signposting elsewhere would be of benefit. It would be beneficial to encourage PCPs to opportunistically ask about this issue more during current primary care contacts.

It would be beneficial to conduct further surveys with more HVs and community-based PCPs (most participants in this survey were GPs). It would also be beneficial to explore the role perceptions and differences between types of PCP, particularly between general practices staff and HVs. There were some unexpected findings regarding some participants who reported that parents and HVs were less important for the management of chronic insomnia and this should be explored further. The interviews (Chapter Six) give more in-depth views and experiences on role perceptions.

5.5.3 Strengths and limitations

This was the first study to survey UK PCPs about their beliefs, knowledge, and current practice regarding the management of chronic insomnia in young children in primary care. Therefore, it provides novel research findings about UK PCPs, specifically GPs, management of chronic insomnia which was lacking in previously published research.

An important limitation is that the proportion of community PCPs in this sample was small and most survey participants were GPs, thereby limiting generalisability of the survey findings to GPs in general practice. Surveys including more HVs and other community PCPs in the future would be beneficial. It is also difficult to be sure of the representativeness of the sample to all PCPs. The sampling method for this survey – whilst effective to achieve desired response rate – risked sampling bias, as it may have attracted individual PCPs who were more interested and/or knowledgeable in this topic. For example, most of the survey participants had personal experience of caring for children in this age group. Nevertheless, the overall sample in this study was large and from multiple regions in England, thereby providing a broad range of views from different settings to inform research findings.

Another limitation, as with much survey research, is that some questions and response options may have been interpreted differently by participants. For example, a definition of chronic insomnia in otherwise healthy children was given at the beginning of the survey, however a

definition of primary care was not. Primary care may have been interpreted differently by participants in the questions about the suitability of managing chronic insomnia in primary care (e.g. some GPs may not have included HVs within this question). With more time and capacity, it would have been beneficial to formally conduct validation analyses on the survey used in this study. Nevertheless, many of the survey questions were either from validated sleep surveys published in the literature, or adapted from them. This also enabled some comparisons to findings with similar research in other countries. Moreover, some questions were adapted to give further detail than previous research.

There were also some other limitations of the survey worth noting. Chronic insomnia was described at the beginning of the survey as insomnia due to behavioural reasons. The definition was designed to exclude responses based on treatment of insomnia in children with co-morbid conditions. On reflection, this could have potentially biased participants responses towards reporting a preference for behavioural management approaches e.g. framing/leading bias ²⁵⁹.

Regarding the question about likely recommendations, although participants reported their likelihood of making individual recommendations for different age ranges, further information is needed to understand whether these responses reflect their personally preferred approaches, or what they would usually recommend after a discussion with parents, in other words reflecting their experiences of parent preference. Therefore, their responses could equally be due to their perceptions of what parents prefer (see Chapter Six for further discussion on an individualised approach to management, based on the qualitative interview findings).

There are other aspects of practice in relation to the management of children's chronic insomnia which could have been included within the likely recommendations question (e.g. changing sleep and wake routine, napping routine, feeding routine, and other aspects of sleep hygiene, or sleep hygiene more broadly instead of, or as well as 'positive bedtime routines'). These aspects may be more commonly discussed by PCPs and may have been more likely to be recommended. This is a complex area where many different recommendations can be given and this may depend on a variety of child/family circumstances and preferences. However, quantitative methods are limited by using closed categorical data collection methods. It was deemed important to keep the survey as brief as possible to achieve an adequate number of respondents and completion rates.

Bedtime routines is a category commonly captured in the literature ^{73,210,211,216,220-222,224,227} and the question as it was designed provides some informative data regarding differences between other types of behavioural intervention, and positive bedtime routines (an important aspect of sleep hygiene). It is therefore important to consider these quantitative findings alongside qualitative findings (whereby participants responses to likely recommendations are not limited to closed

categories) to adequately capture PCP practice. Therefore, a pragmatic decision was made to only include these response options, due to the planned in-depth qualitative interviews that were to follow. Qualitative findings in Chapter Six not only suggested that participants would recommend bedtime routines, but they also described other aspects of sleep hygiene such as environment and caffeine intake.

Lastly, regarding the question that asks participants about their confidence in following up, it is not certain whether participants' responses were due to their perceptions of their own ability (e.g. knowledge/training) or whether this was perceived as due to other reasons such as time constraints. Although this question was mostly taken from a previously validated survey, it would be useful to clarify the reasons for their perceived confidence. This is explored further in qualitative findings in Chapter Six. On reflection, given the developmental differences in sleep/wake patterns in infants and children up to the age of five (discussed in Chapter One) and the differences for different age ranges in who initiates discussion / advises that the problems will resolve over time, it would also be useful to have asked participants about their confidence levels in relation to advising about management for different age ranges. For example, they may have more confidence for younger babies where more night wakings are expected, than preschool age children.

The self-report nature of survey research means that there was potential for confirmation bias whereby PCPs may have felt obliged to answer one way over another. However, the possibility of keeping the survey anonymous also may have meant that the PCPs were more likely to share information which they may not have shared in an interview.

It would also be useful to further explore individual differences such as between types of PCP, and genders, and to test whether there were significant differences between likely recommendations for different age groups. Tests to be conducted would be Mann Whitney U, Kruskal-Wallis and regression analyses. These were not conducted for this thesis because the focus of the survey was to explore this topic broadly, rather than any specific hypothesis testing and numbers of participating HV were too small for subgroup analysis. Some of these tests will be carried out prior to publication. Similarly, the qualitative analysis of the free text responses was also beyond the scope of this thesis. They were designed to give an idea of any further views or recommendations which had not been included in the survey responses. Most of them have already been further explored in the qualitative analysis of interviews reported in Chapter Six but a qualitative analysis of the free text responses will be conducted at a later date prior to publication.

5.5.4 Conclusions

This study suggested that PCPs (particularly UK general practice HCPs) perceive an impact of chronic insomnia on many domains for children and believe it should be addressed in healthcare, and generally in primary care. PCP's reported that they infrequently experience consultations specifically about chronic insomnia in children aged 0-5 yrs. When they do, they would most likely recommend positive bedtime routines, and least likely recommend unmodified extinction and pharmacological treatment. Most PCP's reported having received no or minimal formal teaching about childhood insomnia during or since professional training. Knowledge and confidence around the management of these problems varied. PCP's had low awareness of sleep management resources.

Further research is needed to explore role differences within different types of PCPs and to inform the design of suitable learning materials for PCPs who wish to undertake further training and improve their awareness of resources to signpost to parents.

Chapter 6 Qualitative Interviews of Primary Care Providers' Views, Understanding and Current Practice Regarding the Management of Paediatric Chronic Insomnia in Primary Care

6.1 Overview

This chapter presents the qualitative findings from the third empirical study of this thesis, a mixed-methods study of online surveys and qualitative interviews with UK-practicing PCPs regarding the management of paediatric chronic insomnia. This qualitative aspect of the mixed-methods study was designed to gather richer in-depth data to further explore the topics in the online survey.

6.2 Introduction

6.2.1 Background and rationale

As discussed in the background within Chapter Five, previous research, and the systematic review reported in Chapter Three, suggest that despite perceiving the management of chronic insomnia in children as part of their role, believing an impact of chronic insomnia, and generally endorsing behavioural management of chronic insomnia, PCPs have varied knowledge and confidence in management. The findings were to be treated cautiously because included studies were from various countries and limited primary care settings. Specifically, there was minimal up to date research including GPs and UK HVs. An internet forum study of parent perceptions, reported in Chapter Four, suggested that parents have unmet needs regarding management of their children's sleep. Only a small proportion of the data related to management within primary care and suggested mixed experiences with HVs and limited experiences with GPs. Therefore, there was a need for contemporary good quality research exploring the management of children's chronic insomnia in UK primary care.

A mixed-methods study, the third empirical study within this thesis, addressed this gap in the literature by surveying and interviewing UK PCPs about the management of children up to the age of five years. Chapter Five reported on the survey findings of more than 350 UK PCPs. It suggested that PCPs are aware of the impacts of chronic insomnia and believe it should be managed in

Chapter 6

healthcare, but that chronic insomnia in children is infrequently discussed in primary care consultations. Further, that likely recommendations would be positive bedtime routines, and that PCPs have varied knowledge, varied confidence relating to management of chronic insomnia, and an interest in further training and resources. However, the majority of survey participants were GPs, with few community PCPs, making interpretation of findings for PCP subgroups difficult.

This chapter reports on the qualitative aspect of this mixed methods study, qualitative interviews of UK PCPs. Whilst exploring the same areas as the survey, the interviews gathered richer data and explored topics such as role differences, explanations and context to survey findings, and further information regarding any unmet PCP needs.

6.2.2 Aims and research questions

The aims and research questions for the qualitative aspect of this mixed-methods study were the same as those for the online survey:

1. To explore PCP views about chronic insomnia in children.
2. To understand what PCPs currently know about chronic insomnia in children, and how much formal education they have received on the topic during (and since) training.
3. To explore PCPs' current practice regarding management of children's chronic insomnia.
4. To explore perceived PCP unmet needs regarding managing children's chronic insomnia.
5. To find out whether there are any particular types of support tool that PCPs would like, to manage children's chronic insomnia.

6.3 Methods

6.3.1 Design and sample

A mixed-methods study involving an online survey and in-depth qualitative interviews with a subset of participants. This chapter reports the qualitative aspect of the study and the triangulation between the survey and qualitative findings. Please see Chapter Five for the survey methods and findings.

6.3.2 Ethics approval

As stated in Chapter Five, this study was reviewed and approved both by the University of Southampton Research Governance Office (RGO ref 53955), and by the Health Research Authority (HRA, IRAS ref 277619). A research passport and letter of access was also acquired.

6.3.3 Study setting

It was initially planned that interviews would be face-to-face with participants taking part at their home, at their office for work, at the university or over the telephone. However, due to the Covid-19 pandemic, all interviews took place remotely via Microsoft Teams.

6.3.4 Sample and recruitment

6.3.4.1 Eligibility criteria

UK-practicing PCPs (or community PCPs) who had taken part in the online survey. Please see Chapter Five for full eligibility criteria.

6.3.4.2 Sample size

It was aimed to recruit 15-30 interview participants, or until data saturation²⁶⁰ was achieved. It is also recommended that for a PhD project with thematic analysis of interviews as part of a larger study, 15-20 interviews are sufficient¹⁸².

6.3.4.3 Recruitment and sampling technique

Please see Chapter Five for details of recruitment of the survey participants. At the end of the online survey, participants were invited to take part in this interview study (also briefly mentioned in the survey participant information sheet). The researcher's contact details were provided and if the participant was interested in finding more about the interview, they were prompted to contact the researcher directly, or enter their email address in the survey to express an interest. The researcher then contacted people who expressed an interest, providing further details about the interviews so that they could decide if they would like to take part.

Purposive sampling was used to select participants for interview (sampling on gender, type of practice such as general practice or community practice, region of practice and ethnicity). Specifically, towards the end of data collection, male participants and HV PCPs were purposively sampled as they were underrepresented. Snowballing sampling was also added as an amendment shortly after data collection began, so that interview participants could pass on details of the

survey and/or interview to others who may have been interested in taking part. No expressions of interest for the interview only were received.

6.3.4.3.1 Consent

People who expressed an interest were sent an interview participant information sheet (see appendix C.3.4) and consent form (see appendix C.3.5) to read and complete before the interview took place. Because participants took part in the interviews remotely, they signed and scanned the consent form before the interview took place. In light of the covid-19 pandemic, participants were able to sign the form electronically if they were unable to print it, so long as the consent statements were reread at the beginning of the interview.

6.3.5 Data collection

Qualitative data collection started in September 2020 and finished in February 2021. The interviews were semi-structured and audio recorded. It was initially planned to conduct many of the interviews face-to-face (home, university or place of work), with the option of a telephone interview instead due to the busy nature of HCPs' work schedules. However, due to the coronavirus disruption, all interviews took place remotely.

The semi-structured topic guide was developed in supervisory meetings and was pilot tested with a HV and school nurse, prior to the start of data collection. See Appendix C.3.6 for the HRA approved version of the topic guide. It contained open ended questions which asked about views, current practice, knowledge and training. The questions were similar to those of the online survey but were designed to gather more in-depth data. General and question-specific prompts in the guide further enabled the collection of rich data. Transcribed verbatim, the data were uploaded into NVivo for analysis. At the end of the interview, the participants were given a debrief statement (see appendix C.3.7).

6.3.6 Data analysis

As described in Chapter Four, the qualitative data analysis was originally planned to be based on methods for reflexive thematic analysis^{182,188,189} because it is theoretically flexible. As also already described in Chapter Four, a qualitative descriptive analysis (as described by Sandelowski, 2000¹⁹⁸) of a large data set resulted, to enable a more data-driven descriptive summary of the topic, presenting summaries of PCPs perceptions and experiences in relation to the research questions, as descriptive themes. Transcripts were read and re-read, data were coded descriptively in NVivo and a codebook created to organise the codes into descriptive themes and subthemes. The codes,

codebook, themes and subthemes were developed in discussion within supervisors. Analysis began whilst interviews were still in process, allowing the interview guide to be adapted according to emerging findings.

6.3.6.1 Triangulation of findings

The overall mixed-methods study was of a convergent parallel study design, whereby the surveys and interviews underwent data collection and analysis independently, before being compared to one another with triangulation (²⁶¹ as cited in ¹⁹³). To compare the qualitative and quantitative findings, they were triangulated based on the methods for the triangulation protocol outlined by Farmer and colleagues²⁴⁸, suitable for mixed-methods studies²⁶². To do this, a table was created (please see Appendix C.5) to compare the quantitative and qualitative findings to see how much they agreed with one another, and whether there were any disagreements, or findings which appeared in one part of the study, but not the other. Within the table, qualitative and quantitative findings were compared in relation to 'contextual themes' within each research aim. It was then decided whether the findings were in agreement, partial agreement, silence (whereby one presents findings that were not present in the other), or disagreement (conflicting findings)²⁴⁸.

6.3.7 PPIE

The first PPI contact for this thesis commented on the plans for this mixed-methods study prior to the design of study documentation. Comments and their influence on study design are detailed in Chapter Five, section 5.3.7).

Three other PPI contributors commented on the emerging themes. PPI confirmed that the themes and codes made sense and perceived them to be in the correct places. In particular, the distinction between types of extinction method were deemed important. One of the contributors suggested some wording changes to the name of some themes or terms to make them clearer. Where feasible, the changes were implemented. One stated that parents may not be as interested in the perceived role differences between types of PCP but more interested in the help they get from whoever they approach. Perceived roles were kept because findings from Chapter Five suggested there may be differences between PCPs, and investigating role differences could help improve management in the future.

6.4 Results

6.4.1 Sample characteristics

Over 100 out of 357 survey participants expressed an interest in the interview. 21 interviews were conducted. Most participants were female (85.7%). Most were GPs (85.7%) and participants had an average of 12 years' experience practicing in a primary care/community setting. All but one participant had personal experience of caring for children aged 5 or under. See Table 23.

These characteristics were similar to those of the survey demographics, whereby more survey participants were female GPs and most had personal experience caring for children aged five and under. However, although there were still fewer HV than GP participants, the percentage was higher in the interview sample (14.3%) than the survey sample (1.7%).

Table 23. Interview participant demographics.

		N (%) or Mean (SD)	SD	Median	Range
Age		41.11	8.62	42	25-58
Gender	Male	3 (14.3)			
	Female	18 (85.7)			
Ethnicity	White British	14 (66.7)			
	Asian or Asian British: Indian	3 (14.3)			
	White Irish	1 (4.8)			
	Asian or Asian British: Pakistani	1 (4.8)			
	White & Asian	1 (4.8)			
	Not specified	1 (4.8)			
Setting	Primary care	18 (85.7)			

	Community	3 (14.3)			
PCP	GP	18 (85.7)			
	HV	3 (14.3)			
Years since qualified		16.43	8.98	14	1-35
Years in primary care/community		12.19	8.03	12	1-29
Personal experience of caring for children aged 5 or under		20 (95.2)			

6.4.2 Themes and subthemes

Seven overarching themes were developed from the data (see Table 24). The themes and subthemes are described, with example quotes from participants. Participant details such as gender are not presented with the quotes to ensure that they are not identifiable. Due to the low number of HVs who participated, HV quotes are not included in this chapter to protect identity, however their data were included in the analysis. Please see Appendix C.4.1 and Appendix C.4.2 for a detailed overview and the full coding manual, respectively.

Table 24 Overview of themes and subthemes

Over-arching theme	Sub-themes
1. Attitudes and views about the importance of sleep problems	View that sleep problems are common in children
	Views about multiple impacts of poor sleep on the family
	Perceptions about causal factors of sleep problems
	Emphasis on the importance of sleep
	Subjectivity around defining sleep problems
	Normalisation of some sleep problems
	Viewing poor sleep as a complex issue
	Perceptions of parent's reluctance to consult in general practice

2. Chronic insomnia is infrequently a primary reason for consulting in general practice	Chronic insomnia is rarely consulted as a single problem in general practice
	Perceived limitations of health services
	Views about missed opportunities to discuss sleep problems in primary care
3. Views and experiences of advice and recommendations	Signposting in general practice
	Advising about basic advice, bedtime routines and other components of sleep hygiene
	Assessing the situation
	Beliefs supporting an individualised approach to management
	Views and recommendations about specific strategies
	Emotional support and management of the impact on parents
	Awareness of non-healthcare resources
	Follow-ups in health visiting
	Mixed views about referral and secondary care
4. Views regarding roles of different PCPs in the management of chronic insomnia in children	Perception that primary care should address chronic insomnia
	Perception that HVs or community support are more suited to management
	Mixed views around the role of general practice
5. Limited professional training and knowledge regarding chronic insomnia in children	GPs receive minimal or no professional training about paediatric chronic insomnia
	Specialised training options for HVs
	GPs perceive limited or varied knowledge for management
	Knowledge from practical experience
	Interest for information resources

	Interest in future professional training
	Uncertainty in usefulness of further professional training
6. Perceived self-efficacy for managing chronic insomnia in children	Mixed confidence levels
	Perceived barriers to managing sleep problems in consultation
	Positive feelings towards the consultation
7. The influence of the personal experience of being a parent	Personal experiences influence feelings and attitudes
	Knowledge acquired through personal experience rather than professional training
	Usefulness of discussing personal experience in consultation

6.4.2.1 Theme 1: Attitudes and views about the importance of sleep problems

The over-arching theme ‘attitudes and views about the importance of sleep problems’ highlighted that all participants viewed good sleep as important and viewed that it is important that poor sleep in children is improved. Seven sub-themes were developed. For brevity, some sub-themes here are not presented with illustrative quotes, but can be viewed in the coding manual (appendix C.4.2).

6.4.2.1.1 Sub-theme 1.1: Views that sleep problems are common in children

Participants (GPs and HVs) perceived sleep problems as a common problem in young children, however, this was not necessarily described in a professional context. For example, some participants simply described it as a common childhood problem, some also described that it may be more common than it is seen in a professional (GP) context, and some participants described they perceived it as a common problem from personal experiences.

6.4.2.1.2 Sub-theme 1.2: Views about multiple impacts of poor sleep on the family

All participants described an impact of poor childhood sleep problems. Impacts were described in various ways, including an impact on the health and development of the children, but also a particular impact on the family.

6.4.2.1.3 Sub-theme 1.3: Perceptions about causal factors of sleep problems

Often participants (GPs and HVs) discussed potential causes of sleep problems, or factors which contribute to or maintain sleep problems. These included parent-driven factors (e.g. settling/feeding methods, parental mental health, routine), environmental factors (including social support), or potential underlying acute illness (e.g. reflux). Some described the impact of the coronavirus pandemic as a contributing factor to poor sleep, or poor sleep habits (e.g. change in routine or social support).

6.4.2.1.4 Sub-theme 1.4: Emphasis on the importance of sleep

Many participants (GPs and HVs) described the view that good sleep is important and that it is important to improve poor sleep in children, although the importance of addressing poor sleep in children was not necessarily discussed within a professional context. Two GP participants described that within primary care, it is important, but not necessarily as important as other problems that are presented to a GP. For example, *“it’s important as an issue, but as a healthcare problem, I’d probably put it lower down than – than some other – problems which I would consider to be more, strictly speaking, medical problems, if that makes sense”* (participant 91, GP). One HV participant described that in their practice, it was as important as other problems.

6.4.2.1.5 Sub-theme 1.5: Subjectivity around defining sleep problems

There appeared to be various perceptions around defining and labelling of sleep problems. Often, it was described as a problem (GPs and a HV) if there are negative impacts resulting from it. For example, *“what’s a problem with one person, really isn’t necessarily a problem for another one”* (participant 93, GP). Some GPs and a HV described their perception that perception of sleep problems can be influenced by familial, societal, or cultural expectations which can result in the over or under estimation of sleep problems. A small number of GPs talked about their reluctance to label sleep problems as a medical problem.

6.4.2.1.6 Sub-theme 1.6: Normalisation of some sleep problems

Despite viewing sleep problems as an issue that needs to be addressed, some participants (some GPs, one HV) described that childhood sleep problems are normal and/or that some generally do sleep better, without distinction of the differences between good and poor sleepers (e.g. siblings brought up in the same way). For example, *“some children naturally will sleep really well from early on, but others, it takes – it’s like a learned behaviour and it will get better with time, but it’s important to persist”* (participant 87, GP).

6.4.2.1.7 Sub-theme 1.7: Viewing poor sleep as a complex issue

Finally, some participants (GPs and HVs) described the complexity of sleep problems and managing them. Some also described poor sleep as negative cycle. For example: *“if a child doesn’t have enough sleep, their behaviour is affected, which ultimately – is – is very detrimental to a family. I would also say that the same applies in reverse, so that if a parent hasn’t had enough sleep because the child is waking, their tolerance to behaviour – or their tolerance to anything really, is probably – well – mine is diminished, so therefore it’s – it’s a never-ending battle”* (participant 83, GP).

6.4.2.2 Theme 2: Chronic insomnia is infrequently a primary reason for consulting in general practice

Despite participants describing their beliefs around the importance of good sleep, impacts of poor sleep, and importance of addressing poor sleep, GPs described that chronic insomnia is infrequently consulted in their practice and is very infrequently consulted as a primary reason. Four sub-themes were developed.

6.4.2.2.1 Sub-theme 2.1: Perceptions of parents’ reluctance to consult in general practice

GPs often described that parents either do not often bring this issue to come to general practice, or that they perceived parents as reluctant to come to general practice. When describing parents who do consult with this problem, they appeared to feel that parents come out of desperation or a last resort (e.g. *“I think they don’t like to present, so they leave it quite late and come when it’s really – they are at their wits’ end and then they’ll come”* – Participant 98, GP), or that they simply do not think to bring the issue to primary care (e.g. *“I don’t think many – patients, many parents come to the GP with it, so actually I think it’s viewed as not being a GP problem”* – Participant 94, GP). Some described that they felt there was a stigma among parents to consult about sleep problems with a GP, or that they might feel ashamed about not being able to cope with the problem alone. Perceptions about the frequency of consultation in health visiting were more mixed.

6.4.2.2.2 Sub-theme 2.2: Chronic insomnia is rarely consulted as a single problem in general practice

In particular, GPs described that it is rare for parents to consult with this problem alone (albeit slightly more frequent with younger babies); *“I think actual presenting to a GP with a sleep problem – to me – seems to be fairly infrequent; it would normally be, you know, alongside some other issue”* (Participant 96, GP). Often, participants (both GPs and HVs) described that if it was

consulted, it would come up in other consultations as a secondary issue or that the GP will ask the parents about sleep as a factor of another problem in consultation and some described that it will come up in scheduled baby checks or vaccinations; *“They may come for, you know, immunisations and have a question or something unrelated and say – while I’m here, I’m having this issue”* (Participant 99, GP). On the other hand, some participants (one GP and two HVs) described the view that it is a common presentation within health visiting; *“in my experience it hasn’t come to me personally as a GP, but I can imagine it might present quite commonly to – say – health visitors and that sort of thing, as well”* (Participant 91, GP).

6.4.2.2.3 Sub-theme 2.3: Perceived limitations of health services

Some participants (both GPs and HVs) suggested limitations of the health services and how this might impact the management of chronic insomnia within primary care. For example, limitations of accessibility and time pressures (in particular HVs and differences in accessibility because of the coronavirus pandemic); *“I also think it’s always so busy in primary care that – you know – it’s just another thing that – that can easily be brushed under the carpet and the same with the health visiting team in primary care “ – Participant 93, GP.* Some participants (both GPs and a HV) described a view that some parents have had negative experiences when consulting in primary care about this problem.

6.4.2.2.4 Sub-theme 2.4: Views about missed opportunities to discuss sleep problems in primary care

Although participants reported that chronic insomnia is rarely consulted or discussed, some GPs and HVs viewed this negatively, noting missed opportunities for discussion, that it is under-recognised and that where possible, it would be good to be able to help with this problem. For example, *“I think it’s really important worth bearing in mind that it is something that we do need to know about and maybe it’s just something that is under – not asked about very often”* (Participant 90, GP).

6.4.2.3 Theme 3: Views and experiences of advice and recommendations

Whilst participants reported that chronic insomnia is rarely consulted as a single problem in general practice, GPs and HVs still discussed their views and experiences of advice, strategies, and recommendations for the management of chronic insomnia in children. Some also discussed how they would manage it if it came up more. Nine sub-themes were developed.

6.4.2.3.1 Sub-theme 3.1: Signposting in general practice

Firstly, most GPs perceived their role in managing chronic insomnia in children as one of signposting, usually signposting parents to HVs or other HCPs for in depth management. For example, *“Well actually I don’t do it a lot, to be honest, because you normally signpost them to the health visitors” (Participant 82, GP)* and *“I tend to direct to the health visitor because I think it’s quite a time consuming resolution and you need repeat appointments.” (Participant 83, GP)*. Signposting was described either as the first management strategy by a GP, or what they would advise after any assessment and/or basic advice. Some also talked about their role of signposting to other resources, such as support groups, information websites or books; *“And then I may give them some resources or – it sort of depends if they are book reading type parents...or kind of websites or Facebook groups. And, you know, signpost them that way” (Participant 95, GP)*.

6.4.2.3.2 Sub-theme 3.2: Basic advice, bedtime routines and other components of sleep hygiene

Most participants (both GPs and HVs) also described the use of basic advice, and advice about bedtime routines and other aspects of sleep hygiene. For example, they described initial advice for parents to try (*“my role is very – very much supportive, obviously giving the usual routine information about how to – just really simple things – to try and help them combat the insomnia” – Participant 86 (GP)* and *“minimising screen time, making sure there’s plenty of calm down time; making sure there’s a good bedtime routine...using calming lights, calming – music or CDs, relaxation CDs, that kind of thing and – a period of parental time to help them calm” – Participant 82, GP*).

Often participants (both GPs and a HV) also discussed the importance of managing the parental approach, for example parental consistency: *“I think consistency is one thing that I try and impart as being important, so that the child, you know, does – you don’t backtrack all of a sudden” (Participant 96, GP)*. Moreover, some participants (both GPs and HVs) talked about how they would give parents information, such as what is and is not normal and what may be contributing to the sleep problem etc; *“The only thing that I do think is quite good to point out to parents is how much sleep children of different ages – ideally require” (Participant 83, GP)*. This appeared to be for simply explanatory reasons, or to tackle misunderstandings.

6.4.2.3.3 Sub-theme 3.3: Assessing the situation

All participants described how they would assess the situation, for example ask about sleep history, contextual and situational factors, family routines etc. For example:

“I try and explore, you know, what’s been going on; how has it changed, what other – try and take a bit of a history of what exactly is the pattern of sleep or the difficulty that they’re having. What are the sleeping arrangements; what’s the family arrangements: is the problem at home or is it elsewhere” (Participant 95, GP).

Some participants (all HVs, some GPs) mentioned the use of resources such as sleep diaries to do this assessment, and one participant (HV) described the use of a questionnaire to assess for sleep problems.

Although all participants conducted assessments, the purpose of the assessments somewhat differed. All assessed the sleep problem, however, within general practice, a large focus of the assessments appeared to also be looking for any other underlying causes or medical problems:

“as a primary care doctor, I’d be looking for any – underlying, physical reasons for it or developmental issues, you know, screening in my own way for things like ASD or things that might be impacting in that way and if the child was otherwise neuro-developmentally normal” (Participant 93, GP)

6.4.2.3.4 Sub-theme 3.4: Beliefs supporting an individualised approach to management

Most participants (both GPs and HVs) reported that consultation and management strategies should be tailored to each individual family, and that many factors should be involved with management decisions. Examples of factors to be taken into consideration were parenting styles or beliefs, whether parents are first time parents, and the age of the child. For example, one participant talked about the importance of exploring parental beliefs: *“I think how people want to address insomnia in children, at the milder end, comes down very much on to their parenting philosophy... there’s not one size fits all” (Participant 93, GP).*

6.4.2.3.5 Sub-theme 3.5: Views and recommendations about specific strategies

Regarding specific management strategies, participants described what they would usually recommend or their views about specific recommendations. Some GPs and all HVs described that they would recommend behavioural techniques. These were described simply as behavioural techniques, or with specific strategies mentioned such as gradual retreat, controlled crying, or reward charts. Some GPs were aware of behavioural techniques but did not describe recommending them.

For those who talked about their beliefs about extinction methods, many participants (both GPs and HVs) seemed to either disagree with extinction techniques, or prefer gentler extinction

techniques (e.g. gradual retreat and controlled crying) to unmodified extinction (cry-it-out). For example, a participant described the preference for gradual retreat over cry-it-out:

“I think another method that is encouraged is – let your children cry it out. So if the child wakes up to actually just leave them to self soothe in that way. I find that a bit extreme. I try not to judge people if they do choose to use that method; I’m aware that it does work for people. It’s not something I personally feel so comfortable with, particularly for very young children. I’m more moved towards the sort of – gradual withdrawal” (Participant 96, GP)

However, there was one GP who believed controlled crying to be effective. For example, *“... the one that seems, in my experience personally and professionally – controlled crying is really effective...” (Participant 70, GP)*. Often, participants appeared to describe their beliefs to be based on personal opinion or related their beliefs to their own experiences, rather than only professional knowledge and experiences. HVs specifically described the use and effectiveness of gradual retreat.

One GP participant described their view on co-sleeping and emphasised that that would be happy for parents to try it, but that it must be done safely. They described that they would signpost and discuss safe co-sleeping with parents. For example:

“I would usually give kind of recommendations in terms of what the – is it the Lullaby Trust, suggest signposting parents to that, in terms of like are they risky, in terms of are they smokers and so on, but, and I would kind of stick to the guideline recommendations with regards to co-sleeping, but I wouldn’t – I wouldn’t dismiss it if it’s right for that family and if the risks have been addressed” (Participant 95, GP)

Often, GP participants reported that they would not give pharmacological recommendations; *“I mean I certainly wouldn’t be medicating them, you know; I think that’s the last resort for anybody, and certainly not a primary care role, so that would certainly come from the secondary care.” (Participant 93, GP)*. Some stated or described that they prefer behavioural over pharmacological treatment and some reported that they felt some parents come to primary care for a quick pharmacological prescription, which they wouldn’t provide: *“I think we’re often people that families turn to for ... sort of wise advice, but often patients’ families are looking for medication support and that isn’t something I would consider my primary role here” (Participant 85, GP)*. A small number of GP participants did (or expressed a preference to be able to) provide a prescription or described they would do so in specific circumstances.

6.4.2.3.6 Sub-theme 3.6: Emotional support and management of the impact on parents

Both GP and HV participants also reported that they manage the impact of the problem or resulting mental health difficulties for the parents, or they provide emotional support. For example, participants often noted the importance of acknowledging the difficulties that families experience and being empathetic to validate their feelings. For example, *“acknowledging – what they’re experiencing: listening to the story” (Participant 89, GP)*. Some highlighted that they encourage acceptance of the problem and what is normal and that they manage their expectations in terms of the problem and that although it is not an easy fix, it is important to persist. Some participants also described the importance of reassuring parents and empowering them to try any changes.

Some participants (GPs and one HV) also seemed to emphasise the importance of good communication with their patients, such as a non-judgemental approach, honesty and positive approach. For example, *“I think – trying to support the carer, usually the parents, in a non-judgemental, non-confrontational way, but trying to support them towards – towards change” (Participant 96, GP)*. One GP participant described their beliefs about the importance of a good rapport with the families and patients: *“I think it all boils down to the relationship a practitioner has with the patient and the family. I mean that really is key because, you know, if you haven’t got that, then patients will not declare these things going on in their lives” (Participant 99, GP)*.

6.4.2.3.7 Sub-theme 3.7: Awareness of non-healthcare resources

Both GP and HV participants often mentioned their awareness of resources outside of healthcare which parents might use, such as books, websites, family, and friends but had mixed thoughts about books and websites. For example, one participant described being uncertain about parenting books; *“I’m fairly sceptical about anything that I have come across, parenting manuals, because – because I’ve not really seen them work...often these are sort of sold as a one size fits all method and I’m not sure that’s – I think that’s selling a bit false hope, really...” (Participant 91, GP)*. On the other hand, another participant described parenting books positively: *“There’s a really old book now, [name of book], by [author], which I think has really, really good advice about controlled crying” (Participant 70, GP)*.

Sometimes, participants described that it would be beneficial to know of more evidence-based resources which they could either use in practice or signpost parents to.

6.4.2.3.8 Sub-theme 3.8: Follow-ups in health visiting

All HV participants discussed the use of follow-ups, whether for a longer initial consultation about the problem, or as a follow up from management recommendations.

6.4.2.3.9 Sub-theme 3.9: Mixed views about referral and secondary care

Few participants described experiences and views of secondary care. There appeared to be mixed views of secondary care sleep clinics, with some GP participants describing that there were not any clinics in their region, negative views of them, or that they were not aware of any referral routes. For example, *“I don’t think I’ve ever done a referral purely for insomnia and largely because one there are no sleep clinics, and if there are, they don’t – they don’t seem to be able to do anything more than we can, so I don’t think I’ve ever used them” (Participant 81, GP)*. Some HV/GP participants did describe the awareness of sleep clinics or referral to a paediatrician. For example, *“I had to refer them to the paediatrician because they’d tried everything” (Participant 94, GP)*.

6.4.2.4 Theme 4: Views regarding roles of different PCPs in the management of chronic insomnia in children

Participants did seem to feel that primary care is a suitable place to manage (or signpost) parents about chronic insomnia in children, however there were some differences between general practice and community primary care (such as HVs and nursery nurses). Three sub-themes were developed.

6.4.2.4.1 Sub-theme 4.1: Perceptions that primary care should address chronic insomnia

For primary care generally, both GP and HV participants recognised a role to manage paediatric chronic insomnia, even if this was simply to signpost within primary care; *“I think we are well placed to give advice and reassure in a lot of cases; so, yes, I think we have quite an important role there” (Participant 99, GP)*. Some GP and HV participants described the importance of collaboration between different HCPs, and one participant seemed to place more emphasis on the experience of the HCP and who the parent has consulted within primary care, rather than which type of PCP should manage it; *“I don’t think it terribly matters like what the profession of the person is, more what their – what their level of experience and confidence is in that problem...I don’t think you could say that it should be a GP or it should be a health visitor or something like that; I think it would have to depend on the individual practitioner, as to what they can bring to that problem” (Participant 91, GP)*.

6.4.2.4.2 Sub-theme 4.2: Perception that HVs or community support are more suited management

Although participants generally thought of primary care as an important setting to address chronic insomnia in children, role perceptions between general practice and community primary care such as health visiting differed. For example, often GPs described that the problem should be managed by or signposted to HVs in the first instance. This was sometimes described differently for different age groups. For example, *“I think it’s a secondary role: I think primarily it should be addressed. If a child is under 5 by the health visitor and then if after that or if the child is older, then, of course, the child will come to me and also the practice nurse as well” (Participant 98, GP).*

Moreover, often GP and HV participants appeared to believe that community primary care (particularly HVs) have an important role in consultation, management and follow up. This appeared to be due to beliefs around more in-depth knowledge, continuity with families or more suitable settings. For example; *“I think often it’s a case of – if I did come across something like that – referring on so – maybe referring to the community paediatrics team in the first instance or to health visitors or somebody else who might have more knowledge of the area or be able to help with managing these children” Participant 92, GP).* HV participants also viewed the management of chronic insomnia in children as part of their role. Nevertheless, some participants seemed to believe that HVs and GPs are equally suited.

6.4.2.4.3 Sub-theme 4.3: Mixed views around the role of general practice

Although there appeared to be a common belief that HVs and community primary care are best placed for management, the role perceptions around general practice were mixed. Some GPs appeared to believe that general practice is not best placed to manage chronic insomnia, whereas others appeared to believe general practice is suitable alongside HVs. For example, *“I think it’s important to address it, but whether in primary care, who it’s delivered by I think is a – I’m not sure if GPs are the best place to do it” (Participant 89, GP)* versus *“... so it’s about signposting them if there is a health visitor or just advise them. I mean a lot of the time it’s – it’s – it’s a couple of conversations with them, really, that – that you need and direct them to some advice in a book or online or wherever” (Participant 70, GP).* Some GPs felt that parents will often go to the GP before a HV; *“... We all know that in primary care we are asked about a multitude of things. Actually it seems to be more of a default, isn’t it, you know – to go to see your doctor about literally anything from, you know, help with blue badges to – something related to, you know, taxes and bills. So, yes, a default, I think, for many parents would be speak to a GP first and they would be quite happy to do so” (Participant 86, GP).*

6.4.2.5 Theme 5: Limited professional training and knowledge regarding chronic insomnia in children

Despite expressing views about the importance of good sleep and about addressing poor sleep, participants believed GPs received limited professional training regarding the management of chronic insomnia in children. As a result, they appeared to have limited professional knowledge and an interest in future training and resources. Eight sub-themes were developed.

6.4.2.5.1 Sub-theme 5.1: GPs receive minimal or no professional training about paediatric chronic insomnia

Firstly, most GP participants reported having no teaching about chronic insomnia in children during professional training; *“on a professional level, I’ve had zero training on it, to be honest” (Participant 93, GP)*. Some remembered minimal training and/or could not remember specifically what it was; *“I think I’m – the amount of actual teaching we get about this – is very, very small. I remember having one lecture about sleep and children’s sleep and – only one that springs to mind, now I think back. And that was probably postgraduate teaching; I’m sure as an undergraduate I did some but I can’t really remember” (Participant 95, GP)*.

6.4.2.5.2 Sub-theme 5.2: Specialised training options for HVs

On the other hand, all HVs described some professional training on this topic, whether it was training that they themselves attended, or that their colleagues had received and then shared within their team. Some described external training courses which had been accessed. The training seemed to be perceived positively by the HVs.

6.4.2.5.3 Sub-theme 5.3: GPs perceive limited or varied professional knowledge for management

Most GPs perceived limited or varied professional knowledge on the topic. For example, two described their knowledge on a scale of one to ten and described their knowledge as *“probably 3-4” (P85, GP)* and *“about 2 or 3” (Participant 89, GP)*. In particular, this seemed to be as a result of the limited training about chronic insomnia in childhood. Some GPs seemed to feel knowledgeable about basic and initial management, but not for management any further in depth; *“I feel I have sort of – general common sense knowledge about it but I wouldn’t say that I feel I have any additional medical knowledge about it” (Participant 96, GP)*. One GP did appear to feel somewhat knowledgeable; when asked how much knowledge and understanding they had, the participant answered *“I’m not sure how to measure that. ... Some – enough, maybe”*

(Participant 70, GP). On the other hand, all HVs described feeling knowledgeable, although some reported that they would still like further knowledge.

6.4.2.5.4 Sub-theme 5.4: Knowledge from practical experience

Despite limited knowledge from professional training, where GPs reported some knowledge, this usually appeared to be due to practical or personal experience; *“I think all of it is just what you pick up as you go along and then personal experience”* (Participant 93, GP). One participant described having read more about this problem themselves, after experiencing a consultation without any prior knowledge of how to manage the problem; *“It’s basically whatever I’ve read about it, after that case”* (Participant 94, GP). All HVs and one GP described gaining further knowledge from experience in practice or from discussing cases with colleagues or supervisors. Please see theme eight for further details about personal experience influencing knowledge.

6.4.2.5.5 Sub-theme 5.5: Interest for information resources

Many GP participants appeared to be interested in further availability of formal evidence-based resources to use in practice. Examples are resources to signpost parents to, or resources to use themselves to improve knowledge or as guidelines for management. For example; *“I think what could make it easier is – if I did know a little bit more or if there was a clear – primary care guideline that I was aware of, that would tell me, right, first of all, try this: next, do that, next do this; some such framework to plan on, that would be helpful”* (Participant 91, GP). For HVs, one described not needing any further resources and another appeared to be interested in further objective sleep measurement resources.

6.4.2.5.6 Sub-theme 5.6: Interest in future professional training

Many participants (usually GPs, one HV) did seem to express an interest in future professional training, however, their views on the type, modality, and amount of training that they specified differed. For example, some participants simply expressed an interest in training, and others discussed that training for GPs would be useful (*“I really think it should be part of – GP training, for sure”* – Participant 94, GP). Types of training were mentioned by some; *“probably like a little short webinar or – online – like an e-learning or ... even just – a leaflet...I’d be grateful for anything”* (Participant 97, GP). GPs often referred to their interest or need for appropriate training, because of their limited time and attention which is also needed for other problems. For example; *“I think – rather than having extensive training for GPs, I think having an overview would be helpful, of the sort of strategies that perhaps would be advocated and the sort of assessment and management that would be advocated”* (Participant 96, GP). Therefore, future development of training opportunities for GPs must be appropriate, tailored and brief.

6.4.2.5.7 Sub-theme 5.7: Uncertainty in usefulness of further professional training

Despite many GPs expressing an interest in future training, some also seemed to be uncertain around the usefulness of the training. This seemed to be either because of the infrequency of consultations about this problem, the view that management should occur elsewhere or due to the limited time that they already have. For example; *“I don’t know. I think it’s one of those things that it’s probably so individual from one family to another, that specific training might not be terribly helpful and I think if – you know – if you’ve got sort of quite a lot of basic advice you can give and they’re not progressing, I think they probably do need specialist input really, because – yes – to individualise it.”* (Participant 82, GP). One of the HVs described not needing any further training.

6.4.2.6 Theme 6: Perceived self-efficacy for managing chronic insomnia in children

GP and HV participants often also discussed how they felt towards managing this problem in consultation and how confident they felt towards the consultation. Three themes were developed and are discussed below.

6.4.2.6.1 Sub-theme 6.1: Mixed confidence levels

Participants appeared to have mixed confidence levels for the management of chronic insomnia in children. For example, some (GPs) seemed to lack confidence, whereas some (some GPs, most HVs) did not. Some specified that they felt confident to give basic advice, but did not feel confident for anything further; *“I’d say ... low to medium, in that if there are things that – that I’ve found that I can make suggestions and say let’s try that, or, you know, these are things to try, as though I was a listening ear, for you know a few weeks and then re-review them, I think, fine, I’ll probably be reasonably confident with that, but if – if I – you know – certain suggestions or ideas we get nowhere, I think I’d be – I think I’d reach my limit quite quickly...”* (Participant 87, GP).

6.4.2.6.2 Sub-theme 6.2: Perceived barriers to managing sleep problems in consultation

Some participants also appeared to describe some perceived barriers to managing chronic insomnia in consultation. For example, some GPs talked about how the problem is not quickly fixed and this appeared to make it difficult for them to manage. For example; *“It’s just quite frustrating when – I suppose – I can think of the odd occasion when families – it’s just not working, things aren’t – are not – well I think, as families get more and more stressed, it’s difficult to maintain the sort of – trying to keep it proportional, trying to keep it – rather than making it a very upsetting time and everyone dreading the kind of – the bedtime routine, because they just know it’s going to be another battle”* (Participant 89, GP). Moreover, one participant talked about

perceived pressure from parents to solve problems in general practice quickly; *“I think we often feel a pressure on us to be seen to be doing something about it” (Participant 91, GP).*

Some GP and HV participants recognised how parental factors can impact the management within consultations. For example, they talked about the influence of parental readiness to make changes or be open to trying different strategies. One participant talked about the impact of how much parents try different strategies; *“...you kind of have to pick that apart a little bit because when some people say that, kind of when you delve in a bit, you think, well actually, you haven’t, or there are things that you don’t – that you weren’t aware of, that you could try. Other people, you pick it apart and they can tell you quite clearly they’ve – they have tried lots and lots of different things. So I think when someone says – I’ve tried everything, it’s really important to explore that a bit, rather than just take it at face value” (Participant 87, GP).*

6.4.2.6.3 Sub-theme 6.3: Positive feelings towards the consultation

Alternatively, there were some HV and GP participants who talked about positive feelings towards consultations. For example, that they don’t find it a difficult conversation or that it’s a positive conversation in comparison to other issues that are presented to them; *“... it’s not necessarily a particularly difficult consultation; it’s quite nice...because actually there’s stuff that you can do that might help and might make quite a long-lasting difference to the family’s and the kid’s life” (Participant 70, GP).*

6.4.2.7 Theme 7: The influence of the personal experience of being a parent

Finally, almost all participants indicated that their personal experiences of being a parent had an influence on their management of sleep problems. All but one participant had personal experience caring for children aged five years or younger, and all but one of the participants with such experience referred to the influence this has had. Three sub-themes were developed.

6.4.2.7.1 Sub-theme 7.1: Personal experiences influence feelings and attitudes

Firstly, some GP participants described how having their own children influenced their attitudes and understanding of the issue. For example:

“I think my compassion is more, having had children myself and, you know, understanding struggles that parents go through, because I think until you’ve had children ... you know, you just think, oh, that’s – you know – what were you expecting, that’s normal. [Slight laughter] And to a degree, you know, being told that it’s – that is normal – to an extent, you know, can help, but also having somebody who understands that it can make you feel – really –

sometimes quite depressed or anxious or ... you know, like I said, it can affect your relationship and all of those things.” (Participant 95, GP)

It seemed that having their own children may help them empathise, and it may influence their self-efficacy towards dealing with consultations. One participant described how it even influenced how they perceived health visiting services: “I would always – always ask if they’d actually spoken to health visitors, because I’ve got relative experience of speaking to a health visitor when my son was – really small and not sleeping. So the health visitors actually gave me loads of really useful information...” (Participant 86, GP).

6.4.2.7.2 Sub-theme 7.2: Knowledge acquired through personal experience rather than professional training

Most GP participants seemed to emphasise that any knowledge they had on the issue had been acquired through their personal experiences with their own children’s sleep, rather than through any professional training. For example, *“it’s something that I haven’t – come across a lot, in terms of – as part of my training and as part of my career. So it’s something that I think is – I’ve learnt most about probably, in terms of sleep routines and patterns with children, through having my own children, rather than actually through my – my training” (Participant 92, GP)*. Furthermore, the one participant who described that they did not have children, expressed the view that GPs with children have more knowledge on the subject, and related this to her lack of knowledge; *“I feel like if I had kids, I would know more. So GPs who have kids definitely know more. So I was a bit unsure” (Participant 94, GP)*.

6.4.2.7.3 Sub-theme 7.3: Usefulness of discussing personal experiences in consultation

Finally, some GPs talked about using their personal knowledge and experience to help them in discussions with parents in consultation. This seemed to be the case in either recommending strategies which they had tried personally (*“if I felt it was appropriate, then I would give my own personal experience of managing my own child” – Participant 90, GP*), or to improve the patient-doctor relationship; *“you might be able to share a little bit about your own personal experience, which people – you know – as long as it’s appropriate - people often quite like. And then you can say – I had this, it kind of makes them feel that you understand what they’re talking about, at least, rather than just not having a clue” (Participant 70, GP)*.

6.4.3 Triangulation with the quantitative survey results

Themes from the qualitative data were triangulated with the survey findings to interpret how much they agreed or disagreed with one another, based on the triangulation protocol as outlined

by Farmer and colleagues²⁴⁸. Most findings from both research methods were either in agreement and complemented one another, or were categorised as 'silent' whereby they provided extra information which did not come up or was not explored in the other method. Some of the triangulation findings are discussed below in relation to the research aims for the mixed-methods study. See appendix C.5 for the table of full triangulation of survey and interview findings within this study.

6.4.3.1 Aim 1: Explore PCP views

Views about the impact of chronic insomnia in children were in agreement. For example, more than 86% of survey participants (of which most were general practice staff) agreed or strongly agreed that chronic insomnia impacts the child and family, and a common sub-theme within the interviews for both GPs and HVs was 'views about multiple impacts of poor sleep on the family'. Normalisation of sleep problems were also in agreement; some (26.9-46.9%) survey participants would likely recommend most or all of the time that the problems will resolve over time, and a sub-theme, usually from GPs, within the interview findings was 'normalisation of some sleep problems'. Views about behavioural versus pharmacological approaches to management were also in agreement. Views about management in primary care were also in agreement whereby >80% and >67% of survey PCPs (of whom most were GPs) agreed it should be managed in health care and primary care, respectively. This warranted further exploration because different participants may have had different definitions of primary care. However, it was still a fairly high percentage, and a sub-theme within the qualitative results, from both GPs and HVs, was also the 'perception that primary care should address chronic insomnia'.

Interview findings gave more in-depth information to much quantitative data for this aim. For example, despite the findings about the frequency of consultations about this issue in primary care, the interview findings revealed that both GPs and HVs had 'views that sleep problems are common in children' (sub-theme 1.1, not specific to primary care). GP and HV interview participants also had perceptions about causal factors of sleep problems, emphasised the importance of good sleep, and viewed it as a complex issue that can be subjective by definition. Whilst the qualitative and often the quantitative results suggested that HVs/parents are more suited to in depth management than other PCPs, some survey participants reported that HVs and parents were the least or less important than other PCPs, and this needs further exploration.

6.4.3.2 Aim 2: Understand PCP knowledge and training

Both qualitative and quantitative findings agreed that GPs had received minimal to zero professional training on this topic, with 84.8% of survey participants receiving no training before

qualifying, and the sub-theme 'GPs receive minimal or no professional training about paediatric chronic insomnia'. Regarding HVs, interview findings highlighted that HVs have more options for training, which adds depth to the findings about training for PCPs which were not highlighted in the survey.

Both also agreed that GP knowledge regarding this topic varied. Moreover, the interview findings highlighted that often, knowledge that they did have on this topic was often due to experiential experience over any professional training: the personal experience of being a parent (or the perception that GPs with children are more knowledgeable) or from practical experience in consultation. The quantitative survey findings highlighted that many general practice staff do not have knowledge of other resources.

6.4.3.3 Aim 3: Explore PCP current practice

Both methodologies agreed many factors about current practice: (1) that there is Infrequency of GP consultations about chronic insomnia, (2) that GPs/HVs assess the situation / take a sleep history, (3) GPs likely recommend positive bedtime routines and/or other aspects of sleep hygiene most (4) likely recommend behavioural over pharmacological treatment, and (5) GPs have mixed self-efficacy and confidence for management. However, the interview findings often provided further detail or explanations which were not present in the survey. For example, the interviews further distinguished between types of primary care such as a higher frequency of consultations in health visiting. The interviews also provided some explanations as to why the consultations may be infrequent such as perceptions of parents' reluctance to consult and perceived limitations of health services, and they emphasised that when parents do consult, it is usually alongside another issue or brought up in routine consultations.

There was partial agreement between surveys and interviews regarding PCP beliefs about extinction-based sleep interventions. The survey findings in Chapter Five suggested a higher percentage of General practice staff likely recommend gentler extinction techniques to unmodified ones, although the percentages were all still low in comparison to 'positive bedtime routines'. All HV interviewees described recommending a form of behavioural intervention (gradual retreat or graduated extinction). However, the differences in percentages may be due to the small proportion of survey participants who were HVs. Nevertheless, some interview participants (GPs and HVs) expanded on their views by saying they are personally against crying methods and wouldn't recommend them, whereas others described recommending graduated extinction or gradual retreat.

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Interestingly, qualitative findings gave further details insights into current management. For example, highlighting that often GPs signpost or would likely signpost to other PCPs such as HVs. They also highlighted GP and HV beliefs for an individualised approach to management, emotional support and management of parents, possibility of follow-ups in health visiting, and some perceived barriers to managing sleep problems. Regarding resources, a high percentage of survey participants reported they were not aware of other resources for parents, suggesting that GP practice staff do not regularly signpost to resources. Although some interview participants described an awareness of resources, it was more common for GP participants to describe signposting to HVs, than it was for other evidence-based resources.

6.4.3.4 Aims 4 and 5: Explore PCP perceived unmet needs and interest for support tools

Both qualitative and quantitative findings were in agreement that GPs would like further training opportunities. For example, given the chance, more than 80% of survey participants would like access to further training opportunities, and a sub-theme within the interviews was 'interest for future professional training' (usually from GPs), however, the interview findings specified that the training would only be useful and possible to attend if brief and tailored.

The interview findings from GPs also gave further information about their awareness of evidence-based resources, whereby some participants expressed an interest or need for awareness of evidence-based resources to be able to signpost parents to, or for themselves to be able to use for decision making in practice.

6.5 Discussion

6.5.1 Summary of findings

The 21 interviews discussed in this chapter were the qualitative part of the mixed-methods study and further explored PCPs views, knowledge (including training), current practice and potential unmet needs regarding the management of chronic insomnia in young children. These findings addressed five research aims exploring PCP views, knowledge/training, current practice, unmet needs and interest for further resources. In particular, it further explored the frequency and nature of management of chronic insomnia within primary care, PCPs role perceptions, training and potential interest in further types of support (PCP training or resources). The qualitative findings were then triangulated with the quantitative survey results.

Many of the findings complemented one another, whilst others added further detail. In particular, both highlighted that for GPs there are perceptions of varied knowledge, limited training, an

infrequency of consultations about chronic insomnia, and an interest in future training/resources. The interview findings added further detail such as context to likely recommendations (including an individualised approach by both GPs and HVs), personal experience usually for GPs, and specifications for interest in future appropriate GP training opportunities / resources to use in practice. Both the qualitative findings, and the combined findings from the mixed-methods triangulation are discussed below in relation to the overall research aims.

PPI input was valuable to this mixed-methods study; it helped shape the research by recommending to survey/interview PCPs instead of parents, and by suggesting questions for which parents would be interested to know PCP perceptions. Further PPI input at the preliminary findings stage helped to guide interpretation of the results, by ensuring that the findings were clear and grouped appropriately.

6.5.1.1 Beliefs

As discussed in section 6.4.3.1, many of the interview findings complemented those of the survey, highlighting beliefs about the impact of chronic insomnia on the child and family. The interview findings further suggested that GPs and HVs believe it's a common problem that has an impact on the family, that needs addressing (suggesting beliefs about potential missed opportunities), and suggested more information regarding role perceptions for HVs being more suited to in depth management of sleep problems. These findings are similar to those of previous research in other countries, for example qualitative interviews of various 22 US PCPs (e.g. physicians, nurses, psychologists, social workers)²²⁹ carried out to explore perspectives on sleep to direct future US primary care sleep interventions. The first sub-theme mentioned was 'sleep as critical for child wellbeing' and the authors noted an emphasis on emotional and academic domains. This highlights similarities in PCPs' views about the importance of sleep, even with the differences between primary care systems within the US (with a paediatrician within primary care) and the UK (mostly GPs).

As discussed in Chapter Five, PCP beliefs are particularly important to PCPs management and this suggested by the TPB^{166,167} which suggests that attitudes influence behaviour. For example, in relation to PCP management of chronic insomnia in children, having a positive attitude towards the importance of sleep (by believing that it's a common problem that has a negative impact on the family and which needs addressing) would make PCPs more likely to manage this problem. It is therefore promising that the interview findings suggest GPs and HVs have positive attitudes towards improving sleep problems. Other factors within TPB^{166,167} are discussed in relation to other findings.

6.5.1.2 Management

As discussed in section 6.4.3.3, many of the interview findings complemented those of the survey highlighting the infrequency of GP consultations about chronic insomnia in children, GP/HV preferences of positive bedtime routines and other aspects of sleep hygiene, GP/HV recommendations of behavioural over pharmacological management and GP/HV assessment. Whilst bedtime routines were most often mentioned, it provided further detail to Chapter Five, highlighting that participants may also advise about other aspects of sleep hygiene not asked about in the survey. Where feasible, it would be useful to further explore sleep hygiene advice and differences within this category in future studies. These findings are similar to previous research in other countries, for example mixed-methods survey findings in Australian research²³⁰, whereby MCH nurses, described many likely responses to a mother on an infant with night waking problems such as general assessment, settling strategies, bedtime routines, sleep environment and other aspects of sleep hygiene. Sadler and colleagues⁷³ also interviewed various US paediatric providers (e.g. paediatricians and paediatric nurses) and suggested the themes 'bedtime routines for everyone' and 'barriers to healthy sleep', highlighting an impact of poor sleep hygiene.

The interview findings also complemented the survey findings of GP mixed confidence levels, with the qualitative findings relating to self-efficacy. Improving GPs self-efficacy for management is particularly important, self-efficacy theory¹⁶⁸ suggests that it influences their management. A way to improve their self-efficacy could be by improving their knowledge (capability of performing the behaviour). Moreover, the TPB^{166,167} suggests that perceived behavioural control of internal or external factors also influence behaviour. GP and HV Interview participants described some barriers to management, such as time limits in primary care, or parental attitude/readiness to change. Whilst they may have positive attitudes towards managing sleep problems, if they have a low perceived behavioural control or low self-efficacy due to factors such as these, it may make their management difficult.

The interview findings also provided further detail highlighting GP views on signposting to HVs, and, for both GPs and HVs, beliefs supporting an individualised approach to management, emotional support to parents, thoughts about extinction-based interventions, and the impact of personal experience of being a parent. Beliefs about an individualised approach are positive considering different individual/familial differences, for example the developmental differences in normal sleep/wake cycles throughout the first 5 years, described in Chapter One. Thoughts about extinction-based interventions also related to both sides of the debate around extinction techniques; GPs and HVs generally seemed opposed to stricter extinction approaches, whereas

some described recommending controlled crying or gradual retreat in certain circumstances or to reduce short term burden of sleep problems.

Sadler and colleagues (2020)⁷³ also named the theme 'the importance of knowing each family', which suggests an individualised approach to management. Various PCP beliefs about an individualised approach to management support the theory of a stepped-care and flexible approach to extinction-based interventions, proposed by Whittall and colleagues¹⁵⁷. However, interestingly, qualitative UK parent research about information seeking¹³³ for sleep problems suggests parents may perceive PCPs such as HVs to be inflexible in management strategies and recommend 'cry it out'. This suggests that there may be a discrepancy between what PCPs feel ought to happen and what PCPs do, and what parents perceive to happen in consultation. This warrants further investigation. Moreover, Murray and colleagues (2019)²²³ who interviewed various Vietnamese PCPs (doctors, nurses, paediatricians), described that their advice (though also based on personal experience) was to increase parental presence, rather than any behavioural-based sleep intervention, which also contrasted the findings of this thesis. Nevertheless, Murray and colleagues' research findings may be due to cultural differences, whereby parental presence are more accepted and self-settling less accepted²¹.

6.5.1.3 Training and knowledge

As discussed in section 6.4.3.2, the interview findings complemented survey findings highlighting that GPs have a lack of formal training on the issue and varied knowledge. These findings are similar to those of other qualitative research in other countries, whereby various US PCPs²²⁹ and various Vietnamese PCPs²²³ perceived a lack of training and knowledge about paediatric sleep problems. However, the Interview findings in the current study also highlighted that HVs may have more access to training opportunities. The interview findings also gave further detail suggesting that for GP participants personal and practical experience may account for any knowledge rather than professional training, which was also described as the case for the various Vietnamese PCPs in the study reported by Murray and colleagues²²³. These findings further support experiential learning theory^{163,164} (discussed in Chapter Two), whereby HCPs' knowledge comes through personal and practical experience. Moreover, in relation to self-efficacy theory, positive or negative reinforcement from personal experiences may influence how GPs manage sleep issues in practice; if they had positive issues of resolving sleep issues on a personal level, they may be more likely to have higher self-efficacy and recommend the same strategies to parents in consultations.

Although previous research with PCPs were not conducted in the UK, recent qualitative research exploring parent's information seeking in the UK has been conducted and suggests some parents

also perceive PCPs (such as HVs and GPs) to be limited in knowledge and training regarding sleep problems^{133,215}. However, these studies did not explore specifically their views of the management within primary care, so include a small amount of data/findings which relate to the current thesis findings, and should be explored further.

6.5.1.4 PCP unmet needs, and interest in training and resources

As discussed in section 6.4.3.4, the interview findings complemented survey findings by suggesting that the PCPs (usually GPs) were interested in future professional training opportunities. However, the interview findings provided further information explaining that the opportunities may only be useful if brief and tailored due to time pressures on them. Interview findings also highlighted that GPs would like to be aware of, and have access to, more evidence-based resources to use for management (e.g. guidelines) or to give to families. These findings are in line with US qualitative research whereby in an interview study²²⁹ the authors found that various US PCPs wanted more knowledge and resources about children's sleep. Addressing any PCP unmet needs by providing training opportunities or an awareness of evidence-based resources may help management when parents consult about this issue. The TPB^{166,167} suggests that perceived behavioural control influences behaviour. Therefore, by providing resources and training opportunities, GPs may have an increased perceived behavioural control. In particular, increasing awareness of other resources may relieve time pressures on GPs (and also increase perceived behavioural control), by allowing them to signpost to evidence-based resources in short consultations.

Interestingly, in some other US qualitative research⁷³, it is suggested that paediatric providers were aware of other resources already. They described a variety of recommendations to parents such as community PCPs, electronic resources (e.g. videos), classes and educational materials, and visits to the home. The authors did not describe how evidence-based the resources were, however they were described in a way that suggested they were reliable resources. These differences with those of the current interview findings may be due to the types of PCPs within the samples, and the country within which the studies were conducted. For example, as described previously, the UK and US operate vastly different primary care systems. It is more expected that paediatric providers (with more specialised paediatric training) in a primary care setting in the US would have more knowledge of resources than UK GPs (who largely made up the sample of interview participants in the current study). This is supported by the fact that the small number of HVs in the current sample described more access to training.

As discussed in Chapter Five, increasing knowledge by providing more training opportunities, and awareness and access to evidence-based resources, may increase capability, self-efficacy and

perceived behavioural control for the management of chronic insomnia in children. Combined with encouragement to ask parents about this issue more, these factors would positively influence management in practice.

6.5.2 Implications

There are some suggestions for both future research and clinical practice. Firstly, it would also be useful to conduct further research exploring parent perspectives of the management of children's chronic insomnia within UK primary care. These would create a detailed evidence-base for both PCP and parent perspectives on management, and guide future research and clinical changes for any areas requiring improvement. Furthermore, there were relatively few HV participants in the current study so further research on HVs and other community-based PCPs would be beneficial.

Second, it would be beneficial to further support and signpost to HV management where in depth management seems most appropriate, however, it may also be beneficial to develop appropriate brief training opportunities for GPs. The survey findings reported in Chapter Five, suggested PCPs (mainly GP participants) are interested in further training opportunities. However, findings reported in the current chapter specified that training opportunities must be brief and appropriate (e.g. short online module) to be feasible alongside GPs' current workload and other medical problems in practice.

Given PCPs (in particular GPs) time constraints in consultation and the many other problems they have to manage in a short time frame, an effective and efficient way of managing chronic insomnia in children would be to signpost parents to evidence-based resources or to use a resource (such as a guideline) themselves in consultation. GPs in the interviews expressed an interest in gaining an awareness of evidence-based resources or for guidelines to use in practice. Therefore, it would be beneficial to increase awareness of existing evidence-based resources or to develop further evidence-based resources which they can signpost parents to or use themselves for quick decision making.

Finally, both GP and HV interview participants expressed their beliefs that chronic insomnia is a common problem in children that is worth addressing, even though it is infrequently consulted for in general practice. They did however describe that sleep problems can be brought up alongside other issues, or within universal appointments such as vaccinations. Therefore, alongside increasing GP confidence and knowledge through training opportunities and access to resources, it would be beneficial to both increase parents' awareness that it can be discussed as a key concern and encourage GPs to ask about potential sleep problems more often.

6.5.3 Strengths and Limitations

This was the first study to interview PCPs about their management of childhood chronic insomnia in the UK and therefore provides novel research findings. There were over 20 participants and data saturation was felt to be achieved. However, the survey sample was mostly female GPs which could limit generalisability. It would be beneficial to explore this topic with more HV and male participants. Furthermore, similar to the survey, the initial sample was self-selecting, however towards the end of recruitment, purposive sampling was employed to include more male and HV participants. Furthermore, some survey participants in Chapter Five were nurse practitioners (working in general practice) or nursery nurses (in the community), however there were none within the interview sample. Nurse practitioners may also have had different perspectives and experiences due to different levels of training, knowledge and roles within general practice or within the community.

Nevertheless, qualitative interviews allowed an in-depth exploration of the management of chronic insomnia in children in primary care. The in-depth exploration gave transferability of research findings, giving insight into the wider context and explanations behind the survey findings. A possible limitation of the qualitative interviews is that due to direct conversation with the researcher, participants may have been less likely to disclose some information because the interviews are not as anonymous as online surveys.

It was originally planned to conduct the interviews face-to-face, however, due to the coronavirus pandemic, they were conducted virtually. Although there are some benefits to face-to-face interviews, such as potential increased rapport with participants, the remote method ultimately made it easier for participants from many regions within England to take part, and with their busy workload they were more able to take part at a time/place suitable to them.

There are also strengths and limitations of the mixed-methods triangulation which must be noted. Firstly, triangulating the findings addresses the methodological weaknesses of each individual part¹⁸⁴. For example, the survey findings have more generalisability with a larger sample than qualitative findings, but interview findings give more context which would otherwise have been missed and have transferability. Agreement between findings therefore increases their overall reliability. A possible limitation within this research is that the interview participants had previously taken part in the survey and it may be expected that their responses would be similar. Nevertheless, by also taking part in an interview, participants were able to expand on their thoughts, feelings and experiences freely. This provided context to frequent responses and would have highlighted if there were any potential misinterpretations from the surveys. With more time

and an amendment to the ethics committee approval, it would have been ideal to triangulate the findings back with study participants to check their views of the overall study findings.

6.5.4 Conclusion

The interview findings reinforce and add depth of understanding to the survey results (Chapter Five). They highlight that GPs and HVs understand about the impact of chronic insomnia in children up to age five, and that it is a common issue that should be managed in primary care (general practice or by HVs). They also suggest that GPs have limited training and varied knowledge and confidence and are most likely to recommend positive bedtime routines to families. HVs may have more training opportunities on this topic (but further research with more HVs is needed) and are usually perceived as better suited to management. Further research may be needed to develop GP appropriate training opportunities and to increase awareness of and access to evidence-based resources to use or signpost in GP consultations.

Chapter 7 Discussion

7.1 Chapter overview

This thesis explores the management of childhood chronic insomnia in primary care, with a particular focus on children up to and including five years of age within the UK. It includes a range of complementary high-quality research to provide an up to date understanding of the field and highlight potential areas for improving current management and further research. This concluding chapter brings together the current literature and the research findings from this thesis, to answer the thesis research questions and make suggestions for clinical practice. It also reflects on the strengths and limitations of the research within this thesis, how they impacted the research and might direct future research design and focus.

7.2 Overview of thesis studies

The thesis research questions were explored via three research studies. PPI input was sought early in the research programme and within each study. Each study is summarised below.

7.2.1 Study one: Systematic review of existing literature

A systematic review of the literature explored the published evidence base regarding the management of chronic insomnia in children in primary care. This review was not specific to the UK, nor to children under five years of age, to enable an overview of the wider context of the literature. Literature searches were conducted on six electronic databases to find published findings on PCPs beliefs, role perceptions, management and knowledge regarding chronic insomnia in children. Twenty-six studies were included which underwent a systematic narrative synthesis¹⁹⁷ and methodological quality assessment using the MMAT²⁰². Early PPI input confirmed the relevance of exploring PCP attitudes and knowledge. PPI input on a lay summary of emerging findings confirmed relevance, groupings of the findings and the conclusions drawn.

Findings suggested that PCPs are aware of the impact of poor sleep, endorse behavioural management strategies, and generally perceive management as part of their role. However, the identified evidence also suggested that their knowledge and confidence regarding the management of chronic insomnia varies. However, the identified research studies varied in methodological quality, were from a limited number of primary care settings (mostly US paediatricians or UK HVs) and must be interpreted cautiously. Furthermore, the UK evidence was

largely outdated or low in quality, with only two high quality recent research studies focusing on the parent perspective, which differed to PCP perspectives. There have been many changes in technology since the older studies were published, such as opportunity for virtual consultations and online informational or support resources, such as websites, discussion forums, and online documents. This review suggested that knowledge and confidence for PCPs could be improved. It also highlighted a need for further up to date high quality research, such as updated UK research focussing on both parent and PCP perspectives regarding GPs and other community PCP roles.

7.2.2 Study two: Internet forum study of parental perceptions

A qualitative study of parents' posts on online forums was conducted to explore parental concerns and expectations regarding the management of children's BI, awareness of resources online, in the community and in primary care, and perceptions of how their children's sleep problems are managed in primary care. Early PPI input confirmed the importance of exploring parent perspectives and information parents share with one another online and recommended potential forums to include. PPI input on preliminary findings confirmed relevance and groups of the codes, with some minor changes suggested to naming/organisation to make them clearer and more meaningful to people with lived experience of children with chronic insomnia. From two UK parenting forums, 93 discussion threads (approximately 300 pages of data) were analysed with descriptive analysis¹⁹⁸.

Findings suggested that the parents who posted in the online discussion forums had multiple concerns about children's sleep problems, suggesting the parents may have had unmet support needs. Findings also suggested parents often acted as an emotional or practical resource for one another by discussing parents' experiences or sharing advice online as a resource. Despite the concerns and advice commonly shared between parents online, parents infrequently discussed experiences of management within primary care. When primary care was mentioned, it was usually regarding mixed experiences and perceptions of community-based PCPs such as HVs, and there were limited experiences and perceptions of general practice. Parents often discussed other resources for supporting parents with child sleep problems such as online practical or information tools (e.g. apps), non-primary or non-HCPs (e.g. privately paid sleep consultants), and books. Whilst parents shared their own advice and discussed/recommend tools and informational resources to one another, the advice often appeared to be based on personal opinion, or the accuracy of the advice was not explored.

These findings suggested that it would be beneficial to explore further ways to address parents' concerns about their children's behavioural sleep problems, whether that be through creating

further online resources, access to existing evidence-based resources or increasing awareness that freely evidence-based advice can be given or signposted from primary healthcare.

7.2.3 Study three: Surveys and interviews of primary HCPs

A mixed-methods study explored the management of chronic insomnia (described to participants as behavioural) in children aged five years and under, with UK PCP participants. An online survey was advertised via ten LCRNs in England and via a HV manager within an NHS Trust. Survey participants were offered the opportunity to express interest to also take part in an in-depth qualitative interview. Both sub-studies explored knowledge and training, current practice, and views and beliefs. At the design stage, PPI input highlighted the importance of seeking PCP views and suggested questions to elicit meaningful responses to someone with experience of children with chronic insomnia. There were 355 survey participants (mostly GPs) and 21 interview participants (18 GPs and 3 HVs). The surveys were analysed with descriptive statistics and the interviews with descriptive qualitative analysis¹⁹⁸. PPI input on the preliminary interview findings confirmed relevance and readability, with some minor suggestions to names of themes/codes. The findings were triangulated to explore similarities and differences.

Survey findings suggested that the participants perceived a large impact of chronic insomnia and generally believed these sleep problems should be managed in primary healthcare. However, the participants infrequently discuss these problems in consultation. Nevertheless, they appeared more likely to recommend positive bedtime routines than extinction-based strategies or pharmacological treatment. Many participants indicated a lack of awareness of other management resources for parents and a lack of formal training about managing this issue. Knowledge and confidence regarding management appeared to vary.

Interview findings generally echoed the survey findings and provided further detail or explanation. For example, the infrequency of discussion in general practice, potential reasons for this, and why it may be more commonly discussed with HVs. Further context was given to management strategies such as an individualised approach and the role of GP signposting to HVs for in depth management. Findings also suggested that GPs have minimal training and varied knowledge / self-efficacy. HVs suggested they may have more knowledge and access to training, however this needs further exploration. Personal experience was suggested as an influence for PCP feelings, knowledge, attitudes and as a tool for management and to demonstrate empathy.

These findings suggest it would be important to conduct research with more HVs and to potentially increase brief, appropriate GP training opportunities and awareness of evidence-based resources.

7.3 Comparison of findings across studies

The studies within this thesis addressed six research questions, discussed below.

7.3.1 What are PCPs' knowledge, attitudes and beliefs regarding paediatric chronic insomnia?

This research question was addressed by the systematic review reported in Chapter Three and the mixed-methods study reported in Chapters Five and Six.

7.3.1.1 Beliefs: the impact of chronic insomnia

Findings from both the systematic review (Chapter Two) and the mixed-method study (Chapters Five and Six) suggest that PCPs are aware of the importance of good sleep and the impact of chronic insomnia, particularly on psychosocial domains. In quantitative studies in the systematic review and in the Chapter Five survey, there were impacts rated for 'general physical health', 'weight gain' and 'accidental injury', however these were slightly lower rated than psychosocial and family impacts. Further evidence and discussion are in relevant chapters.

The rating scales used for the survey's impact question (Chapter Five) had good face validity when reviewed by myself and expert supervisory team. We adapted them to be specific to chronic insomnia, and the wordings were slightly changed following a pilot with a HV. Prior to this research, they were used in US studies (Faruqui and colleagues²¹⁷, Owens²²⁵, Mindell and Owens¹³⁵). Their data specific to perceived impact were not included in the systematic review because the data was not specific to chronic insomnia. All three reported high impact ratings for all domains, with slightly higher percentages on psychosocial impacts over physiological ones. Findings are also similar to other research using these scales in other settings with general sleep problems. . For example, Richardson and colleagues²³⁷ and Gruber and colleagues²³⁶(Australian medical practitioners and Canadian HCPs, respectively) found participants rated the impact of sleep problems very highly on psychosocial and familial domains (particularly parental stress), and high on other domains. Similarly, qualitative findings both within the mixed-methods study (Chapter Six) and in previous US research^{73,229} highlights PCPs perceptions about the importance of good sleep and impact of chronic insomnia.

It is positive that PCP research reports awareness of the potential impacts of chronic insomnia on psychosocial health. As discussed in the theory chapter (Chapter Two), and chapters Five and Six, the TPB¹⁶⁵⁻¹⁶⁷ suggests that attitudes influence behaviour, so beliefs about reducing the risks of persisting insomnia may positively influence PCP's management. As research indicates PCPs already have good beliefs about the impacts on psychosocial health, in future research or development of support tools / interventions for PCPs, the main focus could be on other attitudes or components of related theories to help improve management. For example, , given the strong evidence base for associations of sleep problems and risk of obesity²⁴ in later childhood, it may be beneficial to address attitudes and increase awareness of potential physiological impacts of childhood insomnia. Other aspects of the TPB such as perceived behavioural control (discussed in 7.3.1.2) which may be limited in GPs could also be a helpful focus.

7.3.1.2 Knowledge: PCP knowledge varies

Studies included within the systematic review generally assessed knowledge via questionnaires, and suggested knowledge varied (as discussed in Chapter Three). However, there were no UK quantitative PCP studies on PCP knowledge prior to this thesis. The survey reported in Chapter Five used questionnaire sub-scales from Mindell and colleagues²²² and Owens²²⁵ and also reported knowledge varied. These quantitative findings are similar to qualitative research in other countries^{223,229} where PCPs reported a lack of training and knowledge about paediatric sleep. Moreover, findings from qualitative interviews within Chapter Six demonstrated that UK GPs had varied perceptions of their knowledge, usually with knowledge coming from personal experience. The small sample of HVs within the qualitative interviews suggested that HVs may have more knowledge than GPs but further research in a larger sample is needed to confirm this. Differences in knowledge between PCPs (e.g. GPs and HVs) and between geographical locations should also be further explored to appropriately target further education.

UK qualitative studies exploring parent help-seeking for sleep problems generally echo research with PCP participants regarding limited or varied PCP knowledge. Cook and colleagues (2020)²¹⁵ explored parents' barriers to help seeking through an online survey; a qualitative analysis of open-ended responses from 62 parents suggested that parents believed HCPs to lack knowledge and training. The HCPs listed in the survey question were primarily PCPs, and illustrative quotes referred to HVs. Similarly, Hatton and Gardani (2018)¹³³ interviewed 15 UK mothers about perceived advice. The authors suggested that nearly all parents believed professionals to have limited knowledge and training, referring to HVs and GPs in the illustrative quotes. Whilst the parents' posts within the internet forum study (Chapter Four) did not refer to perceived knowledge of PCPs, the parents did have mixed attitudes towards their HVs and their advice,

suggesting that some parents did not perceive their HVs to be knowledgeable. Thus, there appears to be a disjoint between parent and HV perspectives of HV knowledge and more research with HVs and parents is required.

An important finding, as highlighted in Chapter Five, was that nearly 70% of PCPs (who were mostly GP practice staff) were unaware of other resources for parents of children experiencing chronic insomnia, which is concerning. Many evidence-based resources exist that would be useful to parents, such as UK NHS websites (NHS Choices ²⁵²⁻²⁵⁴, 0-18 Healthier Together ^{255,256}) and international resources²⁵⁷. An awareness of evidence-based resources could be an efficient and effective management strategy in consultation, even if PCPs have little knowledge of individual strategies themselves.

As discussed in Chapter Two, there are several theories which suggest factors that could influence management by PCPs. The design of any future resources or interventions should focus on improving knowledge of management strategies and existing evidence-based resources which could be easily signposted. This could improve attitudes (towards management strategies and discussing management with families) and perceived behavioural control (within the TPB ^{166,167}) and capability, anticipated consequences (within SCT ¹⁷⁰) and self-efficacy theory ¹⁶⁸. PCPs may feel better equipped, more positive and more confident toward managing this issue. This could in turn improve experience and perceptions of management from parents.

7.3.1.3 Knowledge: PCPs receive little professional training regarding the management of chronic insomnia in children

Whilst the systematic (Chapter Three) did not explore the professional training specifically due to capacity, many studies have reported that HCPs and PCPs receive little to no professional training regarding sleep problems or chronic insomnia. For example, Honaker and Meltzer's narrative review of the management of sleep problems (not specific to chronic insomnia) in primary care ¹³⁴, reported that PCPs had insufficient training. None of the existing research of PCP participants was conducted in the UK. The UK survey and interview study (chapters five and six) reflected existing research with almost all survey and interview GP participants reporting little or no training on this topic during or since professional training. Any knowledge which GP interview participants discussed was usually a result of personal or practical experience, rather than professional training.

This is supported by experiential learning theory ^{163,164} discussed in Chapter Two, whereby differences in PCP's knowledge may be due to factors other than lack of professional training, such as different levels of personal and practical experience of managing chronic insomnia.

Personal experience could be useful in combination with professional knowledge in practice, however, if it is the only source of knowledge, this could carry risks. If the PCP has only had negative experiences with evidence-based interventions, they might be less likely to discuss them as an option with families, or have biased views. Experiential learning theory^{163,164} could be useful for designing any potential future training tools. It may be useful to incorporate brief case studies into training so GPs can practice / think through management and gain more professional experience of managing this issue.

Qualitative UK parent research studies by Cook and colleagues²¹⁵ and Hatton and Gardani¹³³ who reported parents perceived a lack of PCP knowledge, both also suggested that parents perceived HCPs such as GPs and HVs to lack training on paediatric sleep problems. Similar to assessed/perceived knowledge (7.3.1.2), UK PCP data within this thesis suggests that there are differences in training opportunities for HVs compared to GPs. Whilst Chapters Five and Six suggested that GPs have minimal training, the small sample of HVs (Chapter Six) suggested they may have more access to training opportunities either directly or indirectly through colleagues. As discussed previously, further research to survey and interview a larger sample of HVs would help clarify HV training opportunities and inform appropriate targeting of training opportunities to different PCPs.

In March 2022 (after completion of this thesis), a UK programme for managing infant sleep (up to 12 months old) has been made available (for a fee) to HCPs²⁶³. The programme, called 'Sleep, Baby & You', is based on an intervention developed in Australia called 'The Possums Sleep Program'. The intervention was adapted to a UK setting and the UK programme includes training and resources for HCPs (to facilitate their discussions with parents), alongside parent resources. The practitioner training available online includes recordings, guides and both HCP and parent resources²⁶⁴. Previous feasibility testing of the programme with practitioners (including HVs) and parents suggested the intervention would be acceptable and useful to practitioners and parents.²⁶⁵ The positive responses in this feasibility testing highlights the usefulness of increasing PCP training opportunities. However, these training materials are targeted at improving sleep in infants under the age of 12 months (as discussed in Chapter One there are developmental differences in sleep/wake patterns in babies and children), and the HCP training appears more targeted to HCPs who have more in depth contact with infants (such as HVs). It would be useful to explore widening accessibility of resources such as this, to also explore training options regarding toddlers and preschool children, and to explore training options for different types of PCP such as HVs (more in depth training) and GPs (lighter touch training with parent resources and awareness of more in depth resources).

As suggested in 7.3.1.3 and reflecting on behaviour change theories discussed in Chapter Two, increasing training opportunities (in particular for GPs), should increase GP knowledge and should improve PCP's perceived behavioural control (TPB^{166,167}), capability (SCT¹⁷⁰) and self-efficacy¹⁶⁸ and chronic insomnia management. GP consultations are particularly time-constrained and have multiple other areas of health to consider. Training opportunities could focus on brief management strategies and awareness of evidence-based resources for signposting.

7.3.1.4 Attitude: Confidence varies

The systematic review reported in Chapter Three summarised seven studies using quantitative rating scales and revealed PCPs to have varied confidence levels for statements related to management of behavioural sleep problems.. The survey study as discussed in chapter five revealed similar findings, using the same questions from Faruqui and colleagues' study²¹⁷ (specified to chronic insomnia in children aged up to five years old). These findings are similar to studies which employed confidence rating scales but were not included in the systematic review (chapter three) due to lack of specificity to chronic insomnia, or clarity about PCP status. For example, Richardson and colleagues 2021²³⁷ reported that in a sample of 'medical practitioners', mean confidence rating from one to five, was 2.5 for managing 'sleep problems' (not specific to behavioural problems).

A qualitative study in the systematic review indicated that UK HVs in one locality had improved confidence following the implementation of a HV toolkit, though this may not be generalisable to other HVs. In the interview study (Chapter Six) varied confidence levels were reported in mainly GPs, for example confidence to provide basic advice and signposting to HVs, but not any further support. In general, HV participants had higher confidence levels than GP participants. The interviews demonstrated that confidence and self-efficacy were also influenced by factors other than knowledge and training, such as time limits in primary care, personal experience of dealing with behavioural sleep problems, and parental attitudes. . As discussed in 7.3.1.3, whilst personal experience may be useful, this may carry risks.

Reflecting on theories discussed In Chapter Two such as the impact of self-efficacy on behaviour (self-efficacy theory¹⁶⁸), it would be beneficial to improve PCPs confidence in insomnia management in children. In the UK, improving GP self-efficacy appears to be a key area, although further HV research (to explore self-efficacy and confidence in a larger HV sample) is first needed. Providing training opportunities to increase knowledge could help self-efficacy as discussed previously. Given the time constraints in primary care, additional resources or tools which can be used efficiently in consultations, to more confidently provide recommendations, or to more

confidently signpost to other primary care (e.g. from GPs to HVs) or to other support should help management decisions.

7.3.1.5 Attitude: PCP attitudes and role perceptions towards the management of chronic insomnia

Despite varied confidence and knowledge, it appears that PCPs generally perceive management as part of their role. These findings are from studies of mixed qualities within the systematic review (Chapter Three) ^{73,210,217,219,226,228-230}, but also are supported in the survey and interview study (Chapters 5 and 6) which consisted mostly of GPs. As discussed in these chapters, survey participants may have perceived definitions of primary care differently but interview participants also discussed the role of primary care and it seemed that perceptions of general practice and HV roles differed. General practice was often seen as a setting for basic advice or signposting to other PCPs such as HVs, whereas HVs and community primary care roles were seen as more suited to in-depth support and management.

There appears to be a disjoint between parent and PCP perspectives of PCP attitudes. Cook and colleagues' ²¹⁵ conducted a qualitative analysis of parents' free text responses in an online survey about barriers to professional help seeking. The authors suggested that sleep problems (not specific to chronic insomnia, though many parents related to chronic insomnia issues) were not perceived as important to HCPs, that parents believe they are wasting their time and the time of the PCP, or that they have had negative experiences with PCPs in the past. Although data specific to primary care were limited in the internet forum study (Chapter Four), findings suggested mixed experiences and attitudes towards HVs, and a reluctance from parents to consult in general practice due to anticipation of embarrassment or fear of being negatively judged.

It therefore appears that PCPs generally perceive management of childhood chronic insomnia as part of their role, although the management roles may differ between types of PCPs. The disjoint between parent and PCP perceptions warrants further exploration, regardless of whether GPs act as a primary source of advice or to signpost on. Reflecting on theories discussed in Chapter Two, the TPB ^{166,167} suggests attitudes towards management could influence PCP behaviour in consultation, so this could usefully be targeted in intervention/training. When applying the TPB to parents, parental attitudes and beliefs about PCP attitude and role perceptions could influence their decision as to whether to seek support from a PCP and whether to implement any advice they give. Further research could explore this and parents' perceptions and experiences in more detail.

7.3.2 What is the current practice and discussion regarding management of children with chronic insomnia during consultation in primary care?

This research question was addressed by all studies conducted as part of this thesis.

7.3.2.1 Chronic insomnia is infrequently consulted in general practice

Despite the perception that there are major impacts of chronic insomnia on the child and family, and that primary care is suited to management (even if this is just for signposting within or outside of primary care), it appears that it is infrequently discussed in UK general practice.

The qualitative internet forum study (Chapter Four) revealed that the parents posting in the online forums rarely discussed their perceptions of and experiences within primary care. It is uncertain as to whether this is because they do not often go to primary care with this issue, or whether they simply did not talk about it online. Nevertheless, when mentioned, GPs were usually in relation to other issues (such as for reflux or allergies, or to exclude underlying physical causes) and HVs were generally in relation to a range of problems (including behavioural sleep problems), suggesting that this issue may be more frequently discussed with HVs. The survey and interview findings (Chapters Five and Six) echoed these impressions; with the survey participants (mainly GPs) suggesting infrequent consultations, and the interviews highlighting that chronic insomnia was rarely a primary reason for consulting GPs but may be a more common problem for HVs. These findings are similar to previous research such as the narrative review by Honaker and Meltzer¹³⁴ which suggested that sleep problems (not specified to chronic insomnia) are not often addressed in primary care.

Given that parents infrequently consult in general practice with chronic insomnia, that they rarely talk about GP consultations for this online, and that GPs have limited confidence in this area, these findings prompt the question of whether general practice should be the place to consult with chronic insomnia. Should the focus simply be more on signposting to and exploring HV management? HVs seem to be better suited to in depth management and advice. Although consultations are still time-limited, they are the primary contact for children aged up to five^{250,251}. Primarily, further exploration of HV management is required to better support HVs in managing parents.

Nevertheless, research indicates that some parents may have a reluctance to consult in general practice due to anticipation of judgement or a lack of GP knowledge, or that they had already tried their HV and perceived this as unsuccessful (Chapter Four). Thus the frequency of consulting in general practice may be different if parental perceptions about GPs were different. Interview findings (Chapter Six) suggested that some GPs perceive that some parents go to GPs as a last

resort or out of desperation. Providing GPs with the knowledge of where to access high quality resources for signposting parents to will be important to ensure parents who consult GPs are not left feeling unsupported.

Given the prevalence of chronic insomnia symptoms in children up to the age of five, these findings indicate the need for improved quality, evidence-based management or signposting to help for chronic insomnia in primary care when needed. It would be most useful to further support HVs but also to potentially complement this with improved confidence and knowledge for other PCPs such as GPs through training opportunities. Encouraging PCPs to ask about sleep problems more in consultations, and to raise parental awareness of resources would help improve care. Behaviour and learning theories such as SCT¹⁷⁰ and experiential learning theory^{163,164}, discussed in Chapter Two, suggest that positive and negative reinforcement influence behaviour, and concrete experiences also influence knowledge. By asking parents about chronic insomnia and managing it successfully in consultation, PCPs knowledge and self-efficacy will also improve, through practical experience and positive reinforcement.

7.3.2.2 PCPs likely recommendations and action

Despite the limited consultation about this issue in primary care (general practice within the UK), PCPs reported what their advice and management is or would be (explored below).

7.3.2.2.1 Assessment

Assessment and screening were not explored within the systematic review (Chapter Three); however, assessment did come up within the internet forum study and mixed-methods studies (Chapters Four to Six), with some differences between types of PCP. As discussed in these chapters GPs seem to assess to both rule out other problems as a cause of sleep problems and take a sleep history, whereas HVs and community PCPs seemed to focus on the sleep problem and sleep history. All survey and interview PCPs (Chapter Five and Six) described taking a sleep history and assessing the sleep situation as part of their management strategies. Taking a history/assessment are similar to findings from Australian research²³⁰, a mixed-methods survey of MCH nurses. General assessment was highlighted as one of various strategies for likely 'advice for the mother of a six month old infant who wakes frequently overnight or is difficult to settle', including both excluding underlying causes and assessing the sleep problem.

The differences in UK PCP assessment could explain the differences in frequency of consultation for GPs to HVs and reflect the different primary roles of the GP and the HV. Parents who consult a GP as a last resort may be consulting because they think there must be another cause of the sleep problem that is not within the role of the HV. However, they could also be consulting as a last

resort because they feel their HV's management advice was not beneficial. This should be explored further. This suggests that whilst management may be better encouraged from the HV, it should not be discouraged from the GP if they can provide basic advice and signpost to other resources.

7.3.2.2.2 Bedtime routines and other aspects of sleep hygiene

Bedtime routines and/or other sleep hygiene recommendations were common recommendations. As discussed in the survey (Chapter Five) positive bedtime routines consistently appeared the most likely recommendation across all ages up to five years in comparison to other interventions. Other aspects of sleep hygiene and the broader term of sleep hygiene were not listed as a response option in to focus more on the bedtime routine aspect in comparison to other types of interventions (see Chapter Five for further details and consideration of implications). However, the broader term of sleep hygiene came up in the interview findings, whereby most participants described basic advice relating to bedtime routines and/or other aspects of sleep hygiene. In the internet forum study (Chapter Four), where parents mentioned recommendations by HVs this sometimes related to practical changes to sleep environment. The findings suggest that bedtime routines are often recommended which is positive considering it is appropriate for all ages and an important and effective aspect of sleep hygiene. Other behaviourally based interventions such as extinction methods are not appropriate for young infants, whereas bedtime routines and other aspects of sleep hygiene can be encouraged. It may be useful to further explore advice about other areas of sleep hygiene which PCPs would likely recommend.

These findings are similar to previous research. For example, the questions within the survey/interview study (Chapters Five and Six) were used/adapted from earlier studies included within the systematic review ^{211,217,225} (Chapter Three) which also reported bedtime routines or sleep hygiene components as common responses. Moreover, US and Australian qualitative research included within Chapter Three ^{73,230} also suggested the importance of bedtime routines. Other relevant research not included within the systematic review ²³⁷ suggested similar findings. For 'bedtime resistance in a pre-schooler' most medical practitioners (83%, not exclusive to PCPs) reported they would recommend a regular sleep schedule at least half of the time, in comparison to none who would recommend watching TV at bedtime.

As discussed, these findings are positive considering the effectiveness of bedtime routines and other components of good sleep hygiene ^{99,111}. Reflecting on Whittall and colleagues' model of barriers and solutions to implementing extinction-based strategies ¹⁵⁷ (discussed in the theory Chapter Two), this suggests that if implementing a stepped-care approach as they included in the

model, PCPs can implement the initial stages of the stepped care and advise families who only require basic information and support (e.g. bedtime routine advice). This is positive considering the types of PCP who would not usually have time for in depth management (such as GPs), suggesting that although varied knowledge and confidence are reported in GPs, they are still currently providing the basic information and support as described by the stepped care approach.

7.3.2.2.3 Preferences within extinction-based behavioural interventions and an individualised approach to management

As discussed in Chapters Five and Six, it appears that for PCPs generally, gentler extinction-based approaches (e.g. extinction with parental presence) may be preferred to unmodified extinction, and for GPs, extinction-approaches overall are less regularly recommended than bedtime routines. Most GPs did not necessarily describe advising extinction-based techniques, rather they described their views of them, whereas HVs appeared to positively advise parents to try graduated extinction and gradual retreat. This is expected given the role differences reported by GPs and HVs in the interviews and reflects that GPs do not have time to discuss management strategies beyond basic advice such as bedtime routines. In the internet forum study (Chapter Four), when discussing advice they had received from PCPs, parents generally described that their HVs recommended variations of extinction techniques such as graduated extinction and gradual retreat. There were mixed parent experiences about being recommended 'cry it out'. It is important to note, however that parents may refer to extinction techniques by different names, whereas the variations of names of extinction techniques in the survey were given. These findings are similar to previous research. For example, in studies within the systematic review reported in Chapter Three, graduated extinction usually appeared preferable to unmodified extinction^{211,222}.

The fact that extinction-techniques were not preferred are reflected in recent research which tested the feasibility of the 'Sleep, Baby & You' programme²⁶⁵. The programme aims more at responsive parenting and managing expectations. Although this is mainly due to the age of the infants being too young for extinction-based techniques, the authors described that the 'responsive parenting' basis of this programme gave HCPs flexibility for advising based on parents' preferences, and that they preferred this themselves.

It appears that PCPs support an individualised approach to management. This was found in the interview study (Chapter Six) and has been suggested in PCP qualitative research findings from other countries⁷³. Within Chapter Six, it was often mentioned in reference to extinction interventions, whereby familial differences must also be taken into account when deciding on intervention. Moreover, the individualised approach within the interview findings suggests that the survey participants' differences in likely recommendations may also be due to their

perceptions of parental preferences. Recent research has also evidenced that parental cognitions about their own sleep are associated with perceptions of child sleep problems and child sleep practices²⁶⁶, which further emphasise the importance of individualised discussion and management advice.

In relation to theories presented in Chapter Two, this is supportive of and explained by both sides of the debate around extinction-based interventions, whereby parents have been reported to have concerns regarding future consequences of extinction-based techniques¹¹⁴, but that evidence suggests they can be effective⁹⁷, often resulting in a preference of gentler techniques over unmodified extinction. It is also supportive of Blunden's application of Bronfenbrenner's model to sleep education¹⁵⁸, and Whittall's theory¹⁵⁷ which include a flexible or stepped-care approach to different sociocultural, infant and parental factors (discussed in Chapter Two). Some interview GPs did describe their own personal opinions regarding extinction techniques which may also reflect their own personal experiences (having children themselves), and further reflect the complexity of the extinction debate.

7.3.2.2.4 Signposting from general practice

Whilst there do not appear to be many recommendations for management techniques beyond bedtime routine advice (suggested in the survey and interviews reported in Chapters Five and Six) and sleep hygiene (suggested in Chapter Six's interviews) in general practice, the value of signposting to other PCPs or resources for further management is recognised. For example In the Chapter Six interviews, GP signposting to HVs or other community PCPs, or signposting to other resources (though this was less common than to other PCPs, they were not necessarily evidence-based). See 7.3.6 for further discussion. However, as discussed in Chapter Five, many GPs were unaware of other resources for parents and this is concerning because GPs cannot signpost to other evidence-based resources if they are not aware of them. There is little other research exploring signposting to resources specifically, however, some US qualitative studies suggested conflicting findings. One²²⁹ suggested PCPs wish for more resources, whereas another⁷³ suggested they already signposted many resources (electronic, other PCPs and printed). No other research has explored UK GPs specifically. As discussed in Chapter Six, awareness of resources may differ between types of PCP. In particular, US paediatricians may have more training on other resources than UK GPs.

It is promising that GPs see it as their role to signpost to other PCPs and resources if they are unable to advise in detail themselves, reflecting a positive attitude (which as suggested by the TPB^{166,167}, discussed in Chapter Two, contributes to behaviour). However, lack of awareness of alternate resources could limit perceived behavioural control' (also TPB^{166,167}) and 'capability' and

'self-efficacy' (SCT¹⁷⁰). It would be useful to confidently be able to signpost other evidence-based resources when needed (particularly for any 'last resort' consultations whereby parents have already sought help from other PCPs such as HVs. Therefore, alongside current practice to refer to HVs, an important future goal is to increase overall perceived behavioural control and capability by increasing awareness of and signposting to evidence-based resources which increase the chances for better outcomes for families.

7.3.2.2.5 Preference of behavioural to pharmacological treatment

Findings within this thesis suggest that PCPs generally preferred behavioural treatment approaches over pharmacological approaches. As discussed in Chapter Five, survey findings suggested that more participants (mostly GPs) agreed that chronic insomnia (described as behavioural) should be managed with behavioural interventions, than for pharmacological approaches. Interview participants (Chapter Six) mostly appeared to be against prescribing pharmacological treatment, with some GP exceptions for particular circumstances, and some GPs perceived that parents sometimes come to primary care, for a 'quick fix' pharmacological prescription which they wouldn't prescribe.

Whilst a higher percentage of survey participants seem to prefer behavioural approaches to pharmacological management, the fact that 21.5% agreed that it should be managed with pharmacological approaches is still high. However, the survey questions in Chapter Five did not differentiate between types of pharmacological treatment. Nonetheless the British National Formulary for Children¹⁰² suggests that melatonin is not prescribed by PCPS, unless being continued and reviewed with a specialist HCP every six months. Further, it is usually used with neurodevelopmental disabilities. Pharmacological recommendations in other research appear to vary. For example, 14.8% of Mindell and colleagues' sample²²², and 58.54% of Bruni and colleagues' sample²¹¹ of US paediatricians would likely recommend pharmacological approaches, though these were not specific to chronic insomnia as the sleep problem. Nevertheless, pharmacological recommendations were less favoured than behavioural interventions. Whilst it is promising that behavioural approaches are preferred to pharmacological ones, international guidelines¹⁰¹ suggest behavioural treatment as a first approach to chronic insomnia, so the percentages of PCPs using pharmacological approaches for chronic insomnia should be further explored.

Reflecting on SCT¹⁷⁰, self-efficacy theory¹⁶⁸ and the TPB¹⁶⁵⁻¹⁶⁷ discussed in Chapter Two, the use of behavioural versus pharmacological approaches could also usefully be discussed in any future HCP training or resources to improve capability and confidence for advising about chronic insomnia where pharmacological management is not appropriate. This would be useful for GPs

when they perceive parents consult for a prescription, but they are unable to advise about in-depth behavioural strategies. Increasing knowledge and confidence (important components of these theories) for advising against unnecessary medication would support discussions with parents.

7.3.2.2.6 Emotional support

As discussed in Chapter Six, a theme within the interview findings relating to GPs and HVs was the role of emotional support and management of wider difficulties experienced by parents of children with chronic insomnia within primary care. Whilst this is not explored specifically in other research, one UK parent study²¹⁵ explored help seeking and suggested some parents had negative experiences from PCPs or the perception that their PCP would not be emotionally supportive. In a free text response on their online survey, 38 parents perceived HCPs to have a “dismissive or patronising attitudes towards parents”. However, the survey may have included other sleep problems. In the internet forum study (Chapter Four), mixed attitudes towards HVs suggested parents perceived mixed emotional support, and some parents described anticipation of (or negative experiences of) negative support from GPs.

Mixed findings regarding emotional support may again suggest differences between PCP and parent perceptions of their PCPs. This should be further explored within parent and HV research, particularly for any differences for PCP type. However, by increasing the frequency with which PCPs ask parents about chronic insomnia in consultation, and their knowledge and resources to signpost to, these parent perceptions may become more positive.

7.3.2.2.7 Normalisation of sleep problems

There appeared to be some recommendations and beliefs that chronic insomnia is normal and that the infants and children will outgrow them. This was reported in the survey findings but the frequency of this decreased as the age of the child increased (see Chapter Five for further details). This could be expected due to developmental changes in sleep/wake patterns in the first five years as discussed in Chapter One, e.g. young babies have more variable sleep patterns²⁶⁷ and are not expected to sleep through the night²⁶. However the significance between age groups in the survey responses was not tested for, and most of the survey participants were GPs. Although normalisation was discussed by some HV interview participants (Chapter Six), this needs further exploration with HVs.

This is similar to other research where nearly 50% in Mindell and colleagues' study²²² and 77.89% in Bruni and colleagues' sample²¹¹ would usually or always say they will outgrow the problem. Wynter and colleagues' (2015)²³⁰ mixed-methods survey of 247 Australian MCH nurses suggested

that for mothers of infants who are frequently waking at night, some (n=55) would 'reassure that some night waking is normal'. The interview findings (Chapter Six) and internet forum study findings (Chapter Four) also highlighted PCP normalisation of sleep problems.

Whilst PCPs are right to reassure/advise families that sleep problems are normal in children, this doesn't mean they will resolve over time on their own. In a longitudinal study of 359 children up to three years old ²⁶⁸, 21% of parent reported sleep problems (a global rating) at the beginning of the study continued. 'Sleep onset latency' and 'sleep duration' scores were significantly associated with their respective score at each time point (six, 12, 24 and 32 months) and night waking was also significantly associated at all times except for non-significant between the six and 36-month time points. In a previous UK longitudinal study with 308 children ⁹², 41% of children with parentally reported behavioural sleep problems at eight months persisted to three years. In an RCT of behavioural intervention at seven months old, 55% and 32.6% of families not receiving the intervention still reported a sleep problem at age 12 months and two years respectively ^{155,269}. Therefore, although children's sleep problems may resolve as they develop, there are still a significant number who may have persisting troubles ²⁶⁸. Given the risks of persisting sleep problems discussed in Chapter One, it is still important to attempt prevention and management.

Normalisation and reassurance that sleep problems in infants and children are a common issue, communicated in the right way, could also be seen positively by parents such as in the form of emotional support described in 7.3.2.2.6. The feasibility study of the 'Sleep, Baby & You' programme for infants up to 12 months old ²⁶⁵ discussed in 7.3.2.1 highlighted that a positive aspect for parents was the reassurance about what was normal. One parent was quoted "knowing that this [night waking] is normal is helpful". (page 8). The question of what was normal was also a prominent concern in the parent online forum study (Chapter Four), highlighting the usefulness of appropriate normalisation.

The PCP normalisation discussed in these studies could therefore be interpreted differently. Some parents may view this negatively as invalidating their concerns in the consultation, whereas others may see it as reassurance that what they are going through is normal. Whilst chronic insomnia is common in young children, if parents are concerned about it, and it is having a negative impact on the family, reassurance can be helpful, but it is also important to make some recommendations as to how to improve the situation. If parents perceive advice as dismissing their valid concerns this could have negative effects such as on their help-seeking in the future. For example, a qualitative study of UK parents highlighted that "dismissive or patronising attitude towards parents" was a barrier to seeking help from HCPs ²¹⁵. Reflecting on theories in Chapter Two, this is supported by relating 'attitude' within the TPB ¹⁶⁵⁻¹⁶⁷ and 'anticipation of outcome'

within SCT¹⁷⁰ to parents. A negative attitude of how they believe the consultation will go, or anticipation of a negative outcome may inhibit the parents' behaviour of PCP help-seeking, regardless of PCP type. Therefore, it may be useful to explore how PCPs such as HVs discuss this topic with parents, and it would be useful to include in any future PCP training resources (regardless of PCP type) information on how to most effectively reassure parents alongside advice.

7.3.2.2.8 Using personal experience

Some GPs (Chapter Six interviews) described the influence of personal experience on their management such as discussing personal experiences with parents to recommend strategies or to improve patient-doctor communication. This is interesting because GPs may not use personal experience in the same way with other aspects of health and this should be further explored. As discussed, using personal experience without professional knowledge carries risks.

7.3.3 What are parents'/families' knowledge and perspectives on the management of children's chronic insomnia within primary care?

This research question was primarily addressed by the qualitative internet forum study (Chapter Four) where although parents did not express much online regarding primary care management, they expressed many concerns about their children's sleep problems. This suggests an unmet need that could be addressed within primary care.

As discussed in 7.3.2.1 It is not certain why parents did not express much online about primary care. However, in combination with findings from Chapter Five, it appears they do not consult in general practice, and some findings in Chapters Four and Six suggest that parents may either not think to consult a GP about this issue, that they leave it to the last minute, or because they have had negative experiences in the past (see the relevant chapters for more information)..

Furthermore, as discussed in 7.3.1.5, parents described negative experiences, or anticipation of negative experiences if they were to consult with this issue, whereas some GPs in the interviews described the perception that some parents do not think to come to primary care. Nevertheless, when parents did discuss perceptions and experiences of primary care in the online discussion forum study (see Chapter Four) these differed by type of PCP and UK HVs were discussed more than GPs. Parents described mixed experiences and recommendations from their HVs and parental attitudes to their HVs also appeared mixed (see Chapter Four for further details) On the other hand, GPs were much more common for non-sleep problems, as a last resort, or in relation to checking whether there were underlying causes instead of managing the sleep problem itself and few parents discussed management in regard to the sleep problem itself.

As discussed in 7.3.1.5, there may therefore be a disjoint between parent and PCP perceptions of primary care's role in managing chronic insomnia in children (e.g. why it's not often discussed in consultation, what is available and how it is actually managed). Parent studies suggested parents had negative perceptions of PCP inflexibility and likelihood of recommending extinction-based interventions. Reflecting on theories in Chapter Two, this further suggests that implementation of approaches such as Whittall and colleagues' model¹⁵⁷ which considers individual differences and a stepped-care approach would be useful. This theory could be helpfully incorporated into any training opportunities or the development of any resources for PCPs to signpost to, or for guidance of which resources to signpost. For example, a guide for stepped care would be useful, highlighting which resources for different levels of care would be most appropriate.

This parent-PCP disjoint should also be explored further with interviews of UK parents specifically about their perceptions and experiences with primary care; for example what they perceive current management to be like, what they feel it should be like, whether they would consult in primary care and with who/why, and whether there are any areas for improvement. This would also expand on parent data regarding their perceptions of both GPs and HVs. Moreover, increasing the frequency with which PCPs ask parents about chronic insomnia, and increasing training opportunities and awareness of resources to signpost to (therefore increasing flexibility in management strategies) could improve perceptions for both parents and PCPs and perceptions may become more positive.

7.3.4 What resources are available online and in the community for parents and caregivers of children with chronic insomnia?

This research question was primarily addressed by the qualitative internet forum study (Chapter Four). Whilst the parents did not often discuss their views and experiences of management within primary care (it did not seem that they saw GPs as a source of information about behavioural management), they did discuss their views and experiences of other resources.

7.3.4.1 Peer emotional / practical support online

As discussed in Chapter Four, parents particularly appeared to act as a practical and emotional resource for one another online, sharing their own routines recommending other resources, or reassuring that others had been in similar situations. Routines and personal advice differed, and there were differing views and advice regarding debates such as the use of extinction-based interventions and co-sleeping. This supports both sides of the theoretical debates about self-settling and extinction-based techniques (discussed in Chapter Two) whereby some parents were concerned about the attachment consequences for their child, and others were more concerned

with increasing their child's current sleep.. Although parents often shared their own advice and routines, it is uncertain how accurate their advice was. Many appeared to be based on opinion. Accuracy should be explored with further research. Some interview participants (Chapter Six) commented on the potential usefulness of online support groups and in person support groups, however no specific groups were named.

This is supported by Hatton and Gardani ¹³³ who interviewed UK mothers about their perceptions of advice on sleep. They suggested that parents liked to seek advice from parents going through the same problems. However, the authors also reported that parents tended to seek advice online as a result of "filling the gap created by both a lack of contact with professionals and family members". They suggested that online advice is perceived as more accessible, however that parents had some concerns about the accuracy of the advice shared. Therefore, whilst parent discussion forums offer valuable emotional support between parents, they do not guarantee quality evidence-based advice.

The differences in parent views about management strategies further emphasise the importance of other flexible sources of advice for families and highlights the potential usefulness of improved care based on theories such as Whitall and colleagues' stepped care suggestion ¹⁵⁷ and Blunden and colleagues' application of Bronfenbrenner's Ecological Model to sleep education ¹⁵⁸. The new programme 'Sleep, Baby & You' ^{263,265} appears to offer this flexible care for families with infants, however it would be useful if there was something similar for toddler and preschool children.

7.3.4.2 Websites, social media, apps and books

Within the internet forum study, other resources were discussed (user experiences, advice relating to them, or soliciting other parents' views about them). Many of the resources were informational or practical tools (see Chapter Four for further details), however it is unclear how evidence-based the resources are. Many evidence-based resources exist online, such as NHS ²⁵²⁻²⁵⁶ and international resources ²⁵⁷, however formal evidence-based resources were not often mentioned.

As previously discussed some interview participants (see Chapter Six for further information) were aware of some books, support groups and parenting courses in particular locations, and social support from family. Some evidence-based informational resources online were mentioned, however, not as much as other informal resources, and Chapter Five suggested that PCPs (who were mainly GPs) were not aware of resources. As also discussed, existing US ^{73,229} research presented conflicting findings about PCP perceptions of other resources for parents. This could depend on different primary care systems within different countries, or different types of PCPs

within countries. For example, UK GPs have a multitude of different problems to manage. HVs also have a high workload, however this is more focussed on common problems in young children²⁷⁰. It would be beneficial to increase accessibility and awareness of common resources through individual ways in which different PCP types already practice.

Therefore, current evidence-based resources do not have much impact and parents and PCPs (particularly UK GPs) may not be aware of them. Alongside increasing access and awareness of current resources, it would be beneficial to create further evidence-based online and community resources which would have more of an impact and be shared between parents and PCPs. As demonstrated by Hatton and Gardani's findings¹³³ which suggested a parental preference for professional advice and some uncertainty of the accuracy of advice online, it may be more impactful if evidence-based resources are signposted by PCPs. As websites, online forums and apps still appear to be popular among parents, online platforms may be useful for the development of more evidence-based resources.

7.3.4.3 Non primary care professionals

Parents in the online forum study (Chapter Four) often discussed the use of consulting others such as secondary HCPs or privately paid sleep consultants/specialists, although there were mixed attitudes towards the sleep consultants also. It is important to note that privately paid sleep consultants are not regulated by a professional body as NHS staff are and are not freely accessible. Therefore, the advice from private consultants may not necessarily be reliable or correct, and can be expensive to access. Mindell and colleagues²⁷¹ reiterated these concerns by highlighting that US non-healthcare 'sleep coaches' (not specific to chronic insomnia) have varied training and qualifications, and a lack of regulations for both knowledge and practice, although training and qualifications are more likely for behavioural sleep problems. They also highlighted legal concerns and concerns with costs limiting access to care for some families. The authors also noted the similarities with these concerns in sleep coaches internationally. This supports the need to increase awareness of evidence-based information through primary care NHS staff, over costly and potentially unregulated private sleep consultants.

7.3.5 What resources/interventions are currently available or accessible in primary care for parents and families of children with chronic insomnia or for PCPs?

This research question was addressed by the qualitative internet forum study (Chapter Four) and the mixed-methods study (Chapters Five and Six).

Chapter 7

As discussed in Chapter Three (section 3.2.1), primary care interventional studies were not included within the systematic review (unless they reported an implemented intervention in primary care), but scoping revealed many interventions exist which could be used in primary care.^{96,97,120} Some studies included within the systematic review suggested that there are some resources and interventions available for families within primary care, however these were individual to different countries and type of PCP. For example, UK HV studies suggested that HVs in one locality have 'packs' which they can use themselves and give to families²⁰⁹, whereas there appear to be behaviour clinics available within some primary care pediatric offices within specific locations within the US²²¹. Other research suggests that there were clinics available for families through UK HV services, however they still required a referral from the HVs, so were not eligible to be included within the systematic review (they were not described as a first point of access as required for eligibility). Within Australia, there are some residential stays for families of unsettled infants, with referral from a GP or sometimes a self-referral. However, these studies were also not included in the systematic review as the intervention required a referral. These studies therefore suggest there are interventions/resources within particular countries and types of primary care, however these are only a small number of studies, and often the authors (particularly of UK HV research) do not provide much detail regarding the content of their recommendations/interventions and there is no research exploring what is available in UK general practice. Moreover, many of them still require referrals, so it is uncertain how quickly and easily parents can access their advice. As parents within the qualitative internet forum study (Chapter Four) rarely discussed primary care, available interventions/resources were not explored beyond mixed attitudes and experiences regarding community primary care and limited experiences regarding general practice. Nevertheless, this may be an indication there are limited resources in primary care and in particular general practice.

As discussed previously, the survey reported in Chapter five and interviews (Chapter Six) suggested limited GP awareness of evidence-based resources. Some resources (Chapter Six) mentioned were 'sleep hygiene maps', questionnaires which help to screen for sleep problems among other issues (used by HVs) and some informational websites, but most referred to awareness of non-evidence-based resources. GP Interview participants expressed an interest/need for further evidence-based resources to signpost parents to, or for guidelines/algorithms to use in consultation. As discussed previously, limited awareness and use of evidence-based resources is concerning, and awareness, accessibility, and use/signposting of evidence-based resources should be improved within primary care. Reflecting on theories discussed in Chapter Two, future development of guidelines/algorithms could be based on stepped care and flexible sleep education models described previously by Whittall and colleagues

¹⁵⁷ and Blunden and colleagues ¹⁵⁸ whereby advice is tailored by familial preferences, cultures and sleep history and circumstances.

As discussed in 7.3.1.3 and 7.3.2.2.3, the 'Sleep, Baby & You' HCP intervention programme was recently pilot tested in the UK and then in March 2022 made available to HCPs online. The programme manages expectations and provides alternative flexible support to extinction-based methods through parental education about these topics to parents reporting infant sleep disruption. The HCPs in the pilot study emphasised the usefulness of providing the parental education as anticipatory and preventative guidance in antenatal and postnatal sessions. As discussed, this intervention is extremely useful, however it would be beneficial to explore similar options for older ages and for similar training/intervention more suited to GPs when needed.

7.3.6 What are PCPs' beliefs about various online community resources for parents/caregivers of children with chronic insomnia?

This research question was addressed by the mixed-methods study (chapters five and six). Given that many participants within the survey were unaware of other resources or sources of support for parents of children with chronic insomnia, there are limited findings regarding beliefs of online and community resources.

For the online and community resources discussed by interview participants (Chapter Six), such as books and support groups online, there appeared to be mixed perceptions of them. As experiential learning theory ^{163,164} suggests, personal experience could therefore influence beliefs and knowledge regarding online and community resources, as well as about managing sleep problems themselves. This could be useful by recommending resources which had worked on a personal level, however if a PCP has had little/negative experiences with resources themselves, they may be less likely to make recommendations. Alternatively, it may influence them to recommend resources to families for which the content may not be suitable to those individuals or are now outdated (e.g. resources about graduated extinction when families are not willing to implement it). Again, it would therefore be beneficial to assess the quality of the resources, and to combine personal knowledge of resources with up-to-date professional knowledge of resources.

7.4 Implications

7.4.1 Future research in the field and beyond this thesis

It would be beneficial to survey and interview parents and carers of children experiencing chronic insomnia. The qualitative internet forum study provided some parents' perspectives; however, interviews and surveys could explore their perceptions, views and experiences in further detail which would complement PCP interviews and surveys. They would provide further information into what parents currently perceive is available to them in primary care and specifically by GPs. It would also be important to conduct further research with community PCPs such as HVs, due to the limited HV sample within this thesis. It is necessary to further explore the knowledge, training and practice of HVs to be able to most effectively target further steps into improving the management of chronic insomnia in children. Interviews and surveys with parents and/or community PCPs could also be used to inform the development of further evidence-based resources or changes to practice. For example, by exploring their views on the best platform for online resources, what information they would like, and the best ways to spread awareness and access to evidence-based resources. It would also be beneficial to explore the accuracy of the information and resources shared by parents with one another in the online discussion forums.

Current evidence-based resources do not seem to be accessed or to have much impact on parents or PCPs. Signposting to evidence-based resources would be a quick and effective strategy for managing chronic insomnia in children with a time constrained consultation. Research is needed exploring the best way to increase awareness of these resources, or to develop further evidence-based resources which are more impactful/ accessible and can be signposted to by PCPs or used by PCPs for decision making. For example, some interview participants in Chapter Six expressed that it would be useful to have more evidence-based resources to signpost to and a clear guidelines or 'algorithm' that could help direct their recommendations.

It may also be beneficial to develop brief and tailored professional training for PCPs (GPs in particular) that want them. There was a clear interest in future training opportunities in the survey and interview findings, however, due to time constraints and priorities with other medical problems, GPs understandably had specific requirements for what would be useful and possible to attend alongside their other work commitments. An example of a training opportunity could be a short online training module which they could complete in their own time.

7.4.2 PCPs and clinical practice

It would be important to support continued HV management of chronic insomnia in children. Nevertheless, it may also be useful to increase GP training opportunities. GP knowledge and confidence appear to vary and a lack of training was an unmet need mainly for GPs within the survey and interviews, and this unmet need and lack of PCP training is in line with similar literature^{134,137,236,272}.

Along with increasing parental awareness that it can be discussed, PCPs such as GPs should also be encouraged to ask about chronic insomnia symptoms in children more often. Chronic insomnia is a common issue for parents who report multiple concerns regarding sleep problems and potential unmet management needs. While PCPs perceive it as a common issue that has a major impact on families, it appears to be rarely discussed in GP consultations despite PCPs feeling that primary care would be a good place to manage or signpost to help. Asking parents about chronic insomnia symptoms more often may prompt them to seek help from primary care when they otherwise would not, or it would provide help before they reach the point of desperation.

Importantly, awareness of and access and signposting to evidence-based resources should be improved. Whilst there are many existing evidence-based resources, particularly online resources such as NHS websites²⁵²⁻²⁵⁶, many GPs are not aware of them, and have mixed views about other resources such as support groups and books.

7.4.3 Implications for parents, children and families experiencing chronic insomnia

Parents have unmet support needs as evidenced in Chapter Four. Hatton and Gardani suggest parents seek online information in response to a lack of professional support (but can also be uncertain about the accuracy of online advice)¹³³. It would be useful to improve awareness and access to trusted evidence-based resources both in and outside of healthcare. These could then be further shared between parents in online discussion forums.

Also important is to raise awareness among parents and families that sleep problems can be discussed with HVs, but also that if they do need to consult a GP, that they would not be wasting PCP time. They do not need to leave the issue until they are desperate, 'as a last resort', and that despite short consultation times, PCPs can signpost to resources or other PCPs who can help.

7.5 Strengths and limitations

There are strengths and limitations discussed individually for each study in the relevant chapter. Overarching thesis strengths and limitations are discussed here.

Chapter 7

This research offers novel insights into the management of chronic insomnia by UK GPs, where data was lacking, and updated contemporary findings on management by HVs.

This thesis largely employed a mixed-methods approach, not limiting the research within to one methodology. The systematic review (Chapter Three) involved a systematic narrative synthesis of all methodologies to summarise the published literature, without excluding any types of primary research studies. Whilst study findings could not be directly compared, it provided a comprehensive view of the existing evidence-base and gaps in the literature to appropriately guide subsequent research within the thesis. The mixed-methods study of surveys and interviews of PCPs allowed each part of the study to provide complementary findings and address the methodological limitations of the other. It would have been useful to also include a mixed-methods approach to exploring parent perspectives, however it was not feasible within the timeframe of this thesis. Previous research suggesting a lack of UK PCP research, as well as PPI input, highlighted the importance of including PCP participants. The viewpoint of parents was still included within the thesis via a detailed qualitative exploration of their posts online.

All three studies generated a sufficient amount of data and participants, with over 300 pages of parents' discussions, more than 350 survey participants (across 10 regions in the UK) and more than 20 interview participants. However, most survey and interview participants were general practice staff (mainly GPs), with few community PCPs in the samples. The survey and interview findings are therefore limited in generalisability and transferability to PCPs other than GPs. Furthermore, because few findings from the online forum study related to primary care, limited inferences can be made about parents' perceptions of management within primary care. Nevertheless, the exploratory nature of the qualitative methodology gives an indication of parent's experiences and the limited reference to primary care is a finding in itself.

PPIE input was sought for all studies. Four contributors were involved, all with personal experience of behavioural sleep problems in their children. One was involved from the early stages, commenting on study plans and the relevance of the research. One commented on the systematic review findings, one on the internet forum findings, and three on the interview findings. It would have been useful to involve more PPI members for each activity at more stages, and to include a more diverse sample of PPI contributors. Nevertheless, one of the PPI contributors remains keen to be involved with any future activities relating to this research. They will be asked to comment on lay summaries of the studies and to be involved in dissemination of the findings (e.g. through publication).

Personally, the development of this thesis has been a challenging yet valuable learning experience. There were challenges in conducting the systematic review (Chapter Three),

particularly synthesising wide-ranging types of studies included. However, the purpose of the review was to provide an overview of as much of the literature as possible which helped to guide the other thesis studies. It was also challenging to adapt the mixed-methods study in response to the coronavirus pandemic, converting to remote interviews and expanding the online survey to multiple LCRN regions in the UK. Nevertheless, this proved to be a valuable experience, not only because it helped increase the survey and interview uptake, but also because it provided experience with a larger network of LCRN regions.

7.6 Conclusion

To conclude, these study findings suggest that PCPs are aware of the importance of sufficient sleep and the prevalence and impact of chronic insomnia on the child and family, and believe that it is something that should be addressed or signposted within primary care. Despite this, chronic insomnia within UK general practice appears to be infrequently consulted about, GPs have varied knowledge and confidence, and minimal professional training in the field, and many GPs are unaware of evidence-based resources which they could use or signpost parents to. Nevertheless, UK PCPs recommend or would recommend sleep hygiene and positive bedtime routine strategies, and generally prefer gentler methods of extinction-based behavioural sleep interventions over complete extinction methods.

Further research should further explore UK HV and parent perceptions of the management within primary care, to guide the next steps to improving the management of chronic insomnia in children. Research should also be conducted to develop and improve awareness/access to current and new evidence-based resources, and to encourage more discussion between parents and PCPs regarding this issue. More signposting from general practice to evidence-based resources and HVs could be a simple, quick and effective management strategy, reducing risks of the consequences of persisting chronic insomnia. Brief and tailored professional training opportunities should also be increased for UK PCPs to meet this expressed need.

Appendix A Chapter Three (Systematic review study)

Appendices

A.1 Initial eligibility criteria

Table 25 systematic review Initial eligibility criteria

	Inclusion	Exclusion
Population	Parents/carers of children presenting in primary care with any sleep problem and GPs treating paediatric sleep problems (or similar such as HVs / community nurses)	A study sample that does not include parents (or carers/families) of children with sleep problems) or primary HCPs. Studies which are about children with co-morbid physical or mental health problems/disabilities. If the sleep problem only refers to enuresis / sleep disordered breathing or movement disorders such as rocking.
Intervention	Any intervention or resource for sleep problems, discussion about sleep problems. Interventions also include anything that influences HCPs' knowledge such as educational material, training, courses or curricula.	n/a
Setting	General Practice or the community (if the community setting is based from HCPs, such as HVs or community nurses etc).	Not in a primary care setting or community setting that is based from HCPs such as HVs or community nurses.
Outcome:	GPs' and HVs' understanding, knowledge, perceptions and current practice regarding children's sleep problems in primary care.	Not about children's sleep problems or PCPs' understanding and knowledge of children's sleep

	The primary outcomes will be primary HCP attitudes, knowledge, understanding and current practice regarding the management of BI in primary care. Sleep problems in this review refer to insomnia, dyssomnia, parasomnia, bedtime resistance, sleep quality and efficiency, duration, onset latency, hygiene, routine, night awakenings, daytime napping, daytime sleepiness and/or sleep stability.	problems. Not the correct outcomes. Sleep outcomes that are only about enuresis, sleep disordered breathing disorders or movement disorders (e.g. rocking).
Study design:	Any (including qualitative, quantitative or mixed-methods studies, descriptive and exploratory studies, cross-sectional and longitudinal studies. Randomised controlled trials (RCTs) and non-RCTs).	n/a
Language:	Any	
Publication:	Any type and year. Peer-reviewed	

A.2 Electronic Database Search terms

See below the search strategy for each electronic database. Highlighted in yellow are the additions to the initial search strategy to make the final search strategy in March 2019.

A.2.1 EMBASE 28 March 2019: 3082 results (previously 1887)

1. sleep/ or daytime somnolence/ or dream/ or dreaming/ or drowsiness/ or night sleep/ or nightmare/ or nonrem sleep/ or rem sleep/ or sleep pattern/ or sleep quality/ or sleep stage/ or sleep time/ or sleep waking cycle/ or sleep walking/ or slow wave sleep/ or somnolence/ or sopor/ or unpleasant dream/ or vivid dream/
2. exp insomnia/
3. parasomnia/
4. (sleep* or insomnia* or parasomnia* or dyssomnia* or "limit setting disorder" or "limit setting type" or "sleep onset association disorder" or "sleep onset association type" or "bedtime resistance").mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]

5. 1 or 2 or 3 or 4
6. child/
7. infant/ or baby/
8. toddler/
9. (child or children or infant* or paediatric* or pediatric* or kid or kids or "under fives" or "under 5s" or baby or babies or toddler or toddlers).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
10. 6 or 7 or 8 or 9
11. 5 and 10
12. primary health care/
13. general practice/
14. health visitor/
15. general practitioner/
16. exp nurse/
17. (primary adj3 care).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
18. "first line care".mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
19. "health visitor*".mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
20. ((community or practitioner) adj3 (nurse* or nursing)).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
21. ((family or general or primary) adj3 (doctor* or physician* or practice or practitioner*)).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
22. pediatrician/
23. community care/
24. (pediatrician* or paediatrician*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]

25. (community adj3 (health or service* or care)).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]

26. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25

27. 11 and 26

A.2.2 MEDLINE 28 March 2019: 1281 results (previously 751)

1. exp Sleep/

2. Dreams/

3. exp Sleep Wake Disorders/

4. (sleep* or insomnia* or parasomnia* or dyssomnia* or "limit setting disorder" or "limit setting type" or "sleep onset association disorder" or "sleep onset association type" or "bedtime resistance").mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

5. 1 or 2 or 3 or 4

6. child/ or infant/

7. (child or children or infant* or paediatric* or pediatric* or kid or kids or "under fives" or "under 5s" or baby or babies or toddler or toddlers).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

8. 6 or 7

9. 5 and 8

10. Primary Health Care/

11. exp General Practice/

12. nurses/ or nurse practitioners/ or nurse specialists/ or nurses, community health/ or nurses, international/ or nurses, male/ or nurses, public health/

13. General Practitioners/

14. (primary adj3 care).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

15. "first line care".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word,

protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

16. "health visitor*".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

17. ((community or practitioner) adj3 (nurse* or nursing)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

18. ((family or general or primary) adj3 (doctor* or physician* or practice or practitioner*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

19. pediatricians/ or neonatologists/ or physicians, family/ or physicians, primary care/

20. community health services/ or community health nursing/

21. (pediatrician* or paediatrician*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

22. (community adj3 (health or service* or care)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

23. 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22

24. 9 and 23

A.2.3 CINAHL 28 March 2019: 838 results (previously 634)

S29	S12 AND S28
S28	S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27
S27	community N3 (health or service* or care)
S26	pediatrician* OR paediatrician*
S25	(MH "Community Health Centers") OR (MH "Community Health Services")
S24	(MH "Pediatricians")

Appendix A

S23	(family OR general OR primary) N3 (doctor* OR physician* OR practice OR practitioner*)
S22	(community OR practitioner) N3 (nurse* OR nursing)
S21	"health visitor*"
S20	"first line care"
S19	primary N3 care
S18	(MH "Nurse Practitioners")
S17	(MH "Nurses by Role") OR (MH "Advanced Practice Nurses") OR (MH "Pediatric Nurse Practitioners") OR (MH "Nurse Midwives") OR (MH "Practical Nurses") OR (MH "Family Nurse Practitioners") OR (MH "Neonatal Nurse Practitioners") OR (MH "Nurses")
S16	(MH "Community Health Nursing") OR (MH "Family Nursing") OR (MH "Home Nursing, Professional") OR (MH "Pediatric Nursing") OR (MH "Maternal-Child Nursing") OR (MH "School Health Nursing")
S15	(MH "Physicians, Family")
S14	(MH "Family Practice")
S13	(MH "Primary Health Care")
S12	S8 AND S11
S11	S9 OR S10
S10	child OR children OR infant* OR paediatric* OR pediatric* OR kid OR kids OR "under fives" OR "under 5s" OR baby OR babies OR toddler OR toddlers
S9	(MH "Child") OR (MH "Infant, Newborn") OR (MH "Infant") OR (MH "Child, Preschool")
S8	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7
S7	sleep* OR insomnia* OR parasomnia* OR dyssomnia* OR "limit setting disorder" OR "limit setting type" OR "sleep onset association disorder" OR "sleep onset association type" OR "bedtime resistance"
S6	(MH "Insomnia")
S5	(MH "Sleep Deprivation (Saba CCC)")
S4	(MH "Dyssomnias+")
S3	(MH "Parasomnias+")
S2	(MH "Dreams")
S1	(MH "Sleep+")

A.2.4 PsycINFO 28 March 2019: 950 results (previously 545)

#	Query
S24	S8 AND S23
S23	S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22
S22	community N3 (health or service* or care)
S21	pediatrician* OR paediatrician*
S20	DE "Community Services"
S19	DE "Community Health"
S18	DE "Pediatricians"
S17	(family OR general OR primary) N3 (doctor OR physician* OR practice OR practitioner*)
S16	(community OR practitioner) N3 (nurse* OR nursing)
S15	"health visitor*"
S14	"first line care"
S13	primary N3 care
S12	DE "General Practitioners"
S11	DE "Nursing"
S10	DE "Nurses" OR DE "Public Health Service Nurses" OR DE "School Nurses"
S9	DE "Primary Health Care"
S8	S6 AND S7
S7	child OR children OR infant* OR paediatric* OR pediatric* OR kid OR kids OR "under fives" OR "under 5s" OR baby OR babies OR toddler OR toddlers
S6	S1 OR S2 OR S3 OR S4 OR S5
S5	sleep* OR insomnia* OR parasomnia* OR dyssomnia* OR "limit setting disorder" OR "limit setting type" OR "sleep onset association disorder" OR "sleep onset association type" OR "bedtime resistance"
S4	DE "Insomnia"
S3	DE "Dreaming" OR DE "Lucid Dreaming" OR DE "Nightmares" OR DE "REM Dreams"
S2	DE "Parasomnias"
S1	DE "Sleep" OR DE "Napping" OR DE "NREM Sleep" OR DE "REM Sleep" OR DE "Sleep Deprivation" OR DE "Sleep Onset" OR DE "Sleep Treatment" OR DE "Sleep Wake Cycle" OR DE "Sleepiness"

A.2.5 Web of Science 28 March 2019: 1171 results (previously 733)

#11	#10 AND #2 AND #1 <i>DocType=All document types; Language=All languages;</i>
#10	#9 OR #8 OR #7 OR #6 OR #5 OR #4 OR #3 <i>DocType=All document types; Language=All languages;</i>
#9	TOPIC: (community NEAR/3 (health OR service* OR care)) <i>DocType=All document types; Language=All languages;</i>
#8	TOPIC: (pediatrician* OR paediatrician*) <i>DocType=All document types; Language=All languages;</i>
#7	TOPIC: ((family OR general OR primary) NEAR/3 (doctor* OR physician* OR practice OR practitioner*)) <i>DocType=All document types; Language=All languages;</i>
#6	TOPIC: ((community OR practitioner) NEAR/3 (nurse* OR nursing)) <i>DocType=All document types; Language=All languages;</i>
#5	TOPIC: ("health visitor*") <i>DocType=All document types; Language=All languages;</i>
#4	TOPIC: ("first line care") <i>DocType=All document types; Language=All languages;</i>
#3	TOPIC: (primary NEAR/3 care) <i>DocType=All document types; Language=All languages;</i>
#2	TS=(child OR children OR infant* OR paediatric* OR pediatric* OR kid OR kids OR "under fives" OR "under 5s" OR baby OR babies OR toddler OR toddlers) <i>DocType=All document types; Language=All languages;</i>
#1	TS=(sleep* OR insomnia* OR parasomnia* OR dyssomnia* OR "limit setting disorder" OR "limit setting type" OR "sleep onset association disorder" OR "sleep onset association type" OR "bedtime resistance") <i>DocType=All document types; Language=All languages;</i>

A.2.6 Cochrane (CENTRAL Register for trials) 28 March 2019: 256 results (previously 81)

Search Name: Cochrane edited 28 March 2019

Date Run: 28/03/2019 15:21:59

Comment: 785 results

ID	Search	Hits
#1	MeSH descriptor: [Sleep] explode all trees	5243
#2	MeSH descriptor: [Sleep Wake Disorders] explode all trees	6927

- #3 sleep* OR insomnia* OR parasomnia* OR dyssomnia* OR "limit setting disorder" OR "limit setting type" OR "sleep onset association disorder" OR "sleep onset association type" OR "bedtime resistance" 33883
- #4 #1 OR #2 OR #3 34131
- #5 MeSH descriptor: [Child] explode all trees 1125
- #6 MeSH descriptor: [Infant] explode all trees 15137
- #7 child OR children OR infant* OR paediatric* OR pediatric* OR kid OR kids OR "under fives" OR "under 5s" OR baby OR babies OR toddler OR toddlers 159511
- #8 #5 OR #6 OR #7 159511
- #9 #4 AND #8 4806
- #10 MeSH descriptor: [Primary Health Care] this term only 3719
- #11 MeSH descriptor: [General Practice] explode all trees 2383
- #12 MeSH descriptor: [Nurses] explode all trees 1104
- #13 MeSH descriptor: [General Practitioners] this term only 230
- #14 MeSH descriptor: [Pediatricians] this term only 7
- #15 "primary care" OR "primary health care" OR "first line care" OR "health visitor*" OR "community nurs*" OR "nurse practitioner*" 18443
- #16 "family doctor*" OR "family physician*" OR "family pract*" OR "general doctor*" OR "general physician*" OR "general pract*" OR "primary doctor*" OR "primary physician*" OR "primary pract*" 1013
- #17 MeSH descriptor: [Community Health Services] this term only 934
- #18 pediatrician* OR paediatrician* 1170
- #19 community health OR community service* OR community care 28092
- #20 #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 45855
- #21 #9 AND #20 785

A.3 Study exclusion reasons

Check each possible exclusion reason and if it applies, apply the number to exclude it. These numbers are written in order of importance for inclusion and therefore, though all apply for eligibility, some may be checked before others. In order to save time, not all reasons may be noted for reasons for exclusion. Reasons that are more important and therefore checked first may only be noted. When screening full texts, if there is uncertainty for one exclusion number, move to the next to see if it would otherwise be excluded anyway.

1: Population: Not focussed on children. Samples must include children, children's parents or carers/ families in regard to the children, or primary care professionals (such as GP, health visitor, nurse) treating the children. If the title / abstract does not specify adult or child, move on to the next number. If the full text does not specify analyses/discussion solely for children, exclude.

2: Not primarily about behavioural sleep problems. E.g. exclude if only about sleep disordered breathing, movement disorders or enuresis. If multiple sleep problems are discussed, only include if there are separate analysis/discussion for behavioural sleep problems. Include abstract if more than 50%, or if part of a standard parenting/child regulation study (if sleep is mentioned in abstract). Include full text only if there are sub-analyses for behavioural sleep.

3: Population/Condition: the children have co-morbid physical or mental problems. E.g. exclude if the paper is about sleep problems in children with asthma or ADHD. If multiple samples are present, include the paper only if there is separate discussion/analysis of behavioural sleep problems in otherwise normally developing children.

4: Setting: Not focussed in a primary care setting, or community setting which is based from health professionals. Include if part of wider study AND there are relevant subgroup analyses for this.

5: Outcome: Not about primary health professionals' current knowledge, understanding, perceptions of their role regarding children's sleep, or current practice regarding management of children's behavioural sleep problems. Include if part of wider study AND there are subgroup analyses for this part. Prevalence included only if in relation to prevalence of management. Intervention studies that only generated data for interventions that could be implemented (without PCP baseline / usual care) will be excluded. Intervention studies that do not give data for what PCPs currently practice, believe or understand regarding behavioural management of BI in children, as part of a baseline, usual care or control group be excluded. Exclude pharmacological management (but include if there are subgroup analyses for behavioural management)

6: Publication type: Not the correct type of paper

A.4 Full text assessment

Below is a table listing the full text decisions for the electronic database searches (March 2019 and August 2021), backwards citation chasing and forwards citation chasing.

Table 26 Systematic review: full text decisions

First Author * (title if author is not listed)	Year	Decision
(bibliography of recent literature in sleep...)	1983	E6
(what can be done for night waking...)	1987	E6
(community practitioner courses)	2019	Cannot find/access
(Psychiatric Beliefs) p146.148	2001	E6
(Psychiatric Beliefs) p34-38	2001	E2
(Nursing focus. Online ed...)	2003	E6
(Information from your fam...)	2005	E2
(Focus. Women's health...)	2005	E4
(PeDIATRICS electronic...)	2006	E6
(Sleep hygiene in infants)	2006	E4
(News briefs for the family ph...)	2007	E2
(2008 SNRS abstracts D-E)	2008	E6
(2008 SNRS abstracts F-G)	2008	E6
(2008 SNRS abstracts H)	2008	E6
(2008 SNRS abstracts S)	2008	E6
(In brief)	2009	E4
(Noticeboard)	2011	E2
(Diary)	2012	E6
(Noticeboard)	2012	E6
(26 th Annual Conference of...)	2013	E6
(2013 SYR Accepted Poster...)	2013	E6
(Singapore Health and Bio...)	2013	E6
(e-Pediatrics Perspectives...)	2014	E6

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First Author * (title if author is not listed)	Year	Decision
(Rest and play: supporting...)	2014	E5
(NEWS ROUND-UP)	2015	E6
(Many new mothers get bad...)	2015	E2
(Twitter Tuesdays)	2015	E6
(Health visitors urged to...)	2015	E6
(PEDIATRICS SUMMARY)	2015	E4
(2014 NEI Psychopharmacolo...)	2015	E6
(RNews Digest: 9 November...)	2018	E2
Aas	1959	E7
Abbott	2015	Include
Accardo	2016	E6
Actrn	2019	E3
Actrn (effects of...)	2021	E6
Actrn	2021	E6
Adachi	2009	E5
Adair	1992	E5
Adams	2003	E2
Aggarwal	2019	E2
Amaral	2016	E7
Amintehran	2013	E5
Anders	1979	E4
Anderson	2000	E5
Anderson	1987	E5
Angeles	2010	E6
Anonymous	2005	E2
Anonymous	2009	E6
Anonymous	2009	E6
Anonymous	2015	E6
Anonymous	2016	E6

First Author * (title if author is not listed)	Year	Decision
Appleton	1988	Could not access
Arbabisarjou	2011	E6
Arbabsiarjou	2011	E6
Arboledas	1999	E7
Archbold	2002	E5
Armstrong	2014	E6
Aronson	2005	E6
Auchettl	2020	E6
Augustyn	2020	E4
Austin	2011	E6
Australia	2008	E6
Asch	2019	E6
Astill	1998	E2
Azevedo	2008	E4
Babcock	2011	E5
Baddam	2021	E6
Bailey	2002	E6
Bajaj	2015	E3
Baldwin	2016	E6
Baldwin	2015	E6
Balfour	1988	E4
Ball	2018	E4
Bandla	2007	E2
Bandla	2012	E2
Banerjee	2013	E3
Baran	2009	E6
Barimani	2017	E5
Barfield		E4
Barkin	2005	E2

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First Author * (title if author is not listed)	Year	Decision
Barrios	2018	E4
Barry	2000	E6
Baruch	1981	E2
Barth	1999	E7
Bartle	2014	Cannot find/access
Bartlett	2013	E6
Bathory	2017	E6
Bathory	2016	E5
Bax	2018	E2
Bax	2016	E2
Bax	1976	E5
Beal	2017	E5
Beckerman	2019	E5
Bedingfield	2006	E6
Beebe	2013	E6
Beer	2016	E2
Benhaberou-Brun	2011	E7
Berman	2007	E6
Bernal	1973	E4
Bethell	2001	E2
Bhargava	2011	E6
Bharti	2006	E5
Bidder	1981	E4
Bidder	1985	E4
Bidder	1986	E6
Birleson	2007	E2
Bjorvatn	2017	E1
Blackwell	2004	E6
Blampied	1993	E6

First Author * (title if author is not listed)	Year	Decision
Blunden	2004	E5
Bock	2014	E6
Bock	2016	E5
Boerner (core competencies...)	2015	E1
Boerner (barriers and...)	2015	E4
Bonuck	2016	E5
Bonuck	2020	Include
Boreman	2007	E2
Borrington	2017	E4
Borup	2011	E5
Bowman	2011	E5
Brant	2006	E6
Breitenstein	2016	E2
Bressler	1978	E2
Brophy	2000	E4
Browder	1970	E2
Brown	1979	E5
Brown	2019	E5
Bruni	2018	E4
Bruni	2019	E6
Bruni	2004	Include
Bruni	2015	E6
Bryan (Parental...)	2020	E2
Bryan	2020	E5
Buchan	2019	E6
Bucholz	2012	E5
Burke	2004	E4
Busey	2006	E2
Bush	2015	E2

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First Author * (title if author is not listed)	Year	Decision
Byrd	2018	E6
Caldwell	2019	E2
Callejas	2021	E5
Cann	2020	E5
Cannon	2021	E2
Carey	1975	E5
Carey	2013	E2
Carsley	2015	E2
Carpenter	1990	E4
Carter	1989	Include
Carter	2014	E6
Casey	1986	E6
Cashin	2021	E4
Chandler	1992	E1
Chaney	1995	E4
Chaput	2019	E6
Charles	2011	E2
Chavin	1980	Include
Cheng	2017	E6
Cheng	2020	Include
Cheng	1999	E2
Chervin	2001	E5
Chervin	2013	E6
Chianese	2009	E2
Chinapaw	2020	E4
Chomchai	2013	E2
Christian	2012	E2
Christophersen	2005	E6
Chung	2016	E6

First Author * (title if author is not listed)	Year	Decision
Churchill	2017	E6
Clarke-Stewart	1978	E2
Cicalese (Caregiver-reported...)	2020	E6
Coker	2006	E2
Coker	2009	E2
Coker	2012	E2
Coker	2014	E2
Coleman	1977	E2
Coles	1983	Cannot find
Collins-Anderson	2019	E6
Cook	2017	E6
Cook	2012	E5
Cook	1993	E6
Cook	2020	Include
Corkum	2019	E6
Cornwell	2021	E2
Costello	1985	E2
Costello	1986	E2
Cottrell	2002	E4
Cotrim	2013	E6
Coulombe	2010	E4
Coulombe	2011	E4
Coulombe	2013	E6
Couper	2004	E6
Crawford	1989	Include
Crawford	2020	E6
Cromer	2019	E4
Dabrow	2016	E6
Dahl	1995	E3

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First Author * (title if author is not listed)	Year	Decision
D'Andrea	2009	E6
Daniel	1996	E7
Davies	1995	E4
Davis	2014	Cannot find / access
Daws	1985	E6
Daws	1994	E6
Daws	1999	E6
Deave	2008	E4
De Gioia	2009	E4
De Lago	2018	E2
DelRosso	2015	E6
DelRosso (efficacy of sleep ed...)	2016	E5
DelRosso	2016	E6
Dennis	2021	E5
Dent	2000	E1
Desombre	2001	E7
Devgan	1998	E4
Devolin	2013	E2
Dilliway	2000	E6
Dimond	1997	E2
Diz Andre	2017	E7
Dodds	1993	E2
Doering	2017	E6
Don	2002	E4
Dong	2019	E4
Douglas	1987	E6
Douglas	2017	E6
Douglas	2012	E2
Douglas	2015	E3

First Author * (title if author is not listed)	Year	Decision
Douglas	2020	E6
Draper	2019	E5
Drotar	2002	E6
Drks	2020	E6
Dummont-Mathieu	2006	E2
Durand	1990	E4
Ebarhim	2013	E5
Eckerberg	2002	E4
Eckerberg	2004	E4
Edwards	1994	E6
Eichelberger	2020	E6
El Shakankiry	2011	E6
Eminson	2001	E2
Erichsen	2012	E2
Ersu	2017	Include
Etherton	2014	E6
Evans	2000	E5
Evsyukova	2014	E6
Ewing	1999	E1
Farnes	1987	E4
Farrand	2007	E2
Faruqui	2011	Include
Fehr	2016	E5
Fehringer	2003	E6
Felt	2003	E5
Figueiredo	2019	E5
Finney	1991	E2
Fisher	2004	E4
Fisher	2011	E6

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First Author * (title if author is not listed)	Year	Decision
Fisher	2015	E6
Fisher	2011	E6
Fisher	2004	E4
Forgatch	1979	E2
Flores	1998	E2
Forward	2018	E5
Fogg	2015	E5
Fowler	2019	E4
France	1994	E6
France	1999	E6
France	1991	E6
France	1990	E4
France	1993	E6
Franco	2011	E6
Friman	1999	E5
Friton	1971	E7
Fundudis	1988	Could not find
Galbraith	1993	E4
Gallas	2019	E6
Galuska	2002	E2
Gamaldo	2008	E6
Garcia-Onieva	2010	Cannot find/access
Garg	2021	E2
Garrison	2020	E6
Garrison	2019	E5
Garrison	1992	E2
Gates	1989	E2
Gath	1968	E2
Gavallo	1997	E5

First Author * (title if author is not listed)	Year	Decision
Gerber	2014	E6
Gilgoff	2020	E2
Gillespie	2019	E6
Golding	1986	E4
Goldfeld	2017	E5
Goldman	2012	E2
Goodlin-Jones	2008	E5
Goodwin	1983	E6
Gordon	1960	E2
Gottesman	2003	E6
Gottfarb	1963	E7
Gouge	2016	E5
Gozal	2012	E6
Greenwood	1993	E2
Gregory	2008	E2
Gruber	2017	E4
Gruber	2012	E6
Gruber	2016	E5
Gruber	2011	E6
Gueiros	2003	E7
Gunduz	2016	E7
Gunn	1998	E2
Gupta	2005	E2
Hageman	2019	E6
Hajak	2000	E6
Halfon	2004	E2
Halfon	2004	E6
Hall	2011	E6
Hall	2019	Include

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First Author * (title if author is not listed)	Year	Decision
Hall	2006	E5
Hall	2015	E4
Halle	2004	E2
Hambidge	2007	E2
Hammersley	2020	E6
Hancock	1978	E4
Hanna	2001	E4
Hanna	2002	E6
Harrington	2020	E2
Harwood	2009	E5
Hash	2019	E4
Hatch	2019	E5
Hatton	2018	Include
Hauck	2007	E5
Haut	2016	E6
Hayashi	2001	E7
Healey	2009	E4
Hemminki	1975	E1
Henderson	2012	E5
Herberholz	2015	E6
Herrman	2005	E2
Heussler	2013	E4
Hewitt (overactivity)	1981	E2
Hewitt	1989	Include
Hewitt	1981	E6
Hewitt (The behaviour...)	1989	E5
Hewitt	1988	E6
Hickson	1983	E2
Hicks	1976	E6

First Author * (title if author is not listed)	Year	Decision
High	1998	Include
High	2000	E5
Hill	2020	E2
Himelfarb	2021	E6
Hiscock	2009	E6
Hiscock	2007	E5
Hiscock	2008	E5
Hiscock	2012	E6
Hiscock	2014	E5
Hiscock	2018	E5
Hiscock	2002	E5
Hiscock	2021	E5
Hiscock	2019	E5
Hiscock (sleep disorders...)	2018	E4
Hoch	2011	E7
Hoehl	2010	E7
Hoffses	2018	E6
Hohman	2020	E5
Honaker	2018	E2
Honaker	2021	E5
Howard	2008	E4
Houtrow	2007	E2
Howlett	2020	E4
Hsu	2015	E6
Hsu	2018	E2
Hsu	2017	E3
Huggins	2007	E2
Hunter	2020	E2
Hunter	2021	E6

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First Author * (title if author is not listed)	Year	Decision
In-Albon	2010	E2
Inglis	1976	E4
lrct20200824048499n	2020	E6
lsrctn	2019	E6
lsrctn	2020	E6
lsrctn	2020	E3
Jacobs	1962	E2
Jackson	1977	E5
Jain	2020	E6
Janiak-Baluch	2014	E7
Jee	2020	E2
Jeon	2019	E6
Jewell	2007	E2
Jin	2013	E3
Johnson	2010	E6
Jones	2013	E5
Jones	1983	E4
Jones	2000	E2
Kales	1980	E1
Kales	1979	E2
Kanoy	1985	Include
Karssen	2021	E5
Katz	2014	E2
Katz	2019	E6
Keefe	1988	E4
Keeshin	2019	E6
Kelleher	1994	E2
Kemp	2003	E2
Kerr	1996	E5

First Author * (title if author is not listed)	Year	Decision
Keys	2018	E6
Kheir	2019	E6
Kirk	1990	E1
Kitsaras	2021	E4
Klass	2002	E2
Klass	2008	E2
Klass	2003	E6
Kleitman	1953	E4
Kogan	2004	E2
Kohlhoff	2020	E4
Kohyama	2010	E6
Kohyama	2011	E6
Koplewicz	2015	E2
Kotagal	2003	E4
Kothare	2008	E6
Kovacic	2002	E1
Krishna	2005	E6
Krugman	2014	E2
Kruske	2012	E2
Kuo	2006	E2
Kuo	2009	E2
LaBella	2017	E5
Labella	2017	E5
Lakhaney	2019	E5
Laitinen	2013	E7
Lam	2003	E5
Lamberg	2005	E6
Lamberg	2008	E2
Langford	1957	E4

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First Author * (title if author is not listed)	Year	Decision
Lannon	2008	E2
Larimore	2000	E6
Laurent	1991	E3
Lawton	2012	Cannot find/access
Lawton	1991	E4
Lavallee	2017	E6
Lavigne	2017	E5
Lavigne	1993	E2
Le	2016	E5
Leaf	2004	E2
Leeson	1994	E4
Lehmkuhl	2004	E6
Lee-Chiong	2007	E4
Lemoine	2006	E2
Lempp	2016	E2
Lepkowska	2014	E4
Lester	2009	E2
Linder	2021	E1
Lipton	2019	E6
Liu	2016	E4
Liu	2020	E6
Liu	2019	E6
Llagostera	2014	E6
Lluch	2010	Cannot find/access
Locard	1997	E7
Locke	2019	E6
Loutzenhiser	2014	E4
Lozoff	1985	E5
Lozoff	1988	E6

First Author * (title if author is not listed)	Year	Decision
Lucassen	2003	E2
Lulla	2019	E6
Lurshay	2016	E2
Mackenzie	1956	Cannot find/access
Madden	2020	E6
Maden	2019	E6
Mahendran	2006	E4
Maia	2008	E7
Man	2021	E6
Mao	2018	E2
Mariani	2006	E7
Marks	1981	E2
Marshall	2005	E2
Martin	2005	E2
Martins	2013	E5
Martins	2015	E5
Martil	2019	E7
Martinez	2021	E6
Matthews	2011	E6
Matthey	2008	E4
Mattson	1996	E6
Maute	2018	E4
Mayers	2020	E2
Mbou	2001	E7
McCallum	2011	E5
McCrae	2010	E6
McDowall	2016	E3
McGarr	1980	E5

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First Author * (title if author is not listed)	Year	Decision
McInnes	2015	E4
McKegney	2021	E2
McLaughlin	2001	E6
McLean	1994	E4
McRury	2010	E2
Meadows-Oliver	2012	E6
Meaklim	2020	E6
Mehri	2011	E6
Meltzer	2010	E5
Meltzer	2009	E6
Meltzer	2014	E3
Meltzer	2009	E4
Merino-Andreu	2010	E6
Merenstein	2006	E5
Merrifield	2005	E4
Mesibov	1977	E5
Middlemiss	2005	E5
Middlemiss	2015	E6
Middlemiss	2017	E4
Milan	1982	E3
Milanaik	2019	E6
Milford	2006	E5
Millar	1986	E6
Milner	1982	E6
Milton	2014	E6
Mimila	2017	E2
Minde	2002	E6
Minde	2016	E4
Minde	1994	E5

First Author * (title if author is not listed)	Year	Decision
Mindell	1994	Include
Mindell	2003	Include
Mindell	2017	E6
Mindell (sleep education...)	2011	E4
Mindell (efficacy...)	2011	E4
Mindell (long term...)	2011	E4
Mindell	2015	E4
Mindell	2013	E5
Mindell (give children...)	2011	E6
Mindell	1993	E5
Missler	2018	E4
Mitchell		E6
Mitchell	2020	E5
Mitchell	2021	E5
Moharnmadi	2007	E5
Mole	2019	E2
Monsen	2002	E2
Moore	2019	E2
Morgan	1999	E6
Morgan	2001	Cannot find/access
Morgenthaler	2015	E4
Morrell	2003	E5
Morrell	1999	E5
Moyer	2004	E2
Murray	2019	include
Murray	2019	E4
Muscat	2014	E5
Narring	2000	E7
Nativio	2002	E4

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First Author * (title if author is not listed)	Year	Decision
NCT (Healthy Sleeping and Feeding...)	2005	E6
NCT (Better days, better nights...)	2006	E6
NCT (The rocky sleep study...)	2009	E6
NCT (Early Intervention Marte Meo...)	2013	E6
NCT (Care2BWell...)	2015	E6
NCT (Infant night wakings...)	2016	E6
NCT (What are the effects of supporting...)	2017	E6
NCT (Behavioural Insomnia of Childhoo...)	2017	E6
NCT (Infant Behavioural Sleep Intervention...)	2018	E6
NCT (Coordination of care between...)	2018	E6
NCT (Effectiveness of a motivational...)	2018	E6
NCT (A sleep hygiene intervention...phase 1)	2018	E6
NCT (A sleep hygiene intervention...phase 2)	2018	E6
NCT (Effectiveness of an intervention)	2019	E6
NCT (The impact of a...)	2019	E6
NCT (Look – Your baby is Talking to You)	2019	E6
NCT (piloting conversation...)	2019	E6
NCT (increasing childhood sleep...)	2019	E6
NCT (Infant health...)	2020	E6
NCT (My baby my move...)	2020	E6
NCT (Behavioural sleep intervention...)	2020	E6
NCT (Online peer...)	2021	E6
NCT (nighttime postural...)	2021	E6
NCT (community singing...)	2021	E6
Nelson	2005	E2
Nevin	2002	E2
Ng	2004	E6
Ng	2021	E5
Nikolopoulou	2003	E5

First Author * (title if author is not listed)	Year	Decision
Njoroge	2017	E2
Norlin	2011	E2
Norton	2011	E2
Norton	2010	E2
Norton	2016	E2
Nunes	2011	E2
Nunes	2011	E7
Nunes	2013	E2
O'Bryan	2017	E4
O'Connor	2016	E2
Oddy	2009	E2
O'Donnell	2014	E5
Ogundele (Spectrum of childho...)	2018	E4
Ogundelle	2018	E6
Oliver	2016	E6
Olsen	2021	E5
Olson	2004	Include
Olson	2008	E6
Olson	1988	E2
Orr	1980	E2
Oros	2014	E6
Osborn	1989	E2
Osorio	2020	E2
Ostberg	2005	E4
Owens (the practice of pedia...)	2001	Include
Owens (Insomnia...)	2005	E6
Owens (The use of pharmaco...)	2005	E6
Owens	2000	E6
Owens (Use of the 'BEARS' sle...)	2005	E5

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First Author * (title if author is not listed)	Year	Decision
Owens	2001	E6
Owens (Parental knowledge...)	2011	E5
Owens	2011	E6
Owens	2012	E6
OwensStively	1997	E4
Paiva	2000	E5
Palese	2019	E2
Paruthi	2016	E5
Panza	2020	E2
Papousek	2005	E7
Parthasarathy	2016	E6
Patel	2015	E6
Paton (Impact of...)	2019	E5
Paton (Implementing...)	2019	Include
Patterson	1979	E2
Penfold	2019	E6
Pereira	2015	E6
Perrin	1999	E2
Perrin	2003	E2
Perrault	2019	E5
Perry	2007	E2
Pethe	2013	E6
Phillips	2002	E3
Phillips	2009	E3
Pin Arboledas	1999	E7
Pla	2000	E7
Platt	2018	E6
Polaha	2007	E2
Pollice	2007	E2

First Author * (title if author is not listed)	Year	Decision
Polk	2017	E3
Pommier	2002	E7
Porter	2013	E4
Potter	2005	E2
Poulton	2014	E2
Pressman	2011	E5
Price	2011	E6
Price (content analysis of mot...)	2012	E5
Price	2012	E5
Price	2012	E5
Priddis	2010	E2
Quasem	2003	E2
Radecki	2009	E2
Ram	2010	E1
Ramirez	2018	E7
Rangel	2015	E7
Ras Vidal	2005	E7
Reddy	2011	E6
Redeker	2018	E6
Reid	2011	E6
Reid	2009	E6
Reid	1977	E6
Reigstad	2010	E4
Reinhardt	2003	Cannot find/access
Renkert	2001	E2
Rhodes	2012	E2
Rich	2007	E2
Richards	1992	E4
Richardson	2021	E4

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First Author * (title if author is not listed)	Year	Decision
Rickert	1988	E4
Richman	1985	E4
Rieber	2002	E2
Riley	2019	E6
Riley	2019	E2
Riley	2020	E2
Riveros	2016	E5
Roberts	1986	E4
Roberts (The future...)	1986	E6
Roberts	2008	E5
Roberts	1993	E4
Roberts	2020	E6
Robertson	1961	E2
Rodrigue	1995	E2
Rolls	2001	E4
Ronen	1991	E4
Rosen	1993	E2
Rosen	1998	E2
Rosen	2018	Cannot find/access
Rosen	2001	E1
Rosenthal	2005	E2
Routh	1988	E2
Ross	2014	E6
Rothenberg	1976	E2
Rowe	2012	E4
Rowe	2014	E6
Rowe	2010	E6
Rowe (the contribution...)	2010	E4
Rowland	2012	E6

First Author * (title if author is not listed)	Year	Decision
Rudzik	2016	E4
Russell	2015	E6
Ryan	2014	E3
Saarenpaa-Heikkila	2017	E6
Sadler	2016	E6
Sadler	1994	E5
Sadler	2020	Include
Sadler	2019	E6
Sarah	2019	E6
Saglier	1977	E7
Saing	2018	E5
Sanger	1981	E4
Sansa	2000	E7
Santos	2016	E5
Saphir	2009	E2
Saunders	1984	E4
Sateia	2005	E5
Savage	2018	E5
Scaife	1988	E4
Schaeffer	2018	E2
Schlarb	2010	E7
Schlarb(Insomnia...)	2010	E7
Schlarb	2019	E7
Schnitzer	2008	E2
Schneider	1995	E2
Schonwald	2009	E2
Schor	2009	E6
Schroeder	1999	E6
Schroeder	2004	E6

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First Author * (title if author is not listed)	Year	Decision
Schroeder	1987	E6
Schroeder	1975	E6
Schuster	2000	E4
Schuster	2002	E6
Schwartz	1967	E2
Schwartz	2019	E4
Scott	1990	E5
Scowen	2005	E6
Seabra-Santos	2019	E7
Selim	2006	E5
Sens	2011	E6
Sha	2017	E2
Sharp	1992	E2
Shannon	2017	E6
Shaughnessy	2016	E6
Shaw	2015	E6
Sheppard	1997	E5
Shilts	2021	E4
Shimizu	2014	E5
Shimoda	2013	E2
Shows	1974	E4
Sia	2013	E2
Silverstein	2005	E2
Simcock	1999	E4
Sims	2018	E4
Singer	1989	E2
Siren-Tiusanen	2001	E4
Sirousi	2013	E6
Sivaramakrishnan	2019	E4

First Author * (title if author is not listed)	Year	Decision
Skuladottir	2016	E4
Skuladottir	2016	E4
Skuladottir	2021	E5
Smith	1985	E6
Smith	1967	E2
Snyder	2008	E5
Snyder	2010	E5
Sobel (problems...)	2001	E2
Sobel (Evaluating...)	2001	E2
Sow	2020	E7
Spielvogel	2018	E6
Spirznagal	1976	Cannot find / access
Splaingard	2004	E6
Spoljoric	2009	E6
Sriraman	2019	E2
Stagnara	2017	Cannot find/access
Stagnara		Cannot find/access
Stallard	1992	Include
Steiman	2021	E6
Stein	2001	E3
Stein	2001	E3
Stein	2010	E2
Stein ('Not listening...Pediatrics)	2004	E3
Stein	2002	E3
Stein	2004	E3
Stein	2004	E3
Steinsbekk	2013	E5
Steinsbekk	2015	E3
Stephenson	2018	E6

Appendix A

First Author * (title if author is not listed)	Year	Decision
Stevenson	1993	E4
Stores	1998	E4
Stores	1996	E6
Stores (Medical...)	1998	E2
Stores	1999	E6
Stremler	2006	E5
Sundelin	1999	E7
Sullivan	2019	E6
Svensson	2009	E2
Swinburne	2005	E6
Sykes	1999	E6
Symon	2012	E5
Symon	2017	E5
Symon	2005	E5
Talmi	2012	E6
Tan	2009	E4
Tang	2004	E7
Tanninen	2009	E2
Taveras	2011	E5
Taylor	2011	E5
Taylor	2007	E4
Tedder	2007	E5
Tedford	2021	E5
Teodorescu	2007	E4
Teplin	2013	E4
Teplin	2014	E2
Teplin	2012	E4
Thomas	1982	Include
Thompson	2018	E6

First Author * (title if author is not listed)	Year	Decision
Thompson	2012	E6
Thunstrom	1999	E4
Thunstrom	2000	E3
Tirosh	1998	E2
Tirosh	1993	E3
Tissier	2015	E7
Tomayko		E5
(Top doctor...)	2017	E6
Topan	2020	E5
Triggs	1989	E5
Tsai	2013	E6
Tsai	2014	E3
Tse	2008	E5
Turner	2016	E2
Tyler	2005	E6
Tynan	2004	E6
Uchiyama	2011	E1
Urban	2007	Cannot find/access
Valerio	2009	E2
Vallido	2010	E4
Vanhelst	2021	E2
Van Tongerloo	2012	E2
Varela	2017	E7
Vasileva	2020	E7
Vicario	2010	Cannot find/access
Vidouris	2013	E6
Vidouris	2013	E6
Villo Simerol	2002	E7
Vlasblom	2012	E6

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First Author * (title if author is not listed)	Year	Decision
Wacogne	2016	E2
Wade	2007	E4
Waite	2001	E2
Wake	2011	E5
Waloszek	2015	E3
Walton	2002	E1
Wasserman	2021	E6
Wassmer	2006	E6
Waters	2004	E3
Weick	2009	E6
Weir	1988	E3
Werner	2015	E4
Wert	2015	E2
Whiteford	2004	E2
Wiggs	2007	E6
Wiggs	2001	E3
Wijga	2011	E7
Wijlaars	2013	E6
Wijlaars	2013	E6
Wilkins	2006	E2
Willgerodt	2014	E5
Williams	2019	E6
Williamson	2017	E6
Williamson (caregiver reported...)		E6
Williamson (A stimulus...)	2020	E6
Williamson		E6
Williamson	2020	Include
Williamson (Making sense...)		E2
Wilson	2014	E5

First Author * (title if author is not listed)	Year	Decision
Winsper	2018	E6
Wintersgill	2019	E6
Wolke (A randomised...)	2002	E2
Wolke (Routine examination...)	2002	E2
Wu	2010	E2
Wynter	2015	Include
Wynter	2013	Cannot find/access
Yaari	2019	E6
Yassaee	2017	E2
Yoldas	2021	E2
Young	2013	E2
Zarate	2019	E6
Zhang	2019	E4
Zozula	2005	E1
Zozula	2001	E1
Zuckerman	2004	E2
Zuckerman	2001	E6
Zuckerman	2020	E6
Zulley	2000	Cannot find/access
Zwaanswijk	2003	E6

*Note: Often articles had multiple authors

A.5 Initial findings from before the searches were revised in March 2019

Presented here are the study selection findings from the searches I ran in February 2019, before the search strategy was revised in March 2019.

The database searches in February 2019 resulted in 4631 results which I imported into endnote. I conducted endnote de-duplication and 3387 results remained. Forty-four of the remaining results were still considered duplicates according to endnote, however these were left until a certain decision could be made after beginning screening. The 3387 results were therefore exported to

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Rayyan to begin screening. Rayyan indicated that 860 of the results were possible duplicates, however, after scoping through these possible duplicates, it was decided to exclude certain duplicates after screening, as many appeared to not actually be the same article.

A.6 Full data extraction tables

A.6.1 Study characteristics (detailed)

Table 27 Data extraction: Study characteristics (detailed version)

Study	Study Design	Aim	Country (setting)	Sample				Age of children	Data collection method / procedure	Relevant Outcomes	Analysis
				Type	N	Gender	Other				
Bruni and colleagues (2004)²¹¹	Quantitative	“To investigate the attitudes, practices and beliefs, actual treatment and knowledge of sleep in pediatricians and child neuropsychiatrists”	Italy (paediatricians)	Paediatricians	627 mail out returns 67 interview control	334 M 293 F	Avg. year of graduation = 1974	Questionnaire 1: 1-6 months Questionnaire 2: paediatric age	2 Questionnaires used in Mindell et al 1994, translated and posted to 8050 paediatricians: Validity of mail out compared to face-to-face administration of paediatricians in Rome (control group)	Questionnaire 1: beliefs about sleep difficulties, likely treatments Questionnaire 2 developmental issues (5 questions) and sleep hygiene (5 questions). Validity of postal questionnaire	Descriptive statistics “percentage score (number of correct answers/number of questions *100) for each of the six areas”

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Study	Study Design	Aim	Country (setting)	Sample				Age of children	Data collection method / procedure	Relevant Outcomes	Analysis
				Type	N	Gender	Other				
Hall and colleagues 2019 ²¹⁸	Mixed-methods – multiple components	Explore parents' and infants' needs and explore potential gaps in programming and training	Canada (public health)	Public health nurses	10 Public health nurses (PHN) 23 NRPH&ES nurses	Unknown		Infants	Focus group for PHNs Guided discussion for NRPH&ES nurses	Gaps In programming and training	Qualitative analyses method not specified.
Faruqi and colleagues 2011 ²¹⁷	Quantitative	“To assess general pediatricians' screening practices for sleep-related issues and assess their knowledge on common sleep complaints in children, their perceived barriers to screening for sleep issues, and whether	US (paediatrician)	General paediatricians	346	M = 128 F = 222 (64%)	Age range = n (%) 20-29 = 0 (0) / 30-39 = 79(23) / 40-49 = 131(38) / 50-59 = 84(24) / 60-69 = 41(12) / >70 = 11(3) Race = n (%) White/Caucasian = 256(74). Black/African	Unspecified, though tends to focus more on school age	Survey posted to paediatricians. Closed format questions	Perceptions, practices, confidence and knowledge	Descriptive statistics and “t-tests for differences between dichotomous independent and parametric dependent variables”.

Study	Study Design	Aim	Country (setting)	Sample				Age of children	Data collection method / procedure	Relevant Outcomes	Analysis
				Type	N	Gender	Other				
		they have received training regarding sleep issues.”					American = 14(4). Hispanic/Latino = 21(6). Asian =44(13). Other = 11(3) Location of practice = n(%) Rural: 51(15). Suburban: 185(53). Urban: 110(32)				
Mindell and colleagues 1994²²²	Quantitative	“A series of studies were conducted to investigate pediatricians’ training, knowledge, and practices regarding sleep and sleep disorders in children and adolescents.”	US (paediatrician)	Paediatrician	88 (questionnaire) 181 (survey)	M = 65.9%. F = 34.1% M = 66.7% F = 33.3%	Avg year of graduation: Rhode Island 1972, Pennsylvania was 1966.	Unknown (questionnaire) 6 months to 4 years (survey)	‘Sleep Survey’ knowledge questionnaire created by authors with true/false questions Survey sent to pediatricians in Rhode Island and Pennsylvania	Sleep hygiene subscale and developmental subscale Beliefs about children’s sleep difficulties, likely treatments, effect on family	Descriptive statistics

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Study	Study Design	Aim	Country (setting)	Sample				Age of children	Data collection method / procedure	Relevant Outcomes	Analysis
				Type	N	Gender	Other				
Mindell and Owens 2003 ¹³⁵	Quantitative	To conduct a needs assessment survey for paediatric PCPs	US (paediatric nurse practitioner)	Paediatric nurse practitioners	317	F = 99.7%	Age: Mean=45.23 SD = 9.67, range = 24-71 'Year of graduation': M = 1992.09 SD = 9.34, range 1971-2003 'Years In practice': M = 11.16, SD =9.7, range 0-40 Setting: 'inner city' (16.8), 'urban' (32%), 'Suburban' 38.6 and 'rural' (12.5) Location: 'hospital' (23.7%), 'clinic'	Unknown	Needs assessment survey given to paediatric nurse practitioners at a conference	Confidence in evaluating and treating behavioural sleep problems	Descriptive statistics

Study	Study Design	Aim	Country (setting)	Sample				Age of children	Data collection method / procedure	Relevant Outcomes	Analysis
				Type	N	Gender	Other				
							(28%), 'private' (46%), 'school' (2%) Ethnicity: 'White' (51.9%), 'Hispanic' (21.2%), 'black' (20.3%), 'Asian' (5.2%), 'Native American' (1.4%)				
Owens 2001 ²²⁵	Quantitative	"To assess knowledge, screening, evaluation, treatment practices, and attitudes regarding sleep disorders in children and adolescents in a large sample of community-based and academic pediatricians"	US (paediatrician)	Paediatrician	626	F = 49.7%	46.6 mean age (range 29-83)	Unknown	PSS (developed by author) posted to paediatricians and family practitioners	Knowledge, treatment practices, and attitudes about impact of sleep disorders	Descriptive statistics.

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Study	Study Design	Aim	Country (setting)	Sample				Age of children	Data collection method / procedure	Relevant Outcomes	Analysis
				Type	N	Gender	Other				
Wynter and colleagues 2015 ²³⁰	Mixed methods	"To investigate Maternal and Child Health (MCH) nurses' views on what contributes to mental health problems among new mothers, and their current practices regarding risk factors for maternal mental health problems that are potentially modifiable in primary care"	Australia (MCH service)	MCH nurses	343	Unknown	51% "had been practicing as a MCH nurse for at least 11 years"	Infants	Online survey with closed (quantitative) and open (qualitative) questions.	Views about risk factors, current practices and responses relevant to night waking.	Descriptive statistics Themes, concept maps (to illustrate relative frequencies within themes).
Chavin and Tinson 1980 ²¹³	Quantitative	To see whether sleep problems correlate with birth history and whether it has a problem on the family. Measured who parents thought had been most helpful.	UK	Mothers referred by HVs for severe sleep problem	62 (severe problem)	Unknown		8 months to 3 years	Interviews using quantitative surveys	A question asked who they thought had been most helpful to them (GP, HV, relative, other mothers, park hospital, no support)	Descriptive statistics

Study	Study Design	Aim	Country (setting)	Sample				Age of children	Data collection method / procedure	Relevant Outcomes	Analysis
				Type	N	Gender	Other				
Crawford and colleagues 1989 ²¹⁶	Quantitative (though a quant study, only qual data relevant here from case notes)	HV kept records for treatment for 9 children with behavioural sleep problems, following a course	UK (HV caseload)	Children from HVs case notes	1 HV 9 children	F = 6 M = 3		7-39 months	Records of individualised treatment for children with behavioural sleep problems, following 2 day behavioural implemented training workshop noted in (Hewitt 1989)	Practice	Description of treatment from case notes
Ersu and colleagues 2017 ¹³⁷	Quantitative	“The primary aim of this study was to assess whether a sleep health-care education program could improve knowledge, attitude and awareness of pediatricians with regard to sleep problems”.	Turkey (paediatrician)	Paediatricians	117 intervention 70 control	F=75% / M=25% F =73% / M=27%	Mean age = 31.2 +/- 6.5 years Time since graduation = 5.6 +/- 6.6 years Mean age = 32.9 +/- 5.4 years	Unknown	The study tested an educational intervention for pediatricians with a control group who received no intervention.	Baseline assessments of sleep knowledge of both intervention and control group	Descriptive statistics

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Study	Study Design	Aim	Country (setting)	Sample				Age of children	Data collection method / procedure	Relevant Outcomes	Analysis
				Type	N	Gender	Other				
							Time since graduation:6.5 +/- 5.6 years				
Hewitt and colleagues 1989²¹⁹	Quantitative	Explored the effects of a behaviour training workshop on health visiting practice (beliefs and management) in relation to different behaviour problems – one being sleeplessness.	UK (HV)	HV	7	Unknown	Mean number of preschool children per caseload: 217 Qualified on avg 8 years before (range 1.3-15) Worked as HVs for avg 5 years (range1.3-9)	Unknown	Following a 2-day behavioural workshop given on an annual basis for health visiting and community medical staff. polarised rating scales before and 8/9 months later when they also took part in a structured interview to validate ratings.	Beliefs: role perceptions, difficulty to deal with and whether they were able to cope with the problem Practice: How likely there were to refer	Descriptive statistics
Kanoy and Schroeder 1985²²¹	Quantitative	“describe follow-up evaluations of parents who used the services offered	US (program in paediatric	Parents	25	Unknown	Participated in follow up evaluations during	Over 90% sleep concerns in	Parent follow up following access to a psychologist	Recommendation	Descriptive statistics

Study	Study Design	Aim	Country (setting)	Sample				Age of children	Data collection method / procedure	Relevant Outcomes	Analysis
				Type	N	Gender	Other				
		by Schroeder and her colleagues”	primary care clinic)		Sleep concerns (n=60)		1973-76, 1977-78, 1979-1980 Between 2 months and 2 years of initial contact	preschool children	behaviour clinic (telephone calls or face to face) in primary care some years before. Structured interview		
Olson and colleagues 2004²²⁴	Quantitative	“To describe the content of anticipatory guidance provided to parents of infants and toddlers and to identify primary areas of unmet need as reported by both parents and pediatricians.”	US (paediatricians)	Paediatrician Parents	1100 2068 children	M = 47.3%		Parents (4-35 month children)	Parallel questions to the NSECH, to compare data) collected through AAP periodic survey Parent telephone survey (National Survey of Early Childhood Health: NSECH)	Whether bedtime routines / nightwaking were discussed in well child visits.	Descriptive statistics
Thomas and	Quantitative	“to explore health visitors' opinions of behaviour difficulties in pre-school	UK (HV)	HVs in one county /	53 rating scale	Unknown		“Preschool children”	For each behaviour problem (one being sleep), HVs rated on	Beliefs: Difficulty in management, Extent of family disruption,	Descriptive statistics

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Study	Study Design	Aim	Country (setting)	Sample				Age of children	Data collection method / procedure	Relevant Outcomes	Analysis
				Type	N	Gender	Other				
colleagues 1982 ²²⁸		children in the County of South Glamorgan..."		visiting records	respondents				bipolar scales (80mm in length), by marking where best their feeling was about the sleep.	Frequency of problem, Frequency of parents report as a problem, Ability to cope. Perception of role	
Hatton and Gardani 2018 ¹³³	Qualitative	"The aim of this qualitative study was to develop an understanding of advice available in the United Kingdom (UK) on sleep in young children."	UK (community – HVs / partly GPs)	Parents	15 (interviews). 14 just the mother, 1 with mother and husband	F = 15 M = 1	Mean age 33.4 (range 21-43). 32 children were represented 4 mothers (27%) said at least one child poor sleeper; further 3 (20% at least one child previously slept poorly)	Age (number of children within age group) 0-12 mos: 2 1-3y: 4 3-5y: 16 5-12y: 10	Semi structured interviews	Themes names not relevant, but some text within is (and quotes within). E.g. PCPs practice, knowledge and discussion	Constructivist grounded methodology

Study	Study Design	Aim	Country (setting)	Sample				Age of children	Data collection method / procedure	Relevant Outcomes	Analysis
				Type	N	Gender	Other				
Carter and Mason 1989 ²¹²	Quantitative	To clarify HVs perceptions of normal behaviour (included sleeping).	UK (HVs in Bristol)	HVs	42	Not specified		1 month old babies	Questionnaire circulated to 50 HVs.	What they perceived to be the range of average normal behaviour for sleeping in 1 month old. Views on night wakings	Descriptive statistics
High and colleagues 1998 ²²⁰	Quantitative	“To evaluate a program of anticipatory guidance” to promote reading and bedtime routine.	US (Pediatric residents and nurse practitioners) –	Families (group 1 and group 2)	Group 1: 51 Group 2: 100	Group 1: F=24/51 (47%) Group 2: F = 44/11 (44%)		Group 1: Mean 23.25 months. Group 2: Mean 19.2 months	Cross-sectional comparison of families attending well child visits. Historical control (group 1): Pre-implementation of clinic wide intervention. Interviews	Anticipatory guidance	Descriptive statistics, univariate analysis, t test, multivariate analysis, multiple linear regression
Abbott and Bryar 2015 ²⁰⁹	Qualitative	To evaluate a toolkit given to HVs in practice.	UK (HVs in a London borough)	HVs	7	F	Two localities	Under five	Semi-structured interviews to evaluate	Empowerment by an implemented project, which	Qualitative analysis not specified

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Study	Study Design	Aim	Country (setting)	Sample				Age of children	Data collection method / procedure	Relevant Outcomes	Analysis
				Type	N	Gender	Other				
									the implemented toolkit	includes sleep materials	
Stallard 1998 ²²⁷	Qualitative – case study	None specified	UK (HV)	HV and family	1	F		18 months	Case study, description of the child's sleeping problem and what she did to manage it	HV plan of action prior to consulting with a clinical psychologist	None specified
Cook and colleagues 2020 ²¹⁵	Qualitative	“to explore parentally reported barriers to help seeking from HCPs in the United Kingdom”	UK (HCPs) – some quotes refer to HV/GPs	Parents	182	F = 97%	Age: 21 to 45 years. Ethnicity: White (87.2%). Bachelors degree: 78.9%. ‘High SES’. 48 counties in England	6-36 month old children (M=19.41, SD = 9.26)	Online questionnaire (open-ended question)	Knowledge, Practice (parent report of what they were recommended)	Thematic analysis
Cheng and colleagues 2020 ²¹⁴	Mixed methods	“to examine factors influencing the child obesity prevention practices of CFHNs and to identify opportunities to	Australia (CFHN)	CFHN	Survey = 90 Interviews = 20	F = 100%	51% were 50 or over 50 years old. Less than 5 years experience as CFHN = 19%	0-5 years	Survey Semi structured interview	Sleep knowledge and treatment practices, influence on current practice and attitude towards future training in	Statistical analysis Thematic analysis

Study	Study Design	Aim	Country (setting)	Sample				Age of children	Data collection method / procedure	Relevant Outcomes	Analysis
				Type	N	Gender	Other				
		support them in promoting healthy infant growth”					More than 10 years’ experience = 52%			behavioural sleep problems	
Murray and colleagues 223	Qualitative	“to explore how unsettled behaviour was understood, clinically investigated and responded to by Vietnamese health professionals, and to describe what health education on infant sleep and settling was available.”	Vietnam	Primary care doctors and nurses/midwives	4 doctors and 4 nurses/midwives				Interviews or focus groups, transcribed and translated verbatim	Practice	Deductive thematic analysis
Sadler and colleagues 2020 ⁷³	Qualitative	“to describe: (1) the perceptions of parents, childcare and healthcare providers regarding sleep health among racially and ethnically diverse infants and toddlers who live with economic adversity; (2)	US (Paediatric providers)	Pediatric providers review	10				Semi-structured interviews	Sleep habits ,sleep health and factors contributing to sleep. Excluded data from childcare providers in this review (as not HCP). No relevant data	Thematic analysis

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Study	Study Design	Aim	Country (setting)	Sample				Age of children	Data collection method / procedure	Relevant Outcomes	Analysis
				Type	N	Gender	Other				
		factors that contribute to sleep health and its consequences; and (3) best ways to promote sleep health in their children”							from parent participants		
Paton and colleagues 2019²²⁶	Mixed methods	“to examine the: (1) feasibility, sustainability, and outcomes of a brief training session to increase ESN competence and confidence, knowledge, and skills in delivering behavioral sleep interventions, (2) feasibility and acceptability of ESNs delivering a parent education program from the nurses’ perspective, and (3) implementation costs associated with training and maintaining a	Australia	School nurses	24 baseline survey 15 focus group			Surveys and focus groups. Surveys assessed at various time points of the intervention.	Baseline assessments: perceptions of confidence in management.	Thematic analysis and descriptive statistics	

Study	Study Design	Aim	Country (setting)	Sample				Age of children	Data collection method / procedure	Relevant Outcomes	Analysis
				Type	N	Gender	Other				
		knowledge base within the ESN workforce to deliver the intervention.”									
Williamson and colleagues 2020 ²²⁹	Qual (mixed with parents but not included in review)	“to assess stakeholder perspectives to inform adaptation and implementation of evidence-based behavioral sleep interventions in urban primary care.”	US	PCPs	22	F = 87%	Race: ‘black or African american’ (18%), ‘white’ (73%), ‘asian’ (9%) Age in years: 18-24 (-) 25-29 (4.5%), 30-39 (45.5%), 40-49 (27.3%), >50 (22.7%)	Semi-structured Interviews	Knowledge, practice, views, perception of role, attitude	A priori CFIR codes and grounded theory coding	
Bonuck and colleagues ²¹⁰	Mixed methods	To assess ECE/related communities knowledge about sleep health, application of knowledge and opportunities to enhance knowledge into practice and policy	US	Head start staff	31 headstart staff			Quantitative surveys of head start staff	Preparedness and beliefs	Descriptive statistics	

A.6.2 Knowledge and understanding

Table 28 Data extraction: Quantitative data for knowledge and understanding

Study	PCP type	Country	Participant	Quantitative data: Questionnaires assessing knowledge or other data relating to perceived knowledge/understanding
Bruni and colleagues 2004 ²¹¹	Paediatrician	Italy	PCP	<p>'Sleep Survey' knowledge questionnaire Sleep hygiene items (% score of correct answers): mean = 57.89%; SD=20.31, Median = 50. "Peds with higher ambulatory practice scored significantly higher in the sleep hygiene subscale".</p> <p>'Sleep Survey' knowledge questionnaire Developmental issues items: (% score of correct answers): mean = 60.55; SD = 21.51; Median = 60</p> <p>"PED... made more than 50% of mistakes on items 8 ("Rocking an infant to sleep before placing him/her in the crib is likely to be an effective strategy to improve sleep stability", 11 ("An otherwise healthy teenager who sleeps until noon on the weekends is likely to be chronically sleep deprived" related to sleep hygiene".</p> <p>No significant differences in the above results to the face to face interviews acting as a control group which tested validity of postal questionnaires.</p>
Mindell and	Paediatrician	US	PCP	<p>'Sleep Survey' knowledge questionnaire sleep hygiene items (average total score): 73.5% (SD: 17.07, median 83, range: 30-100).</p>

Study	PCP type	Country	Participant	Quantitative data: Questionnaires assessing knowledge or other data relating to perceived knowledge/understanding
colleagues 1994 ²²²				<p>'Sleep Survey' knowledge questionnaire developmental issues: (average total score): 77.5% (SD: 15.12, median 80, range: 40-100)</p> <p>No sig differences between gender of pediatrician (P > .05)</p>
Owens 2001 ²²⁵	Paediatrician	US	PCP	<p>Pediatric Sleep Survey (PSS) behavioural subscale: looks approximately mean 60% items correct, with around 40-50% all correct. Developmental subscale: looks approximately 75% items correct, with approx. 20% all items correct.</p> <p>No significant differences between community and academic practitioners other than the OSA subscale which is not relevant here. Knowledge scores for behavioural subscales were higher for those "whose own children had sleep problems (3.36 vs 3.15, t (505) 5 = -2.0, P =5 .04)"</p>
Ersu 2017 and colleagues ¹³⁷	Paediatrician	Turkey	PCP	<p>Sleep Knowledge for control (no intervention) at baseline, short term assessment and long-term assessment: N and % of correct response. No significant change across time points from the control group.</p> <p>"Long term negative consequences of sleep problems": 45/70 (64%).</p> <p>"Minimum sleep requirement in childhood according to age group": 28/70 (40%), 28/70 (40%), 27/70 (39%)</p> <p>"Minimum sleep requirement in adolescence": 32/70 (46%), 31/70 (44%), 31/70 (44%)</p> <p>"Behavioural Insomnia in Childhood": 40/70 (57%), 38/70 (54%), 41/70 (59%)</p>

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Study	PCP type	Country	Participant	Quantitative data: Questionnaires assessing knowledge or other data relating to perceived knowledge/understanding
				<p>“Sleep physiology (two questions)”: 33/70 (47%), 33/70 (47%), 36/70 (51%)</p> <p>“Recommendations for prevention of BIC”: 46/70 (66%), 47/70 (67%), 48/70 (69%)</p> <p>Sleep knowledge for intervention group at baseline. N and % of correct response. No significant differences between control and intervention group at baseline p>0.05).</p> <p>“Long term negative consequences of sleep problems”: 73/117 (62%)</p> <p>“Minimum sleep requirement in childhood according to age group”: 48/117 (41%)</p> <p>“Minimum sleep requirement in adolescence”: (54/117 (46%)</p> <p>“Behavioural Insomnia in Childhood”: 66/117 (56%)</p> <p>“Sleep physiology (two questions)”: 53/117 (45%)</p> <p>“Recommendations for prevention of BIC”:71/117 (61%)</p>
Faruqui and colleagues 2011 ²¹⁷	Paediatrician	US	PCP	<p>“School-aged children who are sleepy should be encouraged to take at least 1 nap per day (False)”: 118 answered correctly (34%).</p> <p>“Developmental changes that occur in puberty probably cause delay in sleep onset. (True)”: 173 answered correctly (50%)</p>

Study	PCP type	Country	Participant	Quantitative data: Questionnaires assessing knowledge or other data relating to perceived knowledge/understanding
Cheng and colleagues 2020 ²¹⁴	CFHN	Australia	PCP	87 (96.7%) of CFHN's had access to "educational materials for parents on sleep and settling techniques for infants". 3 (3.3%) did not.
Paton and colleagues 2019 ²²⁶	School nurses	Australia	PCP	"Felt well prepared to help manage child sleep problems": 16.7%

Table 29 Data extraction: Qualitative data for knowledge and understanding

Study	PCP type	Country	Participant	Qualitative data: Knowledge / Understanding
Hall and colleagues 2019 ²¹⁸	Public health nurses	Canada	PCP	When assessing the outcomes of a piloted training workshop through guided discussion, "23 NRPH&ES nurses indicated that it helped address current gaps in nurses' knowledge about developmental changes in infant sleep and to enhance NRPH&ES efforts to assist parents to manage infants' behavioural sleep problems."

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Study	PCP type	Country	Participant	Qualitative data: Knowledge / Understanding
				PHNs in a focus group providing evaluation feedback, felt a campaign would be necessary to “educate community PCPs about sleep”. PHNs felt a “need for more training about developmental changes in infant sleep” and access to empirical support for behavioural interventions”.
Hatton and Gardani 2018 ¹³³	HV / partly GP	UK	Parent	<p>“we had asked for advice and they gave us to let him fall asleep by himself so we put him to bed before he’s not asleep yet and then let him cry, I don’t know how other parents cope but we tried it for 3 or 4 days and then we stopped because we couldn’t take it . . . she [health visitor] came back and we said but . . . she kinda insisted on doing it again and I disagreed and said yes we will do it but never did . . . she was well informed in what she was talking about but I guess she wasn’t really keen to look at alternatives.” P10</p> <p>“Professional advice could potentially overcome these limitations. However, purely theoretical advice was seen as limiting by some, who preferred it if the professional was also a parent: ‘I love when doctors have actually had children . . . because they’ve been there, they are also a bit more understanding that might affect how I follow what they say . . .’ p7</p> <p>“Participants were, however, almost of unanimous opinion that professionals did not have adequate objective knowledge in the area. ‘They [health visitors] show absolutely no consistent training in sleep...so I am quite sceptical about health visitors, I probably wouldn’t have gone to them. I think if I had been really worried, I probably would have gone to my GP but I’m not entirely sure that GPs have very much training...’ P1 “</p>

Study	PCP type	Country	Participant	Qualitative data: Knowledge / Understanding
Cook and colleagues 2020 ²¹⁵	HCPs	UK	Parent	<p>“There was also a prevailing belief amongst some parents that HCPs' knowledge and skills around child sleep were negatively affected by limited or insufficient training on this topic: ‘Recommend CC [Controlled Crying], CIO [Cry it out] etc. no real help. Many don't have children and seem to have minimal training on sleep so I am not happy to turn to them. (Mum, 28, of girl 7 months)’”</p>
Sadler and colleagues 2020 ⁷³	PCPs	US	PCPs	<p>“Many understood that sleep needs varied by age and that all young children have natural drives and circadian rhythms for sleep that make early bedtimes ideal in most cases. In general, healthcare providers were more knowledgeable than childcare providers about children’s sleep requirements, (childcare providers estimated 8 hours), and the effects of sleep on health and brain development. As one healthcare provider stated, “Sleep is a gift to your child.””</p>
Williamson and colleagues 2020 ²²⁹	PCPs	US	PCPs	<p>“Both caregivers and clinicians identified a need for more patient and family education about healthy sleep habits and behavioral sleep intervention strategies in primary care. Some clinicians also expressed a need for more knowledge and resources in this regard for themselves”</p> <p>Theme: Lack of education/knowledge about pediatric sleep: “But I’ve never said, ‘Make sure your child gets 10–13’ [hr]—like I didn’t know that was the recommendation, you know, so um, that’s something I haven’t been educating families about. But again, I don’t really know what education is out there for us in teaching our families that.”</p>

A.6.3 Management/practice

Table 30 Data extraction: Quantitative data for management/practice

Study	PCP type	Country	Participant	Quantitative data: Management / Practice	
				Treatment practice / likely recommendation	Discussion with parents about management
Bruni and colleagues 2004 ²¹¹	Paediatrician	Italy	PCP	<p>% of paediatricians that recommend: Parental intervention: 'Ignore the child' (2.23%); 'Graduated extinction' (35.57%); 'Bedtime routine' (83.41%); 'Keep the child up prior to bedtime' (20.10%); 'Change duration/number of naps in the day' (49.76); 'Soft music / rocking at bedtime' (44.34%). 'Change feeding schedule': (17.54%). 'No intervention': 6.7%.</p> <p>No statistical differences were found between the control group and the paediatricians, for relevant outcomes.</p>	Question asking whether they say that the child will outgrow the problem: "Usually" or "always: 48.9%
Mindell and colleagues 1994 ²²²	Paediatrician	US	PCP	<p>% of paediatricians that recommend: 'Ignore the child' (18.1%), 'Ferber method' (84.6%), 'Bedtime routine' (95.1%), 'Keep the child up' (17.6%), 'nap schedule' (52.8%), 'rock the child' (23.1%), 'feeding schedule' (20.3%), 'No intervention': (3.3%)</p>	Question asking whether they say that the child will outgrow the problem: "Usually" or "always: 77.89%. "Paediatricians in Pennsylvania were more likely to suggest this to parents than paediatricians in Rhode Island, chi square (4) = 9.74, P < .05"

Study	PCP type	Country	Participant	Quantitative data: Management / Practice	
				Treatment practice / likely recommendation	Discussion with parents about management
Owens 2001 ²²⁵	Paediatrician	US	PCP	<p>Sleep treatment practices (participants rated frequency of likely treatments): % of respondents likely to recommend at least 50% of the time:</p> <p>For “frequent night waking in 14 month old routinely rocked to sleep at bedtime”: ‘Co-sleeping with parents’ (3.4% or 12.1% at least occasionally), ‘no intervention’ (13.2%), ‘Increased parental intervention at bedtime’ (24.5%), ‘graduated extinction’ (90%)</p> <p>For “bedtime resistance in pre-schooler with sudden onset of nighttime fears”: Tv at bedtime (8%, or 13.9% at least occasionally), ‘ignoring fears’ (20.6%), ‘Positive reinforcement’ (73.5%), ‘transitional object’ (83.6%)</p> <p>For “insomnia in adolescent attributable to poor sleep habits”: ‘catch up sleep on weekends’ (25.8%), ‘restricting non-sleep activities in bed’ (64.8%) and ‘similar sleep-wake schedule on school and non-school days’ (85.5%)</p>	
Faruqui and	Paediatrician	US	PCP	<p>“Pediatricians were also asked about office-based practices they used with the majority of the school-aged patients who have sleep problems.”</p>	

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Study	PCP type	Country	Participant	Quantitative data: Management / Practice	
				Treatment practice / likely recommendation	Discussion with parents about management
colleagues 2011 ²¹⁷				Behavioural therapy (52.9%). Other responses did not relate to behavioural sleep problems/treatment	
Wynter and colleagues 2015 ²³⁰	MCH nurse	Australia	PCP	<p>In response to advice to a mother of a 6 month old who wakes frequently, there were 4 broad categories of responses:</p> <p>‘General assessment’ (n=280). ‘Education’ (n=220). ‘Specific advice’ (n=247): e.g. ‘feed advice’ (n=60) and ‘settling strategies’ (n=221). For 125 cases, ‘settling strategies were not specified. Among those that did specify, at least 25 different strategies were mentioned’. ‘Referral’ (n=147) to various resources or services</p> <p>220/343 said they would discuss/ explain infant sleep needs, infant development, sleep environment and routines to parents</p>	<p>In response to advice to a mother of a 6 month old who wakes frequently, there were 4 broad categories of responses:</p> <p>55/343 said they would normalise night waking, or emphasise that it is common</p>
Chavin and Tinson 1980 ²¹³	HV	UK	Parent	<p>Parent’s views of who had been most helpful about sleep problem (n=62): GP (34%), HV (40%) Other options (relatives, other mothers, park hospital) but not relevant here.</p>	

Study	PCP type	Country	Participant	Quantitative data: Management / Practice	
				Treatment practice / likely recommendation	Discussion with parents about management
Hewitt and colleagues 1989 ²¹⁹	HV	UK	PCP	<p>Prior to training, referral to clinical psychology did not usually happen (sleep problems were least likely – Mean = 2.29). Following training, referral was even less likely.</p> <p>Rating scales (ratings could have minimum score 0 and max 9): Pre-training ratings indicated they “regarded themselves as providing specific advice, rather than general... for sleeplessness (mean 8.29)”. Did not significantly change following training, but “pre-training ratings...were close to ceiling levels” already.</p>	
Kanoy and Schroeder 1985 ²²¹	Program in primary care clinic	US	Parent	<p>Service given by primary care clinic for behavioural problems. N=60 concerns about sleep for 1973-6, 1977-78 and 1979-1980 follow up.</p> <p>Advice given (number of suggestions):</p> <p>‘Reward appropriate behaviours with star or chart’ (14), ‘Ignore the behaviour e.g. cry it out’ (19), ‘Rearrange child’s schedule’ (10), ‘Be supportive and reassuring to child’ (12), ‘Story and ritual before bed’ (8), ‘Environmental change e.g. night light, toys’ (7), ‘Information on what to expect’ (2)</p>	

Study	PCP type	Country	Participant	Quantitative data: Management / Practice	
				Treatment practice / likely recommendation	Discussion with parents about management
Olson and colleagues 2004 ²²⁴	Paediatrician	US	Parent and PCP		<p><u>Parent report (exact figures not always given, determined by eye):</u></p> <p>4-9 month old: Night waking & fussing: Discussed: approx. 70-75%. 'Not discussed, would have been helpful' :approx. 12.5%. 'Not discussed, would not have been helpful': approx. 12.5%. At least 10% reported unmet need for nightwaking</p> <p>10 to 18 month old: Night waking & fussing: Discussed: approx. 65%. 'Not discussed, would have been helpful' :approx. 10%. 'Not discussed, would not have been helpful': approx. 20%</p> <p>19-35 months: bedtime routine: Discussed: approx. 47%. 'Not discussed, would have been helpful': approx. 15%. 'Not discussed (not helpful)': approx. 40%</p> <p><u>Parent and Pediatrician report respectively:</u></p> <p>Nightwaking & fussing: 4-9 months (74.4% and 52.8%) and 10-18 months (66.6% and 52.3%). Sleep patterns/problems: 10-18 months sleeping with bottle: (63.7% and 68.6%) and 19-35 months bedtime routines (46.5% and 53.9%)</p> <p>"Proportions provided by parents and pediatricians cannot be compared directly: Parent data represent percent of parents who said that a topic was discussed in the past year.</p>

Study	PCP type	Country	Participant	Quantitative data: Management / Practice	
				Treatment practice / likely recommendation	Discussion with parents about management
					Pediatrician data represent those who reported that the topic was discussed at least once with at least 75% of parents of children in the respective age group. Parents of children 4 to 35 months were surveyed; pediatricians were asked about care for patients 0 to 35 months."
High and colleagues 1998 ²²⁰	Pediatric residents and nurse practitioner	US			Group 2: implemented intervention group. "Parents in group 2 reported receiving more anticipatory guidance about... sleep behaviour (P=0.02)... No significant differences between groups 1 and 2 were found for...bedtime routines (P=.30)"
Cheng and colleagues 2020 ²¹⁴	CFHN	Australia	PCP	'Never to sometimes (50% or less)' discussing sleep and settling techniques for infants = 13 (14.8%) 'Often to mostly (51% or more)' discussing sleep and settling techniques for infants = 175 (85.2%)	

Table 31 Data extraction: Qualitative data for management/practice

Study	PCP type	Country	Participant	Qualitative data: Management / Practice. Discussion about management is less frequent, so where there is data for this, it is underneath the heading 'Discussion about management'.
Hatton and Gardani 2018 ¹³³	HV / GP	UK	Parent	<p>'we had asked for advice and they gave us to let him fall asleep by himself so we put him to bed before he's not asleep yet and then let him cry, I don't know how other parents cope but we tried it for 3 or 4 days and then we stopped because we couldn't take it...she [health visitor] came back and we said but...she kinda insisted on doing it again and I disagreed and said yes we will do it but never did...she was well informed in what she was talking about but I guess she wasn't really keen to look at alternatives.' Participant 10</p> <p>'you wouldn't be able to tell them [health visitors] that they [siblings] sleep in a bed, they would be like emm don't do that but he gets a great sleep". Participant 3.</p> <p>'we got more sleep when she was in with us but you can't tell the health visitor that because you know they will string you up...the thing is don't do it so everybody's scared of doing it, so they will sit up on the sofa which is actually more dangerous than lying down in your bed' Participant 4"</p> <p>[Discussion about management]:</p> <p>"The health visiting team gave the pack out then it stops and you don't really, you don't necessarily see them until.... aged 4...are not getting any leaflets through the door...I think there's a relationship gap.' Participant 15</p>

Study	PCP type	Country	Participant	Qualitative data: Management / Practice. Discussion about management is less frequent, so where there is data for this, it is underneath the heading 'Discussion about management'.
				'I don't think there's enough appointments available . . . so trying to get an appointment is nigh on impossible if it's within 2 weeks.' - Participant 12
Abbot and Bryar 2018 ²⁰⁹	HV	UK	PCP	"Health visitors were full of praise for the information packs that came as part of the sleep training, and which they could give to families." "We have got like little packets of information about different sleep training techniques, which have been very useful to give out to parents" (HV5)
Wynter and colleagues 2015 ²³⁰	MCH nurse	Australia	PCP	In response to advice to a mother of a 6 month old who wakes frequently, themes: 'General assessment' <ul style="list-style-type: none"> • 'Assess infant physical wellbeing' • 'Ask about mother' <ul style="list-style-type: none"> • 'Other problems e.g. family' • 'Discuss her expectations and desires about her baby's sleep' • 'Discuss her sleep and support' • 'Assess her wellbeing' • 'Acknowledge her distress, support her' • 'Refer mother to early parenting services'

Study	PCP type	Country	Participant	Qualitative data: Management / Practice. Discussion about management is less frequent, so where there is data for this, it is underneath the heading 'Discussion about management'.
				<ul style="list-style-type: none"> • 'Specific advice' <ul style="list-style-type: none"> • 'Settling strategies' <ul style="list-style-type: none"> • 'Controlled crying / comforting' • 'Patting, sshhhing baby' • 'Infant should self-settle' • 'Partner support / settle infant over night' • 'Resettle without feeding' • 'Increase daytime feeds/ rollover feed' • 'Education: explain or discuss' <ul style="list-style-type: none"> • 'Infant sleep needs / sleep associations / tired cues' • 'Consistency, routine' • 'Feed-play sleep routine' • 'Infant development at 6 months e.g. object permanence' • 'Sleep environment, bedtime' <p>[Discussion about management]:</p> <p>In response to advice to a mother of a 6 month old who wakes frequently: Theme: "reassure some night waking is normal"</p>

Study	PCP type	Country	Participant	Qualitative data: Management / Practice. Discussion about management is less frequent, so where there is data for this, it is underneath the heading 'Discussion about management'.
Stallard 1992 ²²⁷	HV	UK		<p>“The health visitor had agreed a sleep programme with the family. This focussed upon establishing a bedtime routine, making Lucy’s bedroom attractive and cosy, establishing sleep cues and adopting a firm approach to any night-time waking. The health visitor met weekly with the family over a six-week period but, unfortunately, the situation remained the same, with Lucy refusing to go to bed, regularly waking at night and continually coming into her parent’s bed”</p>
Crawford and colleagues 1989 ²¹⁶	HV	UK	PCP case notes	<p>Following attendance of a course mentioned in Hewitt (1979), a HV kept notes of her cases: Individual constructional approach to each treatment: HV also recorded number of improvement (not relevant to this review)</p> <p>Child: Age (months); age in months; duration of problem before treatment in months, weeks; sex, Analysis of problem, recommendation</p> <ol style="list-style-type: none"> 1. 39; 6; F; Analysis: “came to parent’s bed most nights between 1am to 4am. Mother glad to have child in bed when father working night shifts” Recommendation: “Discussed problem with both parents. Did not keep charts but agreed to handle child in the same way every night” 2. 9; 0,5; F Analysis: “Often asleep during the day and awake at night. No ability to settle self”

Study	PCP type	Country	Participant	Qualitative data: Management / Practice. Discussion about management is less frequent, so where there is data for this, it is underneath the heading 'Discussion about management'.
				<p>Recommendation: "Bedtime routine established including settling activities which were also used in instances of night waking".</p> <p>3. 12; 0,6; F</p> <p>Analysis: "Difficult to settle – rocked to sleep downstairs. Unpredictable sleep pattern. In parents' bed most nights. Father worked shifts which affected family's routines."</p> <p>Recommendation: "Predictable bedtime routine established, including settling activities. rough and tumble games avoided before dinner"</p> <p>4. 36; 24; M</p> <p>Analysis: "Settled downstairs, awoke and cried when carried upstairs. In mothers bed every night"</p> <p>Recommendations: "Established bedtime routine which involved settling in own bed"</p> <p>5. 18; 1; M</p> <p>Analysis: "Sleeping in parents bed every night"</p> <p>Recommendation: "<i>Initial interview and baseline recording only</i>"</p> <p>6. 7; 0,6; M</p> <p>Analysis: "Awoke most of each night and frequently slept during day"</p> <p>Recommendation: ""Altered daytime sleep pattern"</p>

Study	PCP type	Country	Participant	Qualitative data: Management / Practice. Discussion about management is less frequent, so where there is data for this, it is underneath the heading 'Discussion about management'.
				<p>7. 10; 0,8; F Analysis: "Settled in parents arms and then put down. Woke by midnight when she was taken into parent's bed" Recommendation: "Established bedtime routine which involved settling in own bed"</p> <p>8. 18; 1,6; F Analysis: "Awake for 2 hours playing in middle of night. Slept until noon" Recommendation: "Mother woke child by 9am"</p> <p>1;F Analysis: "Awake for long periods each night and asleep for long periods during day" Recommendation: "Altered daytime sleep pattern"</p>
Cook and colleagues 2020 ²¹⁵	HV / GP	UK	Parent	<p>'Have found them narrow-minded, judgemental and critical of anything other than cry-it-out, so reluctant to ask them for any advice on anything ever again.' (Mum, 41, of boy 14 months)</p> <p>"Standard answers which leave you feeling like you are doing something wrong. Crying it out is NOT the way to fix anything. When I explained my reservations to the HV [health visitor] she told me that I would have to do it anyway. Horrifying that some mothers may then do this as a result of the appalling information issued.' (Mum, 31, of girl 9 months)</p>

Study	PCP type	Country	Participant	Qualitative data: Management / Practice. Discussion about management is less frequent, so where there is data for this, it is underneath the heading ‘Discussion about management’.
Murray and colleagues 2019 ²²³	Doctors and midwives	Vietnam	PCP	<p>““If the children usually wake up at night and cry a lot without any reason, we’ll suggest the mothers should check that if the child is hungry or they are cold in the winter or hot in the summer. The mothers should find out the reasons that make their child irritated. If the child is hungry, we have to do nothing but feed him. Some reasons for crying include starving, feeling hot or cold feeling or wet. This is my experience I share with the mums.” Midwife, female, urban CHC”</p> <p>“When such cue-based care was recommended, it involved advice to let babies under six months old feed and sleep “on-demand”. Participants did not mention behavioural interventions such as feed-play-sleep programs, or any other specific advice for infants older than six months of age”:</p> <p>“For the new baby they often sleep all day time but they are awake at night time so the mother has to stay awake with them, and then maybe at night they are always hungry, so you must feed them.” Midwife, female, rural CHC</p> <p>“We don’t give the mother direct guidelines, however I think that the baby should be sleeping at the children’s demand. For example, some children want to sleep during the day, but at night they wake up and they play.” Primary care doctor, male, rural CHC”</p> <p>“All participants stated that standard information on infant sleep and settling was not routinely provided to women through such health education activities”.</p>

Study	PCP type	Country	Participant	Qualitative data: Management / Practice. Discussion about management is less frequent, so where there is data for this, it is underneath the heading ‘Discussion about management’.
				<p>“We don’t talk about that (sleep and settling), we are mainly focussed on the topic of breastfeeding and nutrition, how the mother can cook nutritious food.” Midwife, female, rural CHC”</p>
Sadler and colleagues 2020 ⁷³	Paediatric providers	US	PCP	<p>“Bedtime Routines for Everyone.—All providers stressed the importance of structure and routine. They tried to help parents establish sleep routines by providing a template for “winding down” and establishing regular bedtimes. Healthcare providers advocated behavioral sleep approaches with parents of older infants and toddlers. All also tried to help parents recognize children’s cues that signaled sleepiness to avoid “over-tired” children, and they tried to help parents understand that creating structure and setting limits around bedtime helps children feel comfortable and secure...Providers also stressed the advantages of regular child bedtimes for parents (e.g., reducing parental fatigue, allowing for alone time, increased ability to get work done, etc.). Some tried to help parents view sleep routines as ways to handle their own stressors”</p> <p>“Providers’ Sleep Recommendations.—All providers were eager to help parents increase their knowledge and skills about sleep. They recommended the following: community based approaches (reaching parents through childcare programs, public service campaigns, 24-hour sleep hotlines), electronic delivery (videos demonstrating bedtime routines, media messaging, smartphone apps), teaching (classes, parents networking with other parents), printed materials (sleep education materials in waiting rooms, children’s “going to bed” books) and home visiting approaches with in-home assessments and interventions to promote healthy sleep.”</p>

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Study	PCP type	Country	Participant	Qualitative data: Management / Practice. Discussion about management is less frequent, so where there is data for this, it is underneath the heading ‘Discussion about management’.
				<p>“providers uniformly advocated reading books at bedtime and healthcare providers also advised about behavioral sleep interventions (structured approaches for promoting independence in falling asleep, self-soothing, and returning to sleep after brief awakenings at night) for older infants and young children”</p>
<p>Williamson and colleagues 2020 ²²⁹</p>	<p>PCP</p>	<p>US</p>	<p>PCP</p>	<p>“Clinicians often described making the connection between sleep and child wellbeing more explicit for families during their visits.”</p> <p>“Theme: Importance of empowering and collaborative care: “Another intervention facilitator that aligned across stakeholder groups was the importance of care that was both empowering and collaborative, with partnerships between caregivers and clinicians and between caregivers and other family members. A clinician described empowering families to make change by eliciting intervention ideas from families, while another clinician discussed that empowering a caregiver to make change often leads to supporting collaboration with all family stakeholders. Many clinicians emphasized “getting everyone on the same page” in the family to collaborate and support sleep recommendations“ “. . . I think the advice is different depending on what the environmental construct is around sleeping, so I start there and then veer off depending on what is offered to me. . .So. . . rather than giving a prescriptive sleep or bedtime routine, I ask parents for their own suggestions about what may work for their family. Because it doesn’t work the same way for everybody.”</p>

Study	PCP type	Country	Participant	Qualitative data: Management / Practice. Discussion about management is less frequent, so where there is data for this, it is underneath the heading 'Discussion about management'.
				"So just sort of empowering them [families] to recognize that like this [sleep] is a big, like it's a real problem for their child and like, they're allowed to do things that might seem somewhat extreme in the short term if it's in the long-term best interest of their whole family. But then a lot of the time that gets into a conversation about all the other stakeholders in the household."

A.6.4 Beliefs

Table 32 Data extraction: quantitative data for views, attitudes and perceptions of role

Study	PCP type	Country	Participant	Quantitative data: Views, attitudes and perceptions of role		
				Views and perceptions about behavioural sleep	Perceptions of role	Treatment attitude / belief
Bruni and colleagues 2004 ²¹¹	Paediatrician	Italy	PCP	Considerations of factors affecting sleep: 'Parental attention and handling at bedtime' (78.31%); 'Co-sleeping in parents bed' (64.43%); 'Feeding		"Almost all of the physicians believed that a treatment of the disorders of initiating and maintaining sleep is useful in the majority of cases" (92.03%) ... "and preferred behavioural approaches"

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Study	PCP type	Country	Participant	Quantitative data: Views, attitudes and perceptions of role		
				Views and perceptions about behavioural sleep	Perceptions of role	Treatment attitude / belief
				<p>before bedtime' (28.07%) 'Room sharing with siblings' (22.33%)</p> <p>Belief that Insomnia impacts on:</p> <p>'family happiness' (85.01%); 'parental depression' (46.73%); 'work performance' (49.76%), and 'marital satisfaction' (25.36%)</p>		
Mindell and colleagues 1994 ²²²	Paediatrician	US	PCP	<p>Beliefs of factors that affect children's sleep habits: 'Parental attention and handling at bedtime' (96.7%); 'Co-sleeping in parents bed' (81.7%) 'Feeding before bedtime' (33.00%) 'Room sharing with siblings or other' (50.00%)</p> <p>Beliefs that children's sleep problems affect: 'family happiness' (93.3%), 'parental depression'</p>		

Study	PCP type	Country	Participant	Quantitative data: Views, attitudes and perceptions of role		
				Views and perceptions about behavioural sleep	Perceptions of role	Treatment attitude / belief
				(77%) and 'work performance' (75.3%), and 'marital satisfaction' (83.2%)		
Faruqui and colleagues 2011 ²¹⁷	Paediatrician	US	PCP	<p>"Perceived aetiology of sleep problems": Each rated as rarely (<33%), sometimes (34%-66%), usually (>67%). Reported as N and (%) for each respectively:</p> <p>'Caffeine use': 125 (36%), 177 (51%), 27(8%)</p> <p>'Other substance abuse:' 263 (76%), 34 (10%), 10 (3%)</p> <p>'Early school start times': 101 (29%), 161 (47%), 56 (16%)</p>	'96% agreed or strongly agreed that they should counsel about sleep hygiene'. '1% disagreed or strongly disagreed'.	<p>Perceived confidence was rated using a 5 point likert scale ranging from 1 (not confident) to 5 (very confident): Results reported as N and % for each respectively.</p> <p>'Your ability to advise children (or their guardian) regarding sleep hygiene': 1: 7(1%), 2: 17(5%), 3: 97(28%), 4: 183(53%) and 5: 44(13%)</p> <p>'Your ability to motivate children to change their sleep behaviours': 1:16(5%), 2: 73(21%), 3: 162(47%), 4: 82(24%), 5: 13(4%)</p>

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Study	PCP type	Country	Participant	Quantitative data: Views, attitudes and perceptions of role		
				Views and perceptions about behavioural sleep	Perceptions of role	Treatment attitude / belief
				<p>'Excessive school assignments': 124 (36%), 148 (43%), 44(13%)</p> <p>'TV viewing/video game useage/ computer / internet': 9 (3%), 148 (43%), 181 (52%)</p> <p>'Late night texting / cell phone use': 36 (10%), 150 (43%), 132 (38%)</p> <p>'After school activities': 11 (3%), 0, 0</p> <p>“Four possible choices were selected as “usually” causing sleep problems: use of electronic devices (52%); late-night texting/ cell phone use (38%); early school start times</p>		

Study	PCP type	Country	Participant	Quantitative data: Views, attitudes and perceptions of role		
				Views and perceptions about behavioural sleep	Perceptions of role	Treatment attitude / belief
				(16%); and excessive school assignments (13%)”		
Wynter and colleagues 2015 ²³⁰	MCH nurse	Australia	PCP		In response to advice to a mother of a 6 month old who wakes frequently, 280/343 saw gathering info which included sleeping habits as central to their role	
Thomas and colleagues 1982 ²²⁸	HV	UK	PCP	<p>Ratings (scale 0-80mm) ‘Extent of family disruption’ (from ‘disruptive to everyday family life’ to ‘not disruptive to everyday family life’): mean = 60.</p> <p>“It shows that hyperactivity and sleeping problems were perceived</p>	<p>Ratings: (scale 0-80mm) ‘Responsibility for dealing with problem’ (from ‘responsibility of some other agency’ to ‘responsible for dealing with this myself’): mean = 60</p> <p>“It shows that health visitors reported being least able to</p>	<p>Ratings (scale 0-80mm) ‘Ability to cope with problem’ (from ‘feel able to cope adequately with this problem’ to ‘do not feel able to adequately cope with this problem’): mean = 35</p> <p>“It shows that health visitors reported being least able to cope with problems of sleep, anti-social behaviour, hyperactivity, and toileting, although they felt it their responsibility to deal with eating, fears, sleep, and emotional problems themselves”</p>

Study	PCP type	Country	Participant	Quantitative data: Views, attitudes and perceptions of role		
				Views and perceptions about behavioural sleep	Perceptions of role	Treatment attitude / belief
				as both the most difficult to deal with and the most disruptive to family life.”	cope with problems of sleep, anti-social behaviour, hyperactivity, and toileting, although they felt it their responsibility to deal with eating, fears, sleep, and emotional problems themselves”	<p>Ratings (scale 0-80mm) ‘Difficulty of management’ (from ‘difficult to deal with’ to ‘not difficult to deal with’: mean = 50.</p> <p>“It shows that hyperactivity and sleeping problems were perceived as both the most difficult to deal with and the most disruptive to family life.”</p> <p>Rating (scale 0-80mm) frequency of visiting: (‘does not require frequent visiting’ to ‘requires frequent visiting’) Mean = 40</p>
Mindell and Owens 2003 ¹³⁵	Paediatric nurse practitioner	US	PCP			<p>Rating confidence for evaluating/treating sleep problems (With 1 as unconfident, 3 as somewhat and 5 as very, respectively:</p> <p>‘Insufficient sleep’: 1 (10.8%), 2 (14.9%), 3 (27.4%), 4 (27%), 5 (19.9%). Mean = 3.3. ‘Night wakings’: 1 (5.3%), 2 (8.5%), 3 (22.7%), 4 (32.4%), 5 (31.2%). Mean = 3.8.</p>

Study	PCP type	Country	Participant	Quantitative data: Views, attitudes and perceptions of role		
				Views and perceptions about behavioural sleep	Perceptions of role	Treatment attitude / belief
						<p>'Bedtime problems': 1(5.2%), 2 (8%), 3(23.6%), 4 (35.6%), 5 (27.6%). Mean = 3.7</p> <p>No significant differences for whether PCPs had been in practice more or less than 5 years for the above relevant outcomes</p>
Carter and Mason 1989 ²¹²	HV	UK	PCP	<p>Average length of time infant sleeps in a day: 'Average upper limit' 16.8 hours. 'Average lower limit' 11.1. Average range 5.6 hours, varying from 2 to 10.</p> <p>Views on waking in the night for a 1 month old (10pm to 7am): 37/42 (85%) said twice is average. 5/42 (11.9%) said 4 times is average. Approx 50% said once (determined from look of graph). Approx 70%</p>		

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Study	PCP type	Country	Participant	Quantitative data: Views, attitudes and perceptions of role		
				Views and perceptions about behavioural sleep	Perceptions of role	Treatment attitude / belief
				said twice (determined from look of graph)		
Hewitt and colleagues 1989 ²¹⁹	HV	UK	PCP		On rating scale prior to training (ratings could have minimum score 0 and max 9): all rated sleeplessness as a very appropriate problem to treat (mean = 9) which remained post training.	On rating scale (ratings could have minimum score 0 and max 9): Prior to training, sleeplessness was regarded as difficult to deal with (among all other problems) (mean for sleeplessness specifically not given). Training significantly influenced ratings of whether or not they felt able to cope for all behaviours (which included sleeplessness)
Cheng and colleagues 2020 ²¹⁴	CFHN	Australia	PCP			88 participants for: Confidence in consultation regarding “providing advice on sleeping and settling activities” Lower confidence (‘not at all confident’ and ‘somewhat confident’) = 8 (9.1%). Higher confidence (very confident’ and ‘extremely confident’= 80 (90.9%)

Study	PCP type	Country	Participant	Quantitative data: Views, attitudes and perceptions of role		
				Views and perceptions about behavioural sleep	Perceptions of role	Treatment attitude / belief
Paton and colleagues 2019 ²²⁶	School nurses	Australia	PCP		<p>“Nurses should refer rather than treat”: approx. 45.8%</p>	<p>Perceived confidence at baseline: Approximately ‘A little’ – indicated on a graph with the Y axis from not at all to very</p> <p>Perceived competence at baseline: Approximately ‘A little’ – indicated on a graph with the Y axis from not at all to very</p> <p>Treating sleep problems is professionally rewarding: 87.5%</p>
Bonuck and colleagues 2020 ²¹⁰	Head start staff	US	PCPs		<p>Headstart: Beliefs (agree, disagree, neither/don’t know)</p> <p>“educating parents about healthy sleep patterns and routines should be part of</p>	<p>Headstart: How comfortable staff are for advising about...(not at all, somewhat, and very):</p> <p>“best practices surrounding bedtime routines”: 0, 12 (40%) and 18 (60%)</p> <p>“Cultural values in sleep practice”: 5(16%), 14 (45%) and 12 (39%)</p>

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Study	PCP type	Country	Participant	Quantitative data: Views, attitudes and perceptions of role		
				Views and perceptions about behavioural sleep	Perceptions of role	Treatment attitude / belief
					<p>staff training” 30 (100%), 0, 0</p> <p>“counselling parents about behavioural sleep problems should be part of staff training” 27 (90%), 0, 3 (10%)</p>	<p>“methods to help children get to/stay asleep” 2(7%), 15 (50%) and 13 (43%)</p>

Table 33 Data extraction: qualitative data for views, attitudes and perceptions of role

Study	PCP type	Country	Participant	Qualitative data: Views, attitudes and perceptions of role		
				Views and perceptions about behavioural sleep	Perceptions of role	Treatment attitude / belief
Abbot and Bryar 2015 209	HV	UK	PCP			<p>“The health visitor who ran the sleep clinic had evidence suggesting that other health visitors, not interviewed as part of the evaluation, were also feeling</p>

Study	PCP type	Country	Participant	Qualitative data: Views, attitudes and perceptions of role		
				Views and perceptions about behavioural sleep	Perceptions of role	Treatment attitude / belief
						more confident in their practice. 'I am definitely getting referrals for the more complex mothers and not [any more] for the bread and butter sleep management stuff So that is good, definitely good'. (HV4)'''
Sadler and colleagues 2020 ⁷³	PCPs	US	PCP	Theme: "Barriers to Healthy Sleep" —"Providers reported that screen use interfered with their patients' sleep, while conceding that screens were often used as soothing or distracting mechanisms in many homes. They acknowledged the ubiquity of screens and questioned whether using them in a sleep promotion intervention (e.g., smartphone apps) would be useful. They believed that parents' schedules may be barriers to good sleep,	"All providers were eager to help parents increase their knowledge and skills about sleep."	

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Study	PCP type	Country	Participant	Qualitative data: Views, attitudes and perceptions of role		
				Views and perceptions about behavioural sleep	Perceptions of role	Treatment attitude / belief
				<p>since children may wake early or stay up late to spend time with a parent working late shifts or may awaken when picked up from a babysitter by a parent returning from an evening shift. As one healthcare provider related, "They're put to sleep in a relative's home or a babysitter's home and the parent comes home from a shift at 11:00 at night, the child is woken up and then they're transferred to another environment, all of which can disrupt sleep." Providers acknowledged that parents who must balance school/college schedules with family needs and</p>		

Study	PCP type	Country	Participant	Qualitative data: Views, attitudes and perceptions of role		
				Views and perceptions about behavioural sleep	Perceptions of role	Treatment attitude / belief
				routines face many challenges regarding sleep. Some noted that parents who lacked regular schedules for work or school had less structured sleep routines than those who worked or attended school”		
Williamson and colleagues 2020 ²²⁹	PCPs	US	PCP	<p>“Caregivers and clinicians conceptualized sleep as being critical for child wellbeing, although the impact of poor sleep on multiple aspects of child functioning (emotion regulation and academic performance) was described in more detail by clinicians”</p>	<p>“...But I do think that coming here [to primary care], especially for a lot of our family where it’s easier to get here versus having to go to the [main hospital] sleep clinic, [it] would be easier for parents.”</p> <p>Theme: “Primary Care Infrastructure Benefits and</p>	<p>“In response to questions about barriers impacting family-driven intervention components (Figure 1), both caregivers and clinicians similarly highlighted familial and contextual factors. These included: caregiver work schedules; having to manage multiple children; challenges in aligning different caregivers (e.g., co-parenting) and child sleep locations; caregiver stress and exhaustion; and family reliance on electronic items. Caregivers and clinicians raised these barriers in relation to all of the intervention components, frequently referencing multiple barriers</p>

Study	PCP type	Country	Participant	Qualitative data: Views, attitudes and perceptions of role		
				Views and perceptions about behavioural sleep	Perceptions of role	Treatment attitude / belief
			<p>Theme: “Sleep as critical for child wellbeing”: “I think it’s [sleep] very important. I think some of my families don’t recognize it, at least when I first meet them, why it’s so important. Like, they’re coming because this kid is having explosive tantrums. They think he has some sort of maybe ASD [autism spectrum disorder] or another disorder, and then I find out he’s only sleeping 6 hr a night, and then I’m like, ‘actually, let’s start—you know, here.’”</p> <p>“...clinicians emphasized the family context as the main contributor to child sleep</p>	<p>Limitations” - “Clinicians discussed benefits and limitations of the primary care context. One infrastructure benefit was the use of the EHR to provide sleep intervention referrals and facilitate coordinated care across primary care and behavioral health clinicians. Two of the three urban primary care sites also have integrated primary care (IPC) psychologists providing behavioral health services; the third primary care site has plans to initiate these services. Clinicians at the sites with existing IPC</p>	<p>simultaneously. For instance, inflexible or variable work schedules and having multiple children at home resulted in later bedtimes and inconsistent routines. Caregivers and clinicians also noted that having multiple caregivers and, in some cases, multiple sleep locations, impeded management of child behaviors and enforcement of rules around electronics and caffeine. Reflecting the multilevel and interactive nature of these barriers, one caregiver described the impact of her partner’s nighttime work schedule on co-sleeping, which was also influenced by neighborhood safety concerns (Table III). Caregivers and clinicians also discussed caregiver stress and exhaustion as barriers to implementing intervention components... Likewise, clinicians described caregivers as being “overwhelmed” due to difficult work schedules and limited social support. Families’ reliance on electronics at nighttime was another barrier that permeated most</p>	

Study	PCP type	Country	Participant	Qualitative data: Views, attitudes and perceptions of role		
				Views and perceptions about behavioural sleep	Perceptions of role	Treatment attitude / belief
			<p>problems. In this regard, clinicians consistently described caregiver limit-setting difficulties and disorganized home environments as contributing to sleep problems and poor sleep habits”</p> <p>Theme: “Child versus family characteristics as major contributor to sleep problems: “” . . .There’s parents who really just have never even really thought through some of the basic limit setting and then there’s parents who sort of like know what the challenges are but have other barriers to implementing a, like, a successful strategy.”</p>	<p>services referenced the ease of implementing the sleep intervention into this existing model of brief behavioral health treatment in primary care. Clinicians without current IPC services suggested having a sleep interventionist available for “warm hand-off” referrals to the program.</p>	<p>of the intervention components. For instance, caregivers and clinicians gave examples of children staying up late or waking overnight to use electronics, refusing to follow a bedtime routine or stay in bed without electronics, and caregivers providing children with electronics to offset caregiver stress or competing demands. Caregivers and clinicians also described family habits perpetuating nighttime electronics usage, such as children sleeping in shared spaces with adults using electronics, children modeling family behaviors (i.e., using devices in bed), or the belief that electronics items would help their child fall asleep, based on caregivers’ own experiences.”</p> <p>Theme: “Familial and contextual barriers to intervention”</p> <p>“Components Work schedules Multiple children, caregivers, or sleep locations” . . .Work schedules,</p>	

Study	PCP type	Country	Participant	Qualitative data: Views, attitudes and perceptions of role		
				Views and perceptions about behavioural sleep	Perceptions of role	Treatment attitude / belief
				<p>“It’s disorganization. And to be honest with you, sometimes over generations, so the grandparents are disorganized. The parents themselves are disorganized and don’t have routines.”</p>		<p>childcare schedules, and general just sort of household chaos. And sometimes, I should have added lack of control over the home environment if they’re living in a home with a bunch of other people and it’s not their own space, and they can’t kind of set the rules about, you know, lights out and bedtime and electronics and all that stuff.”</p> <p>“I think is possibly parents being overwhelmed. Having possibly multiple children in the same age group, or just multiple children in general. . .I think a big thing could also be possible work schedules. . .So, just various shifts, and also just a mom may just get off at 8, so the child is just not getting home until late, and then the child themselves may be having a 12– 14 [hr] day. . .”</p> <p>Theme: “Need for intervention content flexibility”:</p> <p>“In response to questions about facilitators of intervention content, caregivers and clinicians</p>

Study	PCP type	Country	Participant	Qualitative data: Views, attitudes and perceptions of role		
				Views and perceptions about behavioural sleep	Perceptions of role	Treatment attitude / belief
						<p>converged in their view about a flexible intervention approach... Clinicians also discussed flexibility with regard to guideline recommendations, especially concerning a bedtime before 9:00 p.m., emphasizing instead bedtime routine consistency and sleep duration as more important and realistic goals.”</p> <p>““I think the big thing is just figuring out where that family is, keeping a onsistent—I think the focus should be more so on the number of hours of sleep, not necessarily the time.””</p> <p>Theme: “Caregiver-to-caregiver communication as an implementation strategy”: “Clinicians discussed similar group treatment benefits but expressed feasibility concerns related to the ease of scheduling and the need for an experienced group facilitator to support this format.”</p>

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Study	PCP type	Country	Participant	Qualitative data: Views, attitudes and perceptions of role		
				Views and perceptions about behavioural sleep	Perceptions of role	Treatment attitude / belief
						<p>“I think we, healthcare providers, could be a bit intimidating or disconnected from—you know, a parent where they are, you know. Maybe having a kind of peer support, you know, group. Whether the sessions are, you know, kind of with other peers, you know. So, I think there’s value to having kind of one-on-one, you know, sessions. But hearing about other people— other parents’, you know, strategies and what they’re going through, I think is always helpful.”</p> <p>Theme: “Barriers to treatment access and engagement”: “. . .I assume that coming to visits would be the same obstacles that we all have in terms of coming to visits, which is people work, children are in school and they have to remember that the appointment exists. In terms of calls, a lot of people</p>

Study	PCP type	Country	Participant	Qualitative data: Views, attitudes and perceptions of role		
				Views and perceptions about behavioural sleep	Perceptions of role	Treatment attitude / belief
						don't have working phones. A lot of people text more than call, it seems to me. . ."
Paton and colleagues 2019 ²²⁶	School nurses	Australia	PCP			"Overall, ESNs reported that greater flexibility in delivering the sleep intervention, such as the timing of the components and communication options, could enhance the potential for benefits, as it would allow ESNs to adapt the intervention based on each family's needs."

A.7 Quality assessment using the Mixed Methods Appraisal Tool

Methodological quality of individual studies was assessed using the MMAT version 2018²⁰² For the study designs which were relevant to this systematic review, the MMAT version 2018²⁰² states the criteria as follows:

(1) 'Qualitative'

- 1.1. "Is the qualitative approach appropriate to answer the research question?"
- 1.2. "Are the qualitative data collection methods adequate to address the research question?"
- 1.3. "Are the findings adequately derived from the data?"
- 1.4. "Is the interpretation of results sufficiently substantiated by data?"
- 1.5. "Is there coherence between qualitative data sources, collection, analysis and interpretation?"

(3) 'Quantitative non-randomised'

- 3.1. "Are the participants representative of the target population?"
- 3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?"
- 3.3. "Are there complete outcome data?"
- 3.4. "Are the confounders accounted for in the design and analysis?"
- 3.5. "During the study period, is the intervention administered (or exposure occurred) as intended?"

(4) 'Quantitative descriptive'

- 4.1. "Is the sampling strategy relevant to address the research question?"
- 4.2. "Is the sample representative of the target population?"
- 4.3. "Are the measurements appropriate?"
- 4.4. "Is the risk of nonresponse bias low?"
- 4.5. "Is the statistical analysis appropriate to answer the research question?"

(5) 'Mixed methods'

5.1. "Is there an adequate rationale for using a mixed methods design to address the research question?"

5.2. "Are the different components of the study effectively integrated to answer the research question?"

5.3. "Are the outputs of the integration of qualitative and quantitative components adequately interpreted?"

5.4. "Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?"

5.5. "Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?"

Table 34 MMAT quality appraisal (detailed)

Author (year)	Study type	Criteria and response					Overall rating	Comment
		.1	.2	.3	.4	.5		
Abbott and bryar (2015) ²⁰⁹	1	Y – Approach suitable, however authors do not explicitly state the approach, just the method of data collection	Y – semi-structured interviews, use of topic guide, recorded or with notes.	C – Data analysis process not clearly described.	Y – themes backed up with appropriate quotes	C – Somewhat unclear around analysis and how they arrived at findings	Medium	Doesn't specify analysis type or process which prevents a decision on Y or N.
Bonuck and colleagues 2020 ²¹⁰	5	Y – multiple methods described to give overall view	Y – integrated in discussion	Y – interpreted	Y – discussed in detail – Qual often gives more explanation to quant findings	N	Low, high, low – roverall rating low	Only rated low due to lacking representativeness in quant aspect, however the study was carried out systematically otherwise, and mixed methods were integrated.
	1	Y – collection and analysis described	Y – interviews adequate	Y -thematic analysis described	Y sufficient example quotes	Y		
	4	N – authors described a selected sample	N – authors described lack of representativeness	C – validation of survey measures not described	Y – missing data is low	Y – descriptive statistics		

Author (year)	Study type	Criteria and response					Overall rating	Comment
		.1	.2	.3	.4	.5		
								Overall rated as low because the authors suggest to go by the 'lowest scoring' part.
Bruni and colleagues (2004) ²¹¹	4	Y - Sent to a representative sample chosen with society mailing lists	Y – Low response rate, however reasons for this and attempts to achieve representative population after (control group -face to face interviews) are described	Y – Measurements are appropriate. Mindell's survey translated. Survey's reliability and face validity tested	Y – Although low return rate, the face to face control indicated little significant differences (none which were relevant in this review)	Y – Descriptive statistics and group differences were appropriate.	High	All criteria met
Carter and Mason (1989) ²¹²	4	Y – Circulated amongst colleagues	C – No clear description / indicators of representativeness	C – measures seem appropriate for research question but not clearly described.	N – Not able to get reasons for non-response	C – Statistical analysis seems appropriate, but could be clearer	Very low	Little detail in methods often leads to scoring N or C.

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Author (year)	Study type	Criteria and response					Overall rating	Comment
		.1	.2	.3	.4	.5		
Chavin and Tinson (1980) ²¹³	4	Y – determined sample by HVs of children with sleep problem, and random controls	C – Described target population, but not representativeness	Y – variables defined and appropriate to research question. Questionnaire developed with a pilot study.	Y – HVs selected sample. No non-response reported	Y – Statistical analyses could be clearer	Medium	
Cheng and colleagues 2020 ²¹⁴	5	Y – interviews to give further detail to survey	C – no integration. Data is presented independently and then discussed in discussion	C – no integration. Data is presented independently and then discussed in discussion	Y – no divergence	C	Medium, high, good – Overall medium	Overall rated as medium because the authors suggest to go by the ‘lowest scoring’ part. Ratings were usually because of ‘cannot tell’.
	1	Y – thematic analysis described. Exploratory study	Y – interviews. Semi structured interview guide. Transcribed verbatim	Y – thematic analysis described	Y – sufficient quotes	Y		

Author (year)	Study type	Criteria and response					Overall rating	Comment
		.1	.2	.3	.4	.5		
	4	Y – surveys directly to staff	C – 58% response rate, but didn't discuss demographic target within, only demographic results	Y – survey defined and validated in previous study.	Y – Low non-response	y- types of descriptive statistics discussed in method		
Cook and colleagues (2020) ²¹⁵	1	Y – Qualitative approach to an open-ended survey question. (inductive thematic analysis)	Y – Open-ended question is relevant	Y - Findings adequately derived from data via inductive thematic analysis	Y – themes backed up with appropriate quotes	Y – Clear links between stages.	High	All criteria met
Crawford and colleagues (1989) ²¹⁶	3	N – author acknowledges limited sample (9 children in HV's caseload), but offers some reasons why the other 10 parents who were	C – Measures seem appropriate, however it's not specified whether they are tested before or gold standard	N – some data missing, though it's not much, there are only 9 participants so would be a big proportion missing	C – Not clear	Y	Very low	only qual data used (description of intervention given)

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Author (year)	Study type	Criteria and response					Overall rating	Comment
		.1	.2	.3	.4	.5		
		offered it, chose not to						
Ersu and colleagues (2017) ¹³⁷	3	C – Not described	Y – Measurement seem appropriate. Sleep questions based on literature, curricula, and existing surveys. Discussed with panel, pilot testing, item statistics	Y – “Long-term follow-up data were obtained from 90% (n = 70) of the control group and from 88% (n = 117) of the intervention group, and these participants comprised the final study group.”	Y – Statistical tests conducted to determine differences between groups with various demographics	Y – No obvious interruption to planned intervention.	Good	Only not listed as ‘high’ quality due to ‘cannot tell’ for the first criterion (target population not described).
Faruqui and colleagues (2011) ²¹⁷	4	Y – Mailing list from AAP – eligible PCPs contacted	Y – Target described; factored non-response rate in to determine how many to mail to; sufficient responses achieved	Y – Appropriate measures. Content validity, face validity and internal reliability measured	Y - Statistical compensation for non-response	Y – Descriptive statistics and group differences were appropriate.	High	All criteria met
	5	Y	Y	C	Y	C	Low	

Author (year)	Study type	Criteria and response					Overall rating	Comment
		.1	.2	.3	.4	.5		
Hall and colleagues (2019) ²¹⁸	1	Y	Y	C	C	C		Overall rating of low is due to 'cannot tell' rather than not satisfying criteria.
	4	Y	Y	C	C	Y		
Hatton and Gardani (2018) ¹³³	1	Y – constructivist grounded theory appropriate	Y – In depth-interviews and transcribed verbatim	Y – Findings adequately derived from data via coding and grouping of themes	Y – Themes backed up by adequate quotes	Y – Clear links between stages.	High	All criteria met
Hewitt and colleagues (1989) ²¹⁹	3	N – Authors note small sample size (9) may not be generalisable, although not a self-selected sample	Y – Measures seem appropriate and clearly defined. Additional structured interview sometimes given to validate ratings.	N – Only 7 completed follow up. Some follow-ups had missing questions	N – No mention of trying to control for confounding factors	Y	Low	Rated low usually due to issues with a small sample lacking representativeness

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Author (year)	Study type	Criteria and response					Overall rating	Comment
		.1	.2	.3	.4	.5		
High and colleagues (1998) ²²⁰	3	Y – inclusion/exclusion criteria stated and attempts to achieve representative sample	Y – Intervention tested to work in other study. Interview based on another author and a existing questionnaire. Variables appropriate.	C – Does not specify	Y – Confounding variables clearly considered and investigated e.g. parents who read books themselves	Y – Historical control could not have been impacted because clinic intervention had not been implemented yet	Good	Good - Only not rated highly, due to cannot tell for the criterion about complete outcome data
Kanoy and Schroeder (1985) ²²¹	4	Y – Offered follow up evaluations to all who participated previously.	N – authors note sample may not be representative	C – measurements seem appropriate. Not clear whether the questions were tested pre-data collection	Y - noted that those who did not take part, mostly could not be located/contacted, rather than choosing to refuse	Y – Statistical analyses appropriate	Medium	Rated medium due to issues with representativeness, and uncertainty about validation of the measures
Mindell and	4	Y – (survey 2) SKQ to random sample of 185 practicing	Y/C– (2) return rate 47.6% (3) return rate	Y – (2) knowledge questionnaire appropriate. Item	Y – low non-response rates for surveys. Follow ups sent to	Y – Descriptive statistics and group	Good/High	Some uncertainty around target population,

Author (year)	Study type	Criteria and response					Overall rating	Comment
		.1	.2	.3	.4	.5		
colleagues (1994) ²²²		pediatricians and (survey 3) to all practicing pediatricians in rhode island/ 185 random ones in Pennsylvania.	45% rhode island, 58% pensylvania	analysis conducted. (3) Appropriate survey used	those who didn't respond. For survey 3: some contacts stated questionnaire not appropriate for them	differences were appropriate.		however the authors report the response rate, rather than explicitly stating not measured.
Mindell and Owens (2003) ¹³⁵	4	Y – Survey given out at a national conference for pediatric nurse practitioners	N – Not clear whether all attending the conference took part. Authors note potentially biased sample in discussion	C – Appropriate measure for research question. Not stated whether it was tested psychometrically.	C – Not clear whether all attending the conference took part.	Y - Descriptive statistics and group differences were appropriate.	Low	Little is reported in the paper, so although it may be of good quality, it cannot be rated as such. The paper is part of a bigger article.
Murray and colleagues 2019 ²²³	1	Y – thematic analysis described	Y – method described and transcribed verbatim.	Y – thematic analysis described	Y – quotes to back up data	Y - coherence	High	All criteria met

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Author (year)	Study type	Criteria and response					Overall rating	Comment
		.1	.2	.3	.4	.5		
			Translations checked also.					
Olson and colleagues (2004) ²²⁴	4	Y – Parent data sampled from national survey undertaken by random sampling of parents. Pediatricians sampled from AAP periodic survey	Y – “Data weighted to represent US children aged 4 to 35 months” Responding pediatricians characteristics representative to AAP membership at the time.	Y – Parent survey derived from similar q’s in another survey, and based on literature review. PCP questionnaire designed to ask same things as parent survey	Y – Parents: completion rate 79.2%. Discussed which children were not reached. “Data weighted to represent US children aged 4 to 35 months”	Y – Statistical analyses described clearly and appropriate	High	All criteria met
Owens (2001) ²²⁵	4	Y – Sent to sample of practicing pediatricians (rhode island, Massachusetts, Connecticut) on mailing list	Y – Response rate 30.5%. Reasons why some did not take part were discussed, but could not contact non-responders. Authors compared	Y - Appropriate measures. Psychometric assessment not conducted. Knowledge questions were modelled on previous	N – Not able to get reasons for non-response	Y – Descriptive statistics and group differences were appropriate.	Good	

Author (year)	Study type	Criteria and response					Overall rating	Comment
		.1	.2	.3	.4	.5		
			characteristics to sample mailed to	questionnaires, answers based on empirical data, feedback on q's and answers from pediatric sleep experts and then piloted.				
Paton and colleagues 2019 ²²⁶	c	Y – to provide overall view	Y – qual provides further detail to quant	C – Does not discuss the interpretation of integration in discussion	Y – no divergence	C	Medium /good	Rated as good because only items lacking are 'cannot tell' for the interpretation of the integration of mixed components, and non-validated measures
	1	Y –qual data collection and analysis described	Y – focus group adequate	Y – inductive content analysis sufficient	Y – adequate example quotes provided	Y – clear links	High	
	3	Y – described in discussion	C – not validated measures	Y - Would be C, however the missing data is for post intervention which is	Y – No confounding expected	Y – given as intended	Good	

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Author (year)	Study type	Criteria and response					Overall rating	Comment
		.1	.2	.3	.4	.5		
				not relevant to this review				
Sadler and colleagues 2020 ⁷³	1	Y – qualitative approach, data collection and analysis described.	Y – semi structured interviews	Y – Approach described	Y – adequate quotes	Y – adequate coherence	High	All criteria met
Stallard ²²⁷	1	N/A – Did not pass screening question – no specific research question						
Thomas and colleagues (1982) ²²⁸	4	Y – HVs in county contacted to gain interest.	N – No clear description of representativeness for questionnaire other than 66% of population. Authors discuss small number of visiting records.	C – Measures described. Not clear whether the measures were tested prior to implementation.	C – Discussed potential reasons for lower response rate of visiting records. No clear explanation about questionnaire non-responders.	C – Statistical analyses for questionnaire not clear. Analyses for case records described	Low	Rated low due to ‘cannot tell’ from not enough detail in methods
Williamson and	1	Y	Y	Y	Y	Y	High	All criteria met

Author (year)	Study type	Criteria and response					Overall rating	Comment
		.1	.2	.3	.4	.5		
colleagues 2020 ²²⁹								
Wynter and colleagues (2015) ²³⁰	5	Y – Mixed-methods used for closed and open questions. Integrating data sets	Y – Software used to explore frequencies of responses within themes	Y – Themes, frequencies of responses within themes, and concept maps show integration	Y – no divergencies reported	N – qual criteria are ‘good’ and quant criteria are ‘good’	Good	MMAT suggests to rate overall based on the lowest rated component. Only missing criteria due to ‘cannot tell’
	1	Y – Qual data collection and analysis described	Y – Open-ended questions on online survey to complement other data seem appropriate	Y – Authors sort into themes and generate concept maps with a software	C – quotes not presented	Y		
	4	Y – Link to MCH coordinators who forwarded it one	C – Not enough detail about target criteria within MCH nurses, and representativeness of	Y – Developed in collaboration with stakeholders, existing evidence, interviews in another study. Piloted	Y – authors do not mention reasons for non-response, but do say that they are unable to contact those	Y – Statistical analysis appropriate		

Appendix A

Author (year)	Study type	Criteria and response					Overall rating	Comment
		.1	.2	.3	.4	.5		
			population within sample.	by research staff for face validity.	who were sent the link themselves.			

A.8 'Sleep Survey' knowledge questionnaire (Mindell and colleagues 1994)

A screenshot of the 'Sleep hygiene' section of questions within the survey developed by Mindell and colleagues ²²². The whole survey is listed in the appendix of the published paper. Bruni and colleagues ²¹¹ used a translated version of this questionnaire (in Italian) within their study.

Sleep Hygiene

- T F** Depriving a child of his/her nap is effective in helping children to sleep at night
- T F** Sleep resistance and frequent night wakings in children are often highly amenable to behavioral techniques.
- T F** Rocking an infant to sleep before placing him/her in the crib is likely to be an effective strategy to improve sleep ability.
- T F** In general, infants should be allowed to cry themselves back to sleep.
- T F** A child who regularly has trouble getting to sleep at night should be allowed to sleep later in the morning.
- T F** An otherwise healthy teenager who sleeps until noon on the weekends is likely to be chronically sleep deprived.

A.9 Pediatric Sleep Survey questionnaire (Owens 2001)

Here is a screenshot of the appendix from the paper published by Owens 2001²²⁵. Only data eligible for the current systematic review were extracted.

PEDIATRIC SLEEP SURVEY

I. The purpose of this section of the survey is to gather information about how familiar practicing physicians are with sleep and sleep disorders in children and adolescents. Your answers are anonymous. This is not a test.

Please circle the correct response -True/False/Don't Know

- | | | | |
|---|------|-------|------------|
| 1) There is a physiologically-based increase in daytime alertness in adolescents around the time of puberty. | True | False | Don't Know |
| 2) Children with delayed sleep phase ("Night Owls") may present with bedtime resistance. | True | False | Don't Know |
| 3) The incidence of Obstructive Sleep Apnea Syndrome (OSAS) in pre-schoolers is less than 1%. | True | False | Don't Know |
| 4) Night terrors and sleepwalking often have a familial component. | True | False | Don't Know |
| 5) Please read the following statements in regards to Narcolepsy in children and circle the correct response for each item: | | | |
| a. Does not occur in pre-pubertal children | True | False | Don't Know |
| b. Requires an overnight sleep study and Multiple Sleep Latency Test (MSLT) to diagnose | True | False | Don't Know |
| c. Psychostimulants are usually the treatment of choice | True | False | Don't Know |
| 6) Bright light phototherapy with a light box may be helpful for children with a delayed sleep phase. | True | False | Don't Know |
| 7) Children with ADHD seldom have sleep onset difficulties unless they are on psychostimulant medication. | True | False | Don't Know |
| 8) It is normal for school-aged children to take naps up to several times a week. | True | False | Don't Know |
| 9) Breast-fed babies usually sleep through the night at an earlier age than bottle-fed babies. | True | False | Don't Know |
| 10) Hyperactivity is a common presenting complaint in pediatric OSAS. | True | False | Don't Know |
| 11) Amnesia for the episode is not helpful in distinguishing night terrors from nightmares. | True | False | Don't Know |
| 12) Children with severe developmental delays have an increased risk of developing sleep schedule disturbances. | True | False | Don't Know |
| 13) Average 24-hour total sleep duration for a 3-year old is about 8 hours. | True | False | Don't Know |
| 14) Health care providers should not recommend temporary establishment of a later bedtime as an intervention for a child with difficulty falling asleep. | True | False | Don't Know |
| 15) No combination of clinical symptom severity and physical findings reliably predicts disease severity in children with OSAS. | True | False | Don't Know |
| 16) Nocturnal bedwetting occurs almost exclusively during deep or slow-wave sleep. | True | False | Don't Know |

- 17) School avoidance makes a sleep phase delay in adolescents more difficult to treat. True False Don't Know
- 18) It is normal for young children to awaken briefly during the night at the end of a sleep cycle (every 60-90 minutes). True False Don't Know
- 19) "Learned Hunger" resulting from frequent night feedings can lead to increased nocturnal awakenings in infants. True False Don't Know
- 20) Children from which of the following groups are at increased risk for **Obstructive Sleep Apnea Syndrome** (Please circle the correct response for each item):
- a. Prader-Willi Syndrome True False Don't Know
 - b. Down Syndrome True False Don't Know
 - c. Repaired Cleft Palate True False Don't Know
 - d. Achondroplasia True False Don't Know
- 21) Bruxism (teeth grinding) is uncommon in children. True False Don't Know
- 22) Head banging in infants at bedtime is usually associated with developmental delay. True False Don't Know
- 23) Please read the following statements in regards to **Restless Legs Syndrome/ Periodic Leg Movement Disorder** and circle the correct response for each item:
- a. Does not occur in children under 12 years True False Don't Know
 - b. May be linked to symptoms of Attention Deficit Hyperactivity Disorder True False Don't Know
 - c. May be cause of "growing pains" in children True False Don't Know

- II. The purpose of this next section of the survey is to assess how physicians screen, evaluate, and treat childhood sleep disorders in their own practices. Please answer based on what you actually do, rather than what you think you should do for the following:

- A. **SCREENING** for sleep problems: - In the context of a **Well Child Exam**, which sleep history questions do you include **greater than 75% of the time** in the following age groups? (Please check all that apply):

	INFANTS (0-1 YRS)	TODDLERS/ PRE-SCHOOL (2-4 YRS)	SCHOOL- AGED (5-12 YRS)	ADOLESCENTS (13+ YRS)
a. do not screen for sleep problems in this age group				
b. generally ask single question only about general sleep problems				
c. usual bedtime				
d. usual wake time				
e. usual sleep amount				
f. naps				
g. regularity of sleep-wake schedule				
h. co-sleeping				
i. bedtime resistance				
j. sleep onset delay				
k. night wakings				
l. nighttime fears				
m. sleepwalking				
n. night terrors				
o. nightmares				
p. bedwetting				
q. teeth grinding				
r. frequent leg kicking or twitching during sleep				
s. snoring				
t. breathing pauses				
u. restless sleep				
v. difficulty am waking				
w. daytime sleepiness				
x. daytime behavior problems				
y. family history of sleep problems				
z. question child about sleep habits				

2) If you **do not** routinely screen for sleep problems, please indicate the reason(s). (Check all that apply):

- Sleep problems not important
 Takes too much time
 Lack of reimbursement
 Not necessary because of low incidence of problems
 Takes time away from asking about other health concerns
 Do not feel comfortable asking questions about sleep
 Do not feel knowledgeable about sleep problems
 Sleep problems generally not treatable
 Parent will indicate if there is a problem anyway, even without screening
 Other (Please explain): _____

- B. **EVALUATION** of sleep disorders: For the following **presenting sleep complaints**, indicate how often **you do the following** in your practice: (Please circle the appropriate response:)

1 = NEVER/RARELY
 2 = OCCASIONALLY
 3 = ABOUT HALF
 4 = OFTEN
 5 = ALWAYS

- | | | | | | |
|--|---|---|---|---|---|
| 1) In toddlers with frequent night wakings , focus on the method of falling asleep. | 1 | 2 | 3 | 4 | 5 |
| 2) In a pre-schooler with bedtime resistance , ask about parental disciplinary style. | 1 | 2 | 3 | 4 | 5 |
| 3) In school-aged children with secondary enuresis , inquire about a history of snoring. | 1 | 2 | 3 | 4 | 5 |
| 4) Ask about the timing of the night wakings in evaluating a child for parasomnias . | 1 | 2 | 3 | 4 | 5 |
| 5) Routinely inquire about symptoms of cataplexy in adolescents with profound daytime sleepiness . | 1 | 2 | 3 | 4 | 5 |
| 6) Of the following options for further evaluation of a patient in whom you suspect Obstructive Sleep Apnea on clinical grounds: | | | | | |
| a. obtain x-rays, EKG, or lab tests: | 1 | 2 | 3 | 4 | 5 |
| b. refer to a sleep subspecialist or sleep clinic for evaluation: | 1 | 2 | 3 | 4 | 5 |
| c. refer for an in-hospital overnight sleep study: | 1 | 2 | 3 | 4 | 5 |
| d. refer directly to an otolaryngologist | 1 | 2 | 3 | 4 | 5 |

- C. **TREATMENT** of sleep disorders: In the treatment of the following sleep disorders, indicate how often **you do the following** in your practice (please circle the appropriate response):

- | | | | | | |
|---|---|---|---|---|---|
| 1) Frequent night wakings in a 14-month old who is routinely rocked to sleep at bedtime: | | | | | |
| a. suggest co-sleeping with parents | 1 | 2 | 3 | 4 | 5 |
| b. advise increasing the level of parental intervention at bedtime | 1 | 2 | 3 | 4 | 5 |
| c. advise gradually increasing time intervals between "checking on" child ("Ferber Method") | 1 | 2 | 3 | 4 | 5 |
| d. advise parents that problem will resolve without intervention | 1 | 2 | 3 | 4 | 5 |
| 2) Bedtime resistance in a pre-schooler due to sudden onset of nighttime fears: | | | | | |
| a. advise ignoring fears and setting firm limits at bedtime | 1 | 2 | 3 | 4 | 5 |
| b. suggest transitional object | 1 | 2 | 3 | 4 | 5 |

c. encourage bedtime television viewing "to relax" child	1	2	3	4	5
d. utilize positive reinforcement (sticker chart) for staying in bed	1	2	3	4	5
3) Weekly night terrors in a 7-year old:					
a. suggest diphenhydramine (Benadryl) at bedtime	1	2	3	4	5
b. advise parents about safety issues, but basically just reassure	1	2	3	4	5
c. suggest psychological evaluation for child	1	2	3	4	5
d. encourage regular sleep-wake schedule	1	2	3	4	5
4) Insomnia in an adolescent due to poor sleep habits:					
a. suggest trial of melatonin	1	2	3	4	5
b. encourage "catch-up" sleep on weekends	1	2	3	4	5
c. prescribe hypnotics at bedtime	1	2	3	4	5
d. suggest maintaining a similar sleep-wake schedule on weekdays and weekends	1	2	3	4	5
e. discourage using bed for activities other than sleep	1	2	3	4	5
5) Of the following treatment options for a patient in whom you suspect Obstructive Sleep Apnea on clinical grounds:					
a. If tonsils are enlarged, refer directly to an otolaryngologist for adenotonsillectomy	1	2	3	4	5
b. If obese, refer to a nutritionist, or weight loss program	1	2	3	4	5
c. Prescribe nasal steroids if adenoidal hypertrophy is present	1	2	3	4	5
d. Refer for Continuous Positive Airway Pressure (CPAP)	1	2	3	4	5
e. Refer to orthodontist for oral appliance	1	2	3	4	5
f. Clinical observation only	1	2	3	4	5

III. This final section of the survey asks you for your opinion about several different aspects of sleep disorders in children.

Please rate the following statements, on a scale of 1 (not important) to 3 (somewhat important) to 5 (very important):

A. The **impact** of sleep problems on children's: (Please mark an "X" on the appropriate response:)

	Not <u>Important</u>		Somewhat <u>Important</u>		Very <u>Important</u>
1) general health	1	2	3	4	5
2) mood and behavior	1	2	3	4	5
3) academic performance	1	2	3	4	5
4) parental stress	1	2	3	4	5
5) non-intentional injury rates (falls, burns, etc.)	1	2	3	4	5

B. The **importance** of the following sleep-related public health issues:

	Not <u>Important</u>		Somewhat <u>Important</u>		Very <u>Important</u>
1) educating adolescents about drowsy driving	1	2	3	4	5
2) delaying high school start times	1	2	3	4	5
3) educating school personnel about children's sleep	1	2	3	4	5

Please rate the following on a scale of 1 (not confident) to 3 (somewhat confident) to 5 (very confident): (Please mark an "X" on the appropriate response)

	Not Confident		Somewhat Confident		Very Confident
C. Your ability to screen children for sleep problems	1	2	3	4	5
D. Your ability to evaluate children for sleep problems	1	2	3	4	5
E. Your ability to manage children with sleep problems	1	2	3	4	5

Please estimate the following: (Circle one)

F. **Overall** percentage of patients in your practice with **sleep problems**: 0-25% 51-75%
26-50% 76-100%

G. Percentage of patients in your practice with **sleep problems** in the following age groups: (Circle one)

1) 0-2 years	0-25%	26-50%	51-75%	76-100%
2) 3-6 years	0-25%	26-50%	51-75%	76-100%
3) 7-12 years	0-25%	26-50%	51-75%	76-100%
4) 13+ years	0-25%	26-50%	51-75%	76-100%

THANK YOU VERY MUCH FOR YOUR TIME!

If you would like assistance or consultation regarding any of your pediatric patients' sleep problems or would like to set up an appointment for a patient, please call us at the Pediatric Sleep Disorders Clinic, Hasbro Children's Hospital, (401) 444-8815.

Appendix B Chapter Four (Internet Forum Study) Appendices

B.1 Ethical approval

UNIVERSITY OF
Southampton

19th February 2019

Dear Samantha,

ERGO 47681
Exploring online forums to understand parents' and families' views about current sources of support and resources for managing children's sleep problems in the community and Primary Care.

Thank you for submitting your revision relating to the above study. I am pleased to inform you that full approval has now been granted by the Faculty of Medicine Ethics Committee.


Approval is valid from today until 01/12/2019, the end date specified in your application.

Please note the following points:

- the above ethics approval number must be quoted in all correspondence relating to your research, including emails;
- if you wish to make any substantive changes to your project you must inform the Faculty of Medicine Ethics Committee as soon as possible.

Please note that this email will now constitute evidence of ethical approval. Should you require a paper signed copy of this approval, please contact the FoMEC Administrative Team via email at: medethic@soton.ac.uk. We wish you success with your work.

Yours sincerely



Dr Tracey Newman
Vice-Chair of the Faculty of Medicine Ethics Committee

Please reply to:
Faculty of Medicine Ethics Committee,
Southampton General Hospital, Mailpoint 801, South Academic Block, Tremona Road, Southampton SO16 6YD UK

University of Southampton, Highfield Campus, Southampton SO17 1BJ United Kingdom
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B.2 Overview of emerging themes

Please see an overview of the themes and sub-themes here. Please refer to Appendix B.5 for the full detailed coding manual with themes, sub-themes, descriptions, and example quotes.

OVERVIEW OF EMERGING THEMES AND SUB-THEMES					
Over-arching theme	Sub-theme and codes within				
1. Multiple concerns about children's sleep problems	1.1 Concerns about the child's sleep	1.2 Information seeking	1.3 The impact of sleep problems	1.4 Covid-19 as a barrier or facilitator to support	1.5 Management strategies
	Night waking	Questions about baby phases	Impact on family or family planning		Concerns about cosleeping
	Early morning waking	Uncertainty about correct sleep amounts	Impact on child's health and development		Concerns about sleep training
	Self-settling and bedtime routines	Looking for age-related advice	Parental mental health		What hasn't worked
	Sleep and feeding	Advice/tips to improve sleep			Sense of failure
	Possible medical issues or underlying problem	Whether to seek professional support			
	Concerns about whether something is normal	Anticipatory advice			
	Sleep safety				

OVERVIEW OF EMERGING THEMES AND SUB-THEMES					
Over-arching theme	Sub-theme and codes within				
2. Parents experiences or sharing advice online as a resource	2.1 Peer and emotional support Managing parental expectations, or promoting acceptance In the same boat and/or sympathy Negative/perceived negative support Normalisation or reassurance	2.2 Exchanging information Age-specific guidance and milestones Reiterating professional advice Trying to provide explanation	2.3 Practical advice Advising about different management strategies Practical tools Recommending support from others Sleep environment Self-care advice Go with what works	2.4 Sharing own routines	2.5 Sharing views about healthcare practitioners and non-healthcare workers Commenting on professionals advice and impressions about professionals Encouragement to see a professional Advising to see one professional over another
3. Mixed experiences and perceptions of HVs and nursery nurses	3.1 Reiterating HV advice/action Advising about underlying causes of sleep problems HV advice about co-sleeping HV and sleep training strategies Sleep environment or other practical suggestions	3.2 Mixed attitudes about community PCPs Positive comments Negative comments	3.3 Experiences with nursery nurses		

OVERVIEW OF EMERGING THEMES AND SUB-THEMES					
Over-arching theme	Sub-theme and codes within				
	Referral from HV HV normalisation or not concerned HV signposting to information				
4. Limited experiences and perceptions of general practice	4.1 Reluctance to consult a GP for a behavioural sleep problem Embarrassed to see a doctor Worry about a negative reaction	4.2 Consulting GPs for non-sleep problem or underlying cause of sleep problem	4.3 Experiences of consulting GP for sleep problems Bringing it up when seeing GP for something else Recommendations or advice Referral Seeing doctor as a last resort Unhelpful reaction		
5. Other resources for supporting parents with child sleep problems	5.1 Tools and information resources online, through information sites, social media and apps	5.2 Non-PCPs or non-healthcare workers Secondary care professionals	5.3 Books or parenting expert authors		

OVERVIEW OF EMERGING THEMES AND SUB-THEMES					
Over-arching theme	Sub-theme and codes within				
	Information resources online	Sleep consultant or sleep specialist			
	Resources as tools				

B.3 Coding Manual

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
1. MULTIPLE CONCERNS ABOUT CHILDREN'S	1.1 Concerns about the child's sleep	1.1.1 – Night waking	Often parents describe troubles with night-waking.	<i>“She will have a longer sleep at the beginning of the night, but then wake hourly (sometimes throughout the whole night) from around 12am. Luckily it doesn't take much to settle her, but the nightwaking is so draining.” – P240</i>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
SLEEP PROBLEMS		1.1.2 Early morning waking	Sometimes parents describe concerns of their baby/child waking too early for the day.	<i>My little one wakes early and I really need some help. At the moment she is up early every day by 5 o'clock, when her bedtime every day is around 7pm. She also wakes throughout the night – P670</i>
		1.1.3 - Self-settling and bedtime routines	Many parents were concerned that their child couldn't settle themselves to sleep. Some parents describe bedtime routine struggles.	<i>Rocking or stroking can take ages...if I put him down he soon has a breakdown, or soon wakes up if I put him down after he's asleep... Do any of your little one's settle on their own? I'd be grateful for any information – P1264</i> <i>I can't get a good routine at night before bed. She hates washing in the night and gets in such a state, is sick, and then has to do it all over again because she's been sick – P155</i> <i>There are many issues. One of them is a fight every night around getting into bed – P343</i>
		1.1.4 - Sleep and feeding	Many parents discuss that they cannot get their child to sleep at night because they want feeding. Some parents describe not knowing	<i>I feed him and put him back to bed every time he wakes in the night. With just a dummy he will not settle back down and once I have fed and laid him down he will sleep in around 20 mins. It's so draining.</i>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
			whether they are actually hungry or are using the feeding as comfort.	<i>Every night I am getting up making bottles around 7 times and then he will be up for the day at 7ish. – P90</i>
		1.1.5 – Possible medical issues or underlying problem	Parents sometimes describe their baby or child's sleep issue and are concerned whether a non-sleep problem is behind it.	<i>I's been so long I'm starting to question whether something medical is going on – P577</i> <i>Just wondering, have you checked it's not something like allergies or reflux? – P604</i>
		1.1.6 - Concerns about whether something is normal	Parents often want to know whether something happening with their child is normal. They sometimes ask whether it's happened to anyone else.	<i>Is this regression normal? It's happening every night -P553</i>
		1.1.7 - Sleep safety	Parents describe their concerns about sleep safety, for example if the only way their child will sleep will be by co-sleeping, but they are not confident in doing it safely. Some parents have	<i>If my little boy sleeps on his stomach, he'd sleep for ages, but knowing it's against safe sleep guidelines, I can't relax when doing it. As the night goes on, I will regularly give up and sit up right (staying awake) while he sleeps on my chest. – P111</i>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
			similar concerns if their child will only sleep in a certain position.	<i>My daughter is a couple of months old and will not sleep in her cot. She will only sleep on me (day or night) which is really dangerous as well as impractical. – P1</i>
	1.2 - Information seeking	1.2.1 - Questions about baby-phases	Many parents are often seeking information about phases in development. For example, parents often ask about sleep regression phases.	<i>How did any of you find the sleep regression in the 4th month and how long did it go on for your babies? I'm wondering whether it will just phase out without doing anything, or whether I need to teach self-settling? If you needed to train your little one, could you tell me how you did it? Any advice welcome because I'm really struggling. – P626</i>
		1.2.2 - Uncertainty about correct sleep amounts	Parents often ask advice about the amount of sleep needed. This sometimes involves telling others how long their child's night-time sleep and naps are and comparing them to guidelines, or asking what the recommended amount of sleep is.	<i>My baby is nearly 1 and has never really napped well, but slept for 12 hours from 6 weeks. Then a few months ago it all went wrong. She doesn't nap anymore (has around a quarter of an hour total in the daytime) and now wakes throughout the night and just sits there playing for 1-2+ hours and is up around 6 o'clock. Is this normal at this stage and has anyone experienced this? She doesn't get the</i>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
				<i>amount of sleep in a day which everything seems to recommend. – P439</i>
		1.2.3 - Looking for age-related advice	Parents often look for age-specific advice such as recommendations for particular ages or want to know whether something is normal for a child of a particular age. Some parents express concerns that most information is aimed at babies and young toddlers.	<i>All the information that I've read about seems to be more for the age of a baby or toddler. Do you know of any books out there for older children (such as 5 years), or would the strategies be the same with any age? – P343</i>
		1.2.4 - Looking for advice / tips to improve sleep	Parents often ask for information/tips/recommendations/strategies. This could be for specific management strategies, or for anything that they could try (such as simple routine that may have worked for another parent).	<i>Does anyone have any advice to improve things ? – P388</i> <i>Is there anything that anyone would recommend? The routine worked before. Now he's waking and I'm not sure what we've done wrong.. – P392</i>
		1.2.5 - Asking whether to seek	Parents have asked for peers opinions on whether it is appropriate to see a GP or HV about their sleep problems. This is interpreted	<i>Do any of you have any experience with this and can give me any advice? Should I just do what I usually do, or do we need to see a health professional? - P333</i>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
		professional support	as asking whether the problem is serious enough to see a professional, when wondering about melatonin, or when wondering about non-sleep issues, such as to check if the problem is actually reflux.	<i>I've thought about asking the doctor for [medication]...has anyone done this? – P343</i>
		1.2.6 - Anticipatory advice	Parents look for information that can help them in the future.	<i>We are going to be having another baby this summer. I want to know if there's anything different that I should do to reduce the chances my next baby will have sleep problems. – P590</i>
	1.3 - The impact of sleep problems	1.3.1 - Impact on family or family planning	Includes direct impact on family (such as work, siblings sleep, daily routine), but also the impact on planning for the family in the future (e.g. having another child)	<p><i>I'm a first time mum and this is so difficult. I'm scared that I won't want any more children...I couldn't manage anything more difficult than this! How do parents manage a child with sleep problems, as well as other children. – P250</i></p> <p><i>My little one woke early hours in the morning and woke his sibling up, who has also been awake since and now has to be exhausted at school all day. I feel for him. It might sound like I'm over exaggerating, but it impacts everything. I struggle to work (I'm a</i></p>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
				<i>nurse) and do household chores, my husband works all day as a builder, and it's causing us to argue all the time. – P670</i>
		1.3.2 - Impact on child's health and development	Some parents describe concerns about the impact of sleep problems on the child's health and development. This appears to be both a physical and psychological concern. For example, growth or ability to sleep alone later in life	<i>I'm concerned that my little one won't grow or develop properly because of this – P396</i> <i>I fear that he won't be able to sleep on his own as he grows up. Something similar happened to me when I was little and it took years to be able to sleep alone. – P410</i>
		1.3.3 - Parental mental health	Includes feeling alone, feeling it will never get better, feeling manipulated etc. Also includes frustration at parents who say their children sleep	<i>I'm desperate for some help, please. I usually deal with things really well but this is breaking me mentally. – P194</i> <i>I have regular feelings that I can't do this any more – P1121</i> <i>Is anyone else in a similar position? I don't know anyone else with a child like this and feel so alone. I'm tired, lonely and drained. – P590</i>
	1.4 - Covid-19 being a barrier		Parents discuss the impact of the covid-19 pandemic on their support for handling sleep problems. This is discussed both positively and	<i>We are not working due to lockdown, so he's able to take him at 7 every morning so that I can sleep for a bit before her nap – P371</i>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
	or facilitator to support		negatively. For example, for some parents they have less support (where partners or family/friends cannot be there to help literally or emotionally) whereas others describe that they have more time/support due to being at home more with partners who are not working.	<i>The pandemic isn't helping. I would normally have my sister round to help after she finishes work, but because of lockdown and isolation she can't. My partner also isolates from us because he is still working and doesn't want to give anything to us when he's around at the weekend. It's so difficult with just me and my little one on our own. – P410</i>
	1.5 - management strategies	1.5.1 - Concerns about co-sleeping	Some parents expressed concerns about this when asking for help about their child's sleep problem. They were concerned about either the safety aspect, or about creating bad habits.	<i>I'm happy to co-sleep for a bit, but I know my little one and it would become a habit where I am having to go to bed early with her every night just to help her settle. – PID 396</i> <i>When he was newborn I kept waking up in a panic after hallucinations that we'd fallen asleep lying next to each other. It really scares me to think about co-sleeping – I'm so frightened of SIDS. – P250</i>
		1.5.2 - Concerns about sleep training	Some parents expressed concerns about crying methods (e.g. controlled crying, cry it out, or sleep training in general) when asking for help about their child's sleep problem. Some parents	<i>I understand why some parents try cry it out in certain situations, but I personally don't agree with it and don't think it's right...I'm not sure whether it's true that it doesn't cause any damage – we don't and probably won't ever know if cry it out has done any harm. – P65</i>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
			described that they understood that their thoughts about this would be different to other parents'. Some parents were happy to try sleep training but had concerns about how they would do it.	<i>We have tried settling our girl with the type where you go back in every few minutes (not cry it out, but controlled crying). She gets in such a state and shakes which I can't bear. She's too emotional for me to try full cry it out. – P692</i>
		1.5.3 - What hasn't worked	Different parents describe multiple different strategies/things (including some behavioural/sleep training/ co-sleeping strategies) that they have tried but which haven't worked. This is described when informing parents what they have already done (to provide context to their sleep problem) or as an expression of frustration that things have not worked.	<i>I've tried many things such as:</i> <ul style="list-style-type: none"> • <i>Asked health visitor for advice who blamed lockdown</i> • <i>Leaving baby to cry</i> • <i>Gone in to calm without actually holding baby (worsened it) or sat there without looking at her or talking to her (didn't help)</i> • <i>Wondered about teething so have given her some gel, though I haven't seen any coming through)</i> • <i>Changed nap schedule – P553</i>
		1.5.4 – Sense of failure	Parents often describe concerns that they are doing the wrong thing to either address the	<i>I just feel like I have done all the wrong things regarding getting my little boy to sleep – P553</i>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
			sleep problems, or the concern that they have done the wrong thing that may have caused the sleep problem.	
2. PARENTS EXPERIENCES OR ADVICE ONLINE AS A RESOURCE	2.1 - Peer and emotional support	2.1.1 - Managing parental expectations, or promoting acceptance	Parents try to manage each other's expectations either of the parent themselves and/or their child. Some parents describe that they should just accept it and suggest that then it will feel easier or that it will get better over time.	<p><i>I think your expectations of him are definitely too high (and of yourself). Go easy on yourself and him and contact nap if you need at least to stop him from being in this overtired state.- P230</i></p> <p><i>Your baby's sleep will gradually improve, whether you do anything or not. With my little girl, I found that acceptance really helped and I actually felt less stressed when I realised that my night times were going to be different to what I was used to. – P413</i></p>
		2.1.2 - In the same boat and/or sympathy	Some parents describe that they have no advice to give but want to let them know that they are not alone and/or have sympathy. They are emotionally supporting each other. Some parents also say that they are in the same boat, to join in the thread and look for information/tips too. Some parents, though they	<p><i>I know the pain you are feeling. My 19 month old has never slept through since birth. I don't think I could ever try cry it out methods either. – P71</i></p>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
			have resolved the sleep issues, or they have got better, describe that they have been in the same boat, as emotional support.	<p><i>Firstly, you are not alone with this struggle. I went through exactly the same thing with my little boy! It was dreadful. – P224</i></p> <p><i>I have no recommendations, but am also struggling with it. My daughter's sleep continues to worsen, and she is 6 months old. I'm so tired – P395</i></p>
		2.1.3 - Negative / perceived negative support	This can be negative attitudes of posters, or where parents have perceived someone's posts as negative support.	<p><i>I posted on here in the hope for some recommendations. I'm disappointed about your judgement that my situation is a bad habit, or that I'm over-reacting. Thank you anyhow – P73</i></p> <p><i>Just letting you know, reading your reply really hurt me. I only wanted a bit of advice... - P1246</i></p>
		2.1.4 - Normalisation or reassurance	Parents normalise sleep problems. They also sometimes stress that the sleep problems will get better over time. Reassurance that someone is doing the right thing or that it will get better.	<p><i>It's a really difficult time, I'm sorry but in general, this does seem normal! It'll improve in time – P259</i></p> <p><i>It will get better. Keep going! - P634</i></p>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
	2.2 - Exchanging information	2.2.1 - Age-specific guidance and milestones	Parents give each other age-specific guidance. In particular, parents often advise (or discuss) which age is suitable for sleep training. Parents also talk about specific age's for phases such as 'sleep regression'.	<p><i>It's not recommended to sleep separately from your little one until they are 6 months old – P98</i></p> <p><i>A little baby can't just be left alone crying. It may be the sleep regression, but she is too little for sleep training. I did sleep training with my little boy when he was 6 months old – the right time for your baby will come around quickly, but she's not yet developed enough at 15 weeks to understand the training – P57</i></p>
		2.2.2 - Reiterating professional advice	Some parents described advice that they were given by professionals (PCP or non-PCP) in an effort to either defend their own advice, pass on the advice or when in a discussion with other parents who are trying to help, reiterate what they have been told.	<p><i>I had the same thing with my daughter, so I remember this! Our [health professional] said to ensure we weren't feeding her to sleep which we weren't doing. She also said to make sure we were feeding more in the day, which is just not possible when a baby who is breastfed isn't hungry. – P384</i></p>
		2.2.3 - Trying to provide explanation	Parents trying to give explanations as to why other parents are having problems with their child's sleep. This could be explanation with the aim of informing them to change	<p><i>In this regression phase, sleep cycles change to take on more of an adult pattern with more light sleep intervals. Many cannot yet settle themselves when they do wake from the light sleep each 1 to 2 hours. – P390</i></p>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
			<p>routine/strategy, explanation as to why it is normal, or ac potential non-sleep explanations for the sleep problems, such as reflux, or routine changes due to covid-19.</p>	<p><i>It's the way you settle a baby that causes both night-waking and quick naps (where you aren't able to re-settle naps in the day time past each sleep cycle). – P242</i></p> <p><i>This phase will continue until you can settle your little one in the place where you want them to stay asleep. The cause is that your little one is not falling asleep where he actually sleeps such as in the crib. – P242</i></p>
	<p>2.3 - Practical advice</p>	<p>2.3.1 - Advising about different management strategies</p>	<p>Many parents advise each other about different types of management strategies, and this could include various practical/behavioural strategies, co-sleeping, and/or specific sleep training techniques (or variations of sleep training techniques, or descriptions of sleep training techniques). Different parents were for and/or against cosleeping and sleep training techniques.</p>	<p><i>Babies do not need to be held as soon as they start to cry or they will never learn to settle on their own. I think you are forming a habit by doing that. Sitting with her and stroking her to help her to sleep is enough. – P53</i></p> <p><i>You can try many different forms of sleep training that don't mean leaving your baby to cry. Some don't involve any crying. I get frustrated that when someone mentions that they sleep train, people assume they just leave their baby to cry until they sleep, which is completely incorrect and not how many sleep training techniques work. – P74</i></p>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
		2.3.2 - Practical tools	Parents either recommend particular tools, or talk about tools that they use/used which work for them. These tools include dummies, grow clocks, songs, co-sleeping tools (such as bedside sleepers), comforters etc. Sometimes they also talk about tools which did not work.	<i>Could you give your little boy a comforter? You could first wash it the same way you wash things usually and hold it for a while so that it has your smell before giving it to him. It might not work right away but he could use it to settle on his own. – P1265</i>
		2.3.3 - Recommending support from others	Parents recommend that either they look for support/help from others (friends/family) or increase the help from partners in sharing management of sleep with the child. The help could be practical or emotional.	<i>Can your partner take your little one out in the car or for a walk while you have some sleep? – P233</i> <i>The first night is always going to be difficult, so you just need to get through that and then it won't be as difficult. Do you have a friend that could come over and support you and help with consistency? Wishing you well – P583</i>
		2.3.4 - Sleep environment	Parents make practical suggestions about the baby/child's sleep environment such as putting a stair gate on, adjusting temperature, smell, light...	<i>What's helped my little girl is making the room really really dark (I use black out blinds so there's no light) and white noise. Have you tried these? – P196</i>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
				<i>You might be disturbing her sleep. Have you tried putting her in her own room? It might be that simple – P408</i>
		2.3.5 - Self-care advice	Some parents reinforce that the parents need to look after themselves	<i>I want you to realise that you mustn't forget to look after yourself! It's important that you don't get too tired – P417</i>
		2.3.6 - Go with what works	Parents suggest that they should find whatever works for them to be able to get some sleep and to do that.	<i>Do whatever it takes to get through it in this short period. When your baby is closer to 6 months old, you can start training them to self-settle with a sleep training strategy and by putting them to bed before they fall asleep. – P390</i>
	2.4 - Sharing own routines and experiences		Many parents shared their own routines, either as a recommendation as what other parents could do, or as 'evidence' of what has worked for them. This also includes parents sharing routines that they have tried (for example it could be specific strategies such as co-sleeping or controlled crying, or it could be bedtime routines). Some parents also share routines that haven't worked for them before, when	<i>My daughter is only 5 months old and does her routine of feed, wash and bedtime around 7pm where she settles herself. She has a nappy change and some milk later in the evening and will take a full bottle, but then will sleep the rest of the night until a small stir around 6am before waking an hour later. People have told me I shouldn't be feeding late in the evening, but it really helped us, because otherwise she would wake in the middle of the night for it. I'd rather do it at 11pm than 3am. – P1016</i>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
			discussing strategies in the threads. Some routines are very detailed, whereas others are not.	<i>I'm returning to work soon so we had to try sleep training. Every night feed for a week, we reduced the amount a little bit (but made sure he was full from enough food for his dinner). We then put him in his own room without his dummy and did the controlled crying method where I went in for short periods but then left him to cry for say 15 minutes every time. It was really difficult the first few nights, but his crying was getting shorter so I had to stick with it. After about 10 days he now goes through the night, naps well and settles well. I have to keep to a strict nap routine otherwise he fusses. – P993</i>
	2.5 – Sharing views about healthcare practitioners and non-	2.5.1 - Commenting on professionals advice and impressions about professionals	When parents have commented on recommendations that have been given by professionals, or have an impression about what professionals would advise.	<i>My little one had troubles with sleep until she was just over 2 years old. She's 9 now. We went to a [professional] for some advice. If you use their recommendations, it really helps. – P70</i> <i>I wouldn't bother following their advice. For me, weening at that age was a tough time for sleep – P524</i>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
	healthcare workers	2.5.2 - Encouragement to see a professional	Some parents encourage each other to speak to a professional (some suggest sleep specialists/consultants and others suggest PCPs such as GPs/HVs). For the sleep problems themselves, parents encourage each other to see a sleep consultant or a HV – one suggests a GP. Whereas for non-sleep/non-behavioural part of the problems (such as mental health, for other physical parts such as reflux), GPs and/or HVs are recommended.	<p><i>I advise seeing a [professional]. Invaluable. – P679</i></p> <p><i>If controlled crying isn't successful, alternatives are...sleep specialist...doctor to see if something else is causing the problem. – P197</i></p> <p><i>I wouldn't do this until you talk to a [professional] first. – P1255</i></p> <p><i>If I were you and I were concerned, I would ask the [professional] for specialised help – P1165</i></p>
		2.5.3 - Advising to see one professional over another	Some parents recommend seeing one professional over another. For example, this could be one type of PCP over another, or it could be a HCP over a private sleep consultant	<p><i>A GP isn't going to help really. You could be put recommended to a sleep consultant through a health visitor, or a health visitor might be able to give information. Personally, I looked it up and found sleep consultants online – P1029</i></p> <p><i>I wouldn't recommend getting advice that you have to pay for. If you need it, use your health visitor for recommendations – P1104</i></p>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
3. MIXED EXPERIENCES AND PERCEPTIONS OF HVS AND NURSERY NURSES			Some parents talk about approaching community PCPs such as HVs, nursery nurses or school PCPs. Some parents talk about advice that they were given or about their thoughts of these PCPs.	<i>I'm still waiting to hear back from my health visitor. I rang her for some advice – P568</i>
	3.1 -Reiterating HV advice/action	3.1.1 - Advice about underlying causes of sleep problems	Suggestions about changes which can be made that may be causing the sleep problems - Includes aspects such as feeding (such as dropping night feeds, feeding to sleep, feeding pattern in the day), toileting etc. One parent said that their health visitor explained that isolation (covid 19) was a cause	<i>Our health visitor said to ensure we weren't feeding her to sleep (we weren't). She also said to make sure we were feeding her more in the day, which is just not possible when a baby who is breastfed isn't hungry. – P384</i> <i>We discussed this with our health visitor and they said it was because of isolation – P553</i>
		3.1.2 - HV advice about co-sleeping	Parents discuss HVs advice about co-sleeping. Some are described as supportive of co-sleeping,	<i>For both of my children, I breastfed and co-slept, the guidelines are different now. I sent my health visitor away the first time because she</i>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
			whereas others are not. Includes discussion about safe sleep.	<i>told me off in my house, and I felt I had to pretend many times (about sleeping methods, feeding methods etc). Nowadays, my recent health visitor supports me and I feel I can do it my way. – P1038</i>
		3.1.3 - HV and sleep training strategies	Some parents talk about sleep training strategies recommended by HVs (mentioned as general sleep training, or specific strategies mentioned). These include controlled crying, gradual retreat, withdrawing chair. One Some posters say that HVs do not recommend cry it out.	<i>I think your health visitor is right. Training your little one to sleep is what you need if you're unhappy as it is. – P1218</i> <i>My health visitor thought gradual retreat was the strategy we should try and it really helped. She was great. – P989</i>
		3.1.4 - Sleep environment or other practical suggestions	2 posters talk about other recommendations from the HV. These include sleep environment (sleeping in separate rooms) and swaddling.	<i>Our health visitor suggested we try sleeping separately in different rooms so that he has his own, but I don't want to keep getting up to see him in a different room. – P396</i>
		3.1.5 - Referral from HV	Parents describe referrals from HVs such as to a nursery nurse. Some parents mention referrals to GPs for other parts of the sleep problem (e.g.	<i>I am being put in touch with a nursery nurse through my health visitor – P1114</i>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
			symptoms of depression). Some parents mention referrals to sleep specialists or sleep clinics within the HV team.	<p><i>I spoke with my health visitor about this for a long time when she came over and she recommended I see the doctor for my mental health, but I think it was just exhaustion instead. – P1079</i></p> <p><i>I've been recommended to a sleep specialist health visitor, through my health visitor – P1161</i></p>
		3.1.6 - HV normalisation or not concerned	Some descriptions that HVs have advised sleep problems are normal or a phase. Some say they may grow out of them. Parents who posted these comments had mixed views – some perceived this advice positively whereas others said they were not much help.	<p><i>We were told by our health visitor that if our little one is tired, he will go to sleep and that we don't need to worry about the sleep stages – P389</i></p> <p><i>My health visitor pretty much told me that it's just something that may happen - some little ones don't sleep well and you just have to get through it. – P567</i></p> <p><i>Our health visitor didn't look like she was worried about it. She said that some children just don't need as much sleep. – P1165</i></p>
		3.1.7 - HV signposting to information	A parent discussed that a HV had signposted them to evidence online	<p><i>When we discussed this with her, our health visitor recommended that for the most recently evidenced-based information, we look up the first 5 months on the internet – P1073</i></p>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
	3.2 - Mixed attitudes about community PCPs	3.2.1 - Positive comments	Many comments agreeing with HVs or describing them positively such as helpful, supportive or understanding.	<p><i>I recognise that they can help when they are needed and that they mean well – P512</i></p> <p><i>I think your health visitor is right – P583</i></p> <p><i>I know that my Health visitors have a sleep training service where the best have trained them. It's fantastic – P1022</i></p>
		3.2.2 - Negative comments	Negative comments about HVs, such as disagreeing with their advice, dismissing their advice, hiding things from them, feeling misunderstood or finding them unhelpful. Some describe that accessibility of HVs is challenging. For one parent, this was described as being a consequence of covid.	<p><i>Personally, when my kids woke in the night it was never related to how much solid food I'd given them throughout the day. Sorry to disagree with your Health visitor – P516</i></p> <p><i>Our health visitor didn't understand – she told me that I should be giving my little one extra food in the day. She's not waking because she's hungry, she wants comfort! – P526</i></p> <p><i>I'd be glad if I didn't have to see any, (though I understand that some parents find health visitors really helpful) – P512</i></p>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
				<p><i>I feel that I've been left alone with this. I've been unable to get hold of my HV for the whole week (number doesn't work, no response to my emails). – P806</i></p> <p><i>I'm unable to get a reply from our health visitor during this pandemic – P993</i></p>
	3.3 - Experiences with nursery nurses		Participants talk about experiences with nursery nurses. They are described as having been referred to them through a HV.	<i>We found a nursery nurse who was fantastic and helped with both eating and sleep training with our little boy. We were put in touch through our health visitor. – P1065</i>
4. LIMITED EXPERIENCES AND PERCEPTIONS OF GENERAL PRACTICE	4.1 - Reluctance to consult a GP for a behavioural sleep problem	4.1.1 - Embarrassed to see a doctor	Some describe that they are embarrassed to see a GP.	<i>We did hesitate about going to see our GP because we felt a bit silly saying that our little boy won't sleep, but actually it ended up being reflux and he now has medication for it – P788</i>
		4.1.2 - Worry about a negative reaction	Some expressed concerns about how a GP would react, for example that they wouldn't be taken seriously.	<i>I'm concerned that because our baby is so young, the GP would just laugh at me if I went – P326</i>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
	4.2 - Consulting GPs for non-sleep problem or underlying cause of sleep problem		Although there are limited posts about talking to GPs specifically about sleep problems, there are posts for discussions for non-sleep problems or non-sleep parts of the problem which are affecting (or affected by) sleep (e.g. for reflux). Or to check for anything else going on	<p><i>I've made an appointment to see the GP now because since we last spoke, shes had problems toileting and it's a different colour. – P183</i></p> <p><i>It might be something else like an ear infection. Have you seen the doctor to rule anything like that out? – P56</i></p> <p><i>If controlled crying isn't successful there are other options such as...see a doctor who can see if there's anything else going on (e.g. reflux) that's physical... - P197</i></p>
	4.3 - Experiences of consulting GP for sleep problems	4.3.1 - Bringing it up when seeing GP for something else	Implied participants will speak to the GP about the sleep problem, because they are going for something else anyway	<i>P764: I understand that it sounds like I'm over-exaggerating, but I'm unable to just leave her to cry at all. I feel physically ill when she cries. I do need to speak to my GP nonetheless. I've never breastfed but my little girl got hurt the other day and I experienced lactation.</i>
4.3.2 - Recommendations or advice		One recommendation about controlled crying and one recommendation for an antihistamine	<i>P241: Our doctor made the point that although I don't want to go through controlled crying, it might be better for some nights, because ongoing sleep deficiency is worse.</i>	

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
				<p><i>In the end I went to a doctor after trying so many things at home. After using a sleep diary, we couldn't find a pattern that explained it but the doctor prescribed [medication] after a while when we went nightly with only around an hours sleep. It's an antihistamine, but not really used as sleepiness is a secondary effect. We started with a high dose and then reduced the amount each day, and towards the end missed a couple of days (identical to the way an adult would take it). In the same way that an adult would taking sleeping medication, the plan was to restart his sleeping pattern. It really helped, but we're still not sure why his sleeping stopped. – P345</i></p>
		4.3.3 - Referral	Referral to secondary care or referral to HV	<p><i>We have seen our GP to be recommended to the paediatric department – P66</i></p> <p><i>P977: "What did your doctor tell you?. My son gets so tired too and you can see under his eyes there are red circles and that he doesn't want to sleep!</i></p> <p><i>P983: "Didn't say much, just said that everything else was ok and recommended I ask the health visitor</i></p>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
		4.3.4 - Seeing doctor as a last resort	Some participants appear to describe seeing the GP as a last resort, either from trying many things at home already, or from trying other HCPs too.	<i>It's the nightwaking that's exhausting me (she goes to bed fine). The only thing left that I could try is complete cry it out, but I don't want to do that. I've tried lots of HVs, nursery nurses etc...its now the time to try my GP – P66</i>
		4.3.5 - Unhelpful reaction	Some parents talk about their experience of taking the sleep problem to the doctor and receiving a negative reaction from them, such as not being taken seriously.	<i>I'm at the end of my tether. When I say that my little girl never sleeps, the doctors never take it seriously. I don't think that this has been normal, but they think that because I'm a first time mum I must just need to get used to it. – P194</i>
5. OTHER RESOURCES FOR SUPPORTING PARENTS WITH CHILD SLEEP PROBLEMS	5.1 – Tools and information resources online, through information sites, social media and apps	5.1.1 - Information resources online	Many parents describe using (or recommend) various online resources to look up information about sleep. For example, many specific websites, online forums, social media sites, apps and YouTube are discussed. Parents also simply describe 'googling' for information. Many parents also describe using apps for sleep information. The information they seek could be explanations for sleep problems, or strategies	<i>Hello, [website] is the greatest place that I've personally found sleep information for little ones that is based on the evidence.- P381</i> <i>[parenting website] really helps. It has sleep and night feeding information which is really based on the evidence. I'd recommend it. – P381</i> <i>[app] is really good at explaining the reason for it (makes you realise you're not crazy), saying whether it's a phase, telling you what you can expect and how you can manage it. Use that – P572</i>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
			for how to manage them. This also includes information support resources, such as referring to social media groups or forums.	
		5.1.2 - Resources as tools	Parents also describe (or recommend) using online resources as 'tools' to manage their children's sleep. This is usually in the form of apps. For example, one specific app is mentioned on many occasions to track sleep timings. Other resources as tools include more practical tools (e.g. apps that read stories to children or apps/youtube videos that make sounds such as white noise.	<p><i>White noise works great! Have you given it a go? Personally, we use it on [app] and it works great for us! – P924</i></p> <p><i>It used to take ages to get my little boy to nap and he'd always cry when I it was that time. The app is fantastic. – P1272</i></p> <p><i>We used [app] which had a voice which read a story to our little one when it was time for bed and it really worked. I no longer need to sit there waiting for him to go to sleep, or stay with him when he wakes throughout the night because I can go in turn it back on, and go back</i></p>

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
				<i>to bed myself. It's another voice that he can listen to and focus on that reassures him. – P334</i>
	5.2 - Non-PCPs or non-healthcare workers	5.2.1 - Secondary care professionals	Includes mentions of secondary care professionals such as CAMHS, midwives and osteopaths.	<p><i>My little boy still wakes in the night and he is nearly 2. He slept through a bit over xmas but hasn't since. He struggles with night-waking and napping. I have done all the things I should have, spoken to my [PCP] and also [secondary care professional]. But after an assessment they advised that he's just strong-minded and is fine. – P590</i></p> <p><i>With information from my [secondary care professional], I practice safe co-sleeping. – P284</i></p>
		5.2.2 - Sleep consultant or specialist	Many parents describe (or recommend) the use of a sleep specialist (usually privately, or through a referral of a PCP). Some of the comments about sleep consultants/specialists are positive whereby it has helped, or not positive whereby they have tried them but are still trying to improve the sleep.	<p><i>I tried speaking to a sleep consultant, but I had already given many of their suggestions a go – P396</i></p> <p><i>Using advice from a sleep consultant, we sleep trained our little girl early. I understand it's not what everyone would want to do, however it helped our little one). – P412</i></p>

Appendix B

Theme	Sub-theme	Codes within the themes	Definition/explanation	Example paraphrased quote(s)
	<p>5.3 - Books or parenting/sleep expert authors</p>		<p>Many parents describe using (or recommend) books or parenting/sleep expert authors for information and management options. Some parents also ask for recommendations of books.</p>	<p><i>You can understand your little one's behaviour more by reading around the 4th trimester. I'd also recommend [parenting expert author] for some mild techniques. – P508</i></p> <p><i>We really hope that one of these books we bought about sleep training will help. – P1246</i></p> <p><i>I feel like much of the information around is incorrect or not clear, so I bought [book] and I'm so happy that I got it. It gives information for every worry that I had and it has lots of detail. I'd really recommend getting it if possible as it has so much sleep info – P1257</i></p>

Appendix C Chapters Five and Six (Mixed-Methods Study) Appendices

C.1 Ethical approval

C.1.1 Screenshot of the first page of the HRA approval letter



Miss Samantha. J Hornsey
Primary Care, Population Sciences and Medical
Education. University of Southampton
Aldermoor Health Centre, Aldermoor Close
Southampton
SO16 5ST

28 February 2020

Dear Miss Hornsey

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title: Primary Care Providers' views, understanding and current practice regarding the management of paediatric chronic insomnia - a mixed methods study.
IRAS project ID: 277619
Sponsor: University of Southampton

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, [in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.](#)

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.



Email: hra.approval@nhs.net
HCRW.approvals@wales.nhs.uk

C.2 Amendments

The study had minor amendments made at various time points. The three amendments are listed below.

1. The first amendment was made after the first UK coronavirus lockdown, prior to data collection starting. This was to revise/finalise the online survey questions and to allow survey participants option to express an interest in the interviews quickly, by entering their email address (rather than only being able to email the researcher directly). The practice code tracking question was also revised to include tracking of NHS trust participation (for community PCPs). The amendment also allowed for the survey to be undertaken via Microsoft Forms or via iSurvey (although all surveys were undertaken via iSurvey in the end) and to allow for the qualitative interviews to take place remotely via video call. The protocol, survey, and participant information sheets were updated to reflect these changes where appropriate. The , consent forms were updated to reflect the change in version number and date of the participant information sheets.
2. The second amendment which only needed RGO approval was to allow for electronic signatures from interview participants if needed, due to the covid-19 pandemic. There were no changes to study materials, only the protocol where this amendment was listed.
3. The third amendment was to help recruitment: to add community advertisement (e.g. social media), snowballing recruitment (to pass on details of the survey and/or interview), and study advertisement via non-NHS organisations. The protocol, survey and participant information sheets were amended to clarify that participants only needed to enter their practice code or NHS Trust, if they were identified through NHS recruitment methods (e.g. sent the survey from a health visiting manager or someone in the CRN). Consent forms were updated to reflect the changes in version number and dates of the participant information sheets.

The study materials listed in this appendix are the final versions used throughout the majority of data collection.

C.3 Study materials

C.3.1 Final survey participant information sheet

This is the final approved version used throughout most of the study. See appendix C.2 for details of minor amendments throughout the study.

Document footer: PIS online isurvey [11/10/2020] [Version 1.3] [ERGO: 53955 /IRAS: 277619]

Participant Information Sheet (29/07/2020 version 1.2) [to be copied onto page 1 of the isurvey or Microsoft Forms survey]

Study Title: Primary Care Providers' views, understanding and current practice regarding the management of paediatric chronic insomnia - a mixed methods study.

Researcher: Samantha Hornsey

ERGO number: 53955

IRAS: 277619

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You may like to discuss it with others but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

Chronic Insomnia in children involves difficulty initiating and maintaining sleep. I am a PhD student exploring the management of chronic insomnia in children in primary care. The aim of the present study is to explore primary health care professionals' current practices regarding the management of chronic insomnia in children up to and including five years of age; their thoughts about this and their formal education on managing sleep in children. This study is sponsored by the University of Southampton and funded by the National Institute for Health Research (NIHR) School for Primary Care Research (SPCR). This study is supervised by Professor Hazel Everitt, Dr Catherine Hill, Dr Beth Stuart and Dr Ingrid Muller.

Why have I been asked to participate?

You have been asked to participate in this study because you are a primary healthcare professional or healthcare professional such as a GP, health visitor or nursery nurse. We aim to recruit around 100-300 participants for this study.

What will happen to me if I take part?

If you decide to take part, you will be asked to tick consent boxes on the next page, for the survey. Once you have completed the online consent form, you will be able to proceed to the survey which explores how you manage (or advise) about chronic insomnia in children up to and including the age of five. For some questions, you will be given a choice of answers and for others, you will have the option to type an answer freely. There will also be some demographics questions asking about your professional role, gender and ethnicity. It is anticipated that the survey will take no longer than 15 minutes. You do not need to provide your name or contact details in order to be able to take part, however if you would like to be entered into the draw to win a £100 gift voucher, or express an interest in also taking part in an interview (please see below), you will need to provide your email address at the end so that we can contact you.

At the end of the online survey you will be asked whether you would be interested to continue taking part in this research by taking part in a qualitative interview. If you are interested, you will be asked to provide your email address or email/phone Samantha Hornsey directly (sh7g13@soton.ac.uk / 023 8059 1747). By expressing an interest in the interview this way, you are not obliged to take part in the interview. You will then be sent a separate participant information sheet and consent form, specific to the interview part of this research.

Are there any benefits in my taking part?

Taking part in this study will provide valuable information and help improve current understanding of how children's chronic insomnia is managed in primary care. At the end of the study, you will also be entered into a draw for a £100 give voucher for taking part in this online survey, if you choose to provide your contact details.

Are there any risks involved?

It is not anticipated that there will be any significant risks. The survey and/or interview may involve taking about potentially difficult professional experiences, however the questions are not expected to cause any discomfort or distress.

What data will be collected?

Data will be collected by open and closed choice questions. Data will be collected about your views/ beliefs, current practice, and knowledge/understanding, regarding management of chronic insomnia in children up to and including five years of age. Some demographic data will also be collected about your professional role, as well as some special category data (your gender and ethnicity) in order to provide demographic data and look at group differences and predictors etc. If you are based at a GP practice or NHS trust, and you were informed about the survey from someone in your GP practice (who was informed about it from the Clinical Research Network) or you were informed about it from someone within your NHS trust, we will ask if you could provide your practice code / trust name. This helps us inform the Clinical Research Network about recruitment rates from various practices/trusts. We will not inform your practice/trust about whether you as an individual have taken part. You will only need to enter your email address if you choose to, to express an interest for the interview or for the draw for the £100 voucher.

All data will be handled securely, during all phases of the research, and in line with the University and data protection regulations (GDPR). Please see the next section “will my participation be confidential?” for further details.

Will my participation be confidential?

Your participation and the information we collect about you during the course of the research will be kept strictly confidential. The study team (myself and my supervisors) will have access to the data for the purpose of the study. Your place of work will not be informed whether you as an individual have decided to take part or not. All data will be kept in line with the university and data protection regulations (GDPR). All of your information will be kept in a secure, locked filing cabinet at the university or on a password protected university laptop or university computer.

Only members of the research team (myself and my supervisors) and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data.

All of these people have a duty to keep your information, as a research participant, strictly confidential.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to complete a consent form online to show you have agreed to take part in the online survey.

What happens if I change my mind?

You have the right to change your mind and withdraw from the survey (up until your submission) without giving a reason and without your participant rights being affected. If you have finished and submitted the survey, but not taken part in the interview or provided your name at the end of the survey, your data will have been submitted without the possibility of withdrawal. If we are unable to remove your data from the study, we will keep the information about you that we have already obtained for the purposes of achieving the objectives of the study only.

What will happen to the results of the research?

Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent before. You may also receive a summary of the results if you wish.

Where can I get more information?

If you would like further information after reading this information sheet, please contact Samantha Hornsey by email (sh7g13@soton.ac.uk) or by telephone (023 8059 1747).

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions.

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

If you would like to contact the research team, please contact Samantha by email (sh7g13@soton.ac.uk) or telephone (023 8059 1747). Alternatively, you can contact Samantha's supervisor Professor Hazel Everitt (H.A.Everitt@soton.ac.uk)

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at <http://www.southampton.ac.uk/assets/sharepoint/intranet/Is/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf>

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

Appendix C

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights - such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Thank you for taking the time to read the information sheet and for considering taking part in this research.

Please tick this box to say that you have read and understood the information on this page, before you proceed.

C.3.2 Final survey consent form

This is the final approved version used throughout most of the study. See appendix C.2 for details of minor amendments throughout the study.

Document footer: [11/10/2020] [Version 1.3]

[ERGO: 53955 /IRAS: 277619]

**CONSENT FORM (Online survey) [to be copied onto page 2 of the
isurvey or Microsoft Form survey]**

Study title: Primary Care Providers' views, understanding and current practice regarding the management of paediatric chronic insomnia - a mixed methods study.

Researcher name: Samantha Hornsey

ERGO number: 53955

Please tick the box(es) if you agree with the statement(s):

I have read and understood the information sheet (11/10/2020 version 1.3) and have had the opportunity to ask questions about the study.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	
I understand my participation is voluntary and I may withdraw for any reason without my participation rights being affected.	
I understand that if I withdraw from the study that it may not be possible to remove the data once my personal information is no longer linked to the data.	
I understand that I may be quoted directly in reports of the research but that I will not be directly identified (e.g. that my name will not be used if I have provided it).	
I understand that any personal information collected about me, such as my name or where I live, will not be shared beyond the study team.	
I understand that data on gender and ethnicity will be collected about me to achieve the objectives of the study.	
I give permission for this data to be stored by the department of primary care at the University of Southampton (as specified in the information sheet) for the purposes of this research study.	

C.3.3 Final survey

This is the final approved version used throughout most of the study. See appendix C.2 for details of minor amendments throughout the study.

Document footer:

Draft of the mixed-methods survey_v1.3_11-10-2020

ERGO ID: 53955 / IRAS ID: 277619

MIXED-METHODS ONLINE SURVEY

Survey title: Primary care management of chronic insomnia in childhood (up to and including 5 years)

[Section 1: Participant information sheet]

[Section 2: Consent page]

Section 3: Chronic insomnia in children definition:

This survey refers to Chronic insomnia in children (infants and children) up to and including the age of 5. Chronic insomnia here, refers to persisting problems with otherwise healthy children initiating and maintaining sleep for behavioural reasons. For example, this survey refers to children who have difficulty adhering to bedtime limits, difficulty getting to sleep or who wake frequently throughout the night and need a parent to resettle them. Please answer the questions based on your beliefs, experiences, understanding and views of managing these types of sleep problems in otherwise healthy children up to and including the age of 5 years.

Section 4: Views about managing (or advising about) chronic insomnia in children up to 5 years old.

1. How much does chronic insomnia impact on the following domains? Please rate from 1 (no impact) to 5 (major impact)
 - a. Mood and behaviour
 - b. Learning ability
 - c. General physical health
 - d. Social health (peer and family relations)
 - e. Weight gain

- f. Accidental injury (falls, burns etc)
 - g. Parental stress
2. How much do you agree or disagree with the following statements (*from 1 which is 'strongly disagree' to 5 which is 'strongly agree'*)
 - a. It is important for health services to manage / advise about children's chronic insomnia
 - b. It is important to manage /advise about children's chronic insomnia in primary care.
 - c. It is important to manage /or advise about children's chronic insomnia in my practice.
 - d. Chronic insomnia affects the children experiencing it.
 - e. Chronic insomnia in children impacts the family.
 - f. It is important to manage / advise about children's Chronic Insomnia using behavioural interventions
 - g. It is important to manage / advise about children's chronic insomnia with pharmacological approaches
 3. Please rank the following in order of importance: Who from the following list should manage children's chronic insomnia? (with 1 being the least important and 5 being the most important)
 - a. Health visiting team
 - b. GPs
 - c. Nursery nurses
 - d. GP practice nurses
 - e. Parents
 - f. Other (if you have a particular practice in mind for 'other', please describe this in the question below).
 4. If you have any comments for any of the above questions, please write them here (*text box*).

Section 5: Current practice about the management of (or advising about) chronic insomnia in children.

1. How often do you discuss children's chronic insomnia with parents during consultations?
 - a. Never
 - b. Rarely
 - c. Sometimes
 - d. Frequently
 - e. Very frequently
2. Who tends to bring up the discussion about chronic insomnia most? Please tick 'myself', 'the family' or 'both' for each age group.
 - a. Up to 6 months old
 - b. 6 months old to 12 months old
 - c. 12 months old up to (and including) 5 years old
3. When a parent comes to you about problems with their child's chronic insomnia, do you follow a particular thought process or approach, such as taking a structured clinical history?
 - a. Yes
 - i. (please explain – *text box*)
 - b. No
 - c. Somewhat

- i. (please explain – *text box*)
4. Do you use anything specific to aid your decision making when managing children’s chronic insomnia? (please tick all that apply)
 - a. Existing literature
 - b. Personal experience
 - c. Sleep diary
 - d. General discussion about the child’s sleep history
 - e. I do not use anything specific
 - f. Other
 - i. (please explain – *short text box*)
5. **Please answer this question in relation to the ‘Up to 6 months old’ age group**

On a scale of 1-5, please answer the following question based on how likely you are to make each of the recommendations below for children’s chronic insomnia: (from 1 which is ‘never’ to 5 which is ‘every time’)

 - a. Ignore the child, also known as ‘Cry it out method’ or ‘extinction’
 - b. Controlled crying, also known as ‘Graduated extinction’ or ‘Ferber method’
 - c. Extinction with parental presence / Gradual retreat
 - d. Positive bedtime routine
 - e. Scheduled awakenings
 - f. Delayed bedtime
 - g. Pharmacological recommendations
 - h. Make a referral
 - i. Advise that the problems will resolve over time
 - j. No recommendation
 - k. Other
6. [If you have anything you would like to add for ‘other’ in the previous question, please explain here.](#)
7. **Please answer this question in relation to the ‘6 months old to 12 months old’ age range:**

On a scale of 1-5, please answer the following question based on how likely you are to make each of the recommendations below for children’s chronic insomnia: (from 1 which is ‘never’ to 5 which is ‘every time’)

 - a. Ignore the child, also known as ‘Cry it out method’ or ‘extinction’
 - b. Controlled crying, also known as ‘Graduated extinction’ or ‘Ferber method’
 - c. Extinction with parental presence / Gradual retreat
 - d. Positive bedtime routine
 - e. Scheduled awakenings
 - f. Delayed bedtime
 - g. Pharmacological recommendations
 - h. Make a referral
 - i. Advise that the problems will resolve over time
 - j. No recommendation
 - k. Other
8. [If you have anything you would like to add for ‘other’ in the previous question, please explain here.](#)
9. **Please answer this question in relation to the ‘12 months old up to (and including) 5 years old’ age range:**

On a scale of 1-5, please answer the following question based on how likely you are to make each of the recommendations below for children’s chronic insomnia: (from 1 which is ‘never’ to 5 which is ‘every time’)

- a. Ignore the child, also known as 'Cry it out method' or 'extinction'
 - b. Controlled crying, also known as 'Graduated extinction' or 'Ferber method'
 - c. Extinction with parental presence / Gradual retreat
 - d. Positive bedtime routine
 - e. Scheduled awakenings
 - f. Delayed bedtime
 - g. Pharmacological recommendations
 - h. Make a referral
 - i. Advise that the problems will resolve over time
 - j. No recommendation
 - k. Other
10. If you have anything you would like to add for 'other' in the previous question, please explain here.
11. Are you aware of any resources of support/information for parents of children with chronic insomnia?
- a. Yes
 - i. Please specify – (text box)
 - ii. How often would you typically use these resources?
 1. All of the time
 2. Most of the time
 3. In particular circumstances
 - a. Please specify (text box)
 4. Rarely
 5. N/A
 - b. No
12. If there is anything else that you would be likely to do or recommend in consultation, please explain it here [text box response]
13. Please score your confidence from 1 (not confident), to 5 (very confident) for each of the following statements:
- a. Your ability to advise children (or their guardian) about sleep hygiene
 - b. Your ability to motivate children to change their sleep behaviours
 - c. Your ability to manage and refer children with chronic insomnia
 - d. Your ability to conduct follow-up of the children's chronic insomnia

Section 6: Sleep training and understanding

1. During your medical education / training to become a healthcare professional...
 - a. Did you receive any formal teaching specific to chronic insomnia in children?
 - i. Yes
 1. (please specify – text box)
 - ii. No
 - iii. Not sure
2. Since you completed training to become a healthcare professional,
 - a. Have you had the opportunity to receive any teaching about children's sleep problems, specific to chronic insomnia?
 - i. Yes
 1. (please specify – text box)
 2. Have you attended any of the opportunities which were specific to chronic insomnia in children?

- a. Yes
 - b. No
 - c. Not sure
- ii. No
 - iii. Not sure
3. Do you feel that you should have had any (or more) sleep teaching about children's chronic insomnia when you were training to be a health care professional?
- a. Yes
 - b. No
 - c. Somewhat
4. If you had the chance now, would you like to access further sleep teaching opportunities about chronic insomnia in children?
- a. Yes
 - i. What sort of opportunities would you like? (text box)
 - b. No
5. Sleep questions:
- a. Please answer true/false/don't know for the following statements:
 - i. Depriving a child of his/ her nap is effective in helping children to sleep at night
 - ii. Sleep resistance and frequent night wakings in children are often highly amenable to behavioural techniques
 - iii. Rocking an infant to sleep before placing him/her in the crib is likely to be an effective strategy to improve sleep
 - iv. In general, infants should be allowed to cry themselves back to sleep
 - v. A child who regularly has trouble getting to sleep at night should be allowed to sleep later in the morning
 - b. Please answer true/false/don't know for the following statements.
 - i. It is normal for school-aged children to take naps up to several times a week
 - ii. Breast fed babies usually sleep through the night at an earlier age than bottle-fed babies
 - iii. Healthcare providers should **not** recommend temporary establishment of a later bedtime as an intervention for a child with difficulty falling asleep.
 - iv. It is normal for young children to awaken briefly during the night at the end of a sleep cycle (every 60-90 minutes)
 - v. "learned hunger" resulting from frequent night feedings can lead to increased nocturnal awakenings in infants

Section 7: Demographics

1. What type of primary care professional are you? (Please tick all that apply)
- a. General Practitioner
 - b. Advanced Nurse practitioner
 - c. Practice Nurse
 - d. Nursery Nurse
 - e. Health visitor
 - f. Other
 - i. Please specify (text box)
2. Where is your practice based? (please tick one)
- a. GP practice
 - b. Community

c. Both

3. How long (in years) have you been practicing as a health care professional (since you qualified)? *[drop down box with numbers]*
4. How long (in years) have you been practicing in a primary care/ community setting? *[drop down box with numbers]*
5. What region of the UK do you practice in? (text box)
6. What is your age? *[drop down box with numbers]*
7. What is your gender? *[text box]*
8. What is your ethnicity? *[insert response options given on isurvey or text box]*
9. Do you have any personal experience of caring for children aged 5 or under? *(text box)*

Section 8: Please complete this section and press 'save and finish'

1. If you are based at a GP practice and you were informed about the survey from someone in your practice (who was informed about the survey from the Clinical Research Network), please could you type in your practice code below.

If you are not based at a GP practice and you were informed about the survey from someone within your Trust , please could you type in your NHS trust.

This helps us inform the Clinical Research Network about recruitment rates from various practices. We will not inform your practice that you as an individual have taken part.

[insert free text box]

2. Interview study

We are currently recruiting participants for an interview study on this topic (face to face or over the phone / video call). Would you be interested in this and like us to contact you to provide more information? Expressing interest here does not mean you have to take part.

If so, please type your email address below to express an interest and we will contact you with further information. Alternatively, you can email or phone Samantha directly (sh7g13@soton.ac.uk / 023 8059 1747) to express an interest. Expressing an interest does not mean you have to take part. *(text box for participant to type email)*

3. Draw for £100 gift voucher:

If you would like to be entered into the draw to win a £100 gift voucher, please email or phone Samantha on the contact details above, or enter your email address here. *[text box to type email]*

Section 10: Debrief (appears after survey is finished).

Thank you very much for taking part in this survey. Taking part in this study will have provided valuable information and help improve current understanding of how children's chronic insomnia is managed in primary care.

If you would like any information resources about this topic, you can access these by reading the following article, and/or the references which are cited in it:

- Hill CM, Everitt H. Assessment and initial management of suspected behavioural insomnia in pre-adolescent children. *BMJ*. 2018;363.

If you would like to contact the research team, please contact Samantha by email (sh7g13@soton.ac.uk) or telephone (023 8059 1747). Alternatively, you can contact Samantha's supervisor Professor Hazel Everitt (H.A.Everitt@soton.ac.uk)

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions.

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

C.3.4 Final Interview participant information sheet

This is the final approved version used throughout most of the study. See appendix C.2 for details of minor amendments throughout the study.

Document footer: [11/10/2020] [Version 1.3] [ERGO: 53955 /IRAS: 277619]

Participant Information Sheet (Interview)

Study Title: Primary Care Providers' views, understanding and current practice regarding the management of paediatric chronic insomnia - a mixed methods study.

Researcher: Samantha Hornsey

ERGO number: 53955

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You may like to discuss it with others but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

Chronic Insomnia in children involves difficulty initiating and maintaining sleep. I am a PhD student exploring the management of chronic insomnia in children in primary care. The aim of the present study is to explore primary health care professionals' current practices regarding the management of chronic insomnia in children up to and including five years of age; their thoughts about this and their formal education on managing sleep in children. This study is sponsored by the University of Southampton and funded by the National Institute for Health Research (NIHR) School for Primary Care Research (SPCR). This study is supervised by Professor Hazel Everitt, Dr Catherine Hill, Dr Beth Stuart and Dr Ingrid Muller.

Why have I been asked to participate?

You have been asked to participate in this study because you are a primary healthcare professional or healthcare professional such as a GP, health visitor or nursery nurse and you took part in the online survey for this research. We aim to recruit around 15-30 participants for this part of the study.

What will happen to me if I take part?

Taking part in this part of the study will involve an interview with the researcher (Samantha Hornsey). The interview will involve a discussion with about your views, current practices, knowledge, understanding and training regarding the management of children's chronic insomnia (up to and including the age of five). There will also be some demographics questions asking about your professional role, gender and ethnicity. The Interview will last as long as you would like or are able to talk but it is expected to take no longer than an hour and this can be completed at a time and date agreed between you and the researcher. This can take place face to face at

Appendix C

your home, GP practice (or office of work, if applicable), at the university or over the phone. In response to the Covid-19 pandemic, interviews will be conducted over the telephone or via videocall (Microsoft Teams).

If after reading this information sheet, you decide to take part, you will be asked to complete a consent form before the interview can begin. If your interview takes place over the telephone / video call, you may complete the consent form and post it back, or sign, scan and email it to the researcher. With your consent, the interview will be audio recorded and transcribed. Once the interview is transcribed, the audio recording will be deleted and only the transcription will remain. This will enable the researcher to look back at the discussion and analyse the information for the purpose of the study.

Are there any benefits in my taking part?

Taking part in this interview will provide valuable information and help improve current understanding of how children's chronic insomnia is managed in primary care. If you decide to continue and take part in the interview, you will be given a £10 gift voucher, to thank you for your time.

Are there any risks involved?

It is not anticipated that there will be any significant risks. The survey and/or interview may involve talking about potentially difficult professional experiences, however the questions are not expected to cause any discomfort or distress.

What data will be collected?

Through the interview, data will be collected about your views/ beliefs about chronic insomnia in children up to and including five years of age, about your current practice regarding management of chronic insomnia in children up to and including five years of age, and about your knowledge/understanding of managing chronic insomnia in children up to and including five years of age. Some demographic data will also be collected about your professional role, as well as some special category data (your gender and ethnicity) in order to provide demographic data and look at group differences and predictors etc. If you are based at a GP practice or NHS Trust, and you were informed about the survey from someone in your GP Practice (who was informed by the

Clinical Research Network) or you were informed about it from someone within your NHS Trust, we will ask if you could provide your practice code. This helps us inform the Clinical Research Network about recruitment rates from various practices. We will not inform your practice about whether you as an individual have taken part.

The interview will be audio recorded and transcribed, when the audio recording will then be destroyed. The interview may be transcribed by an appropriate individual/ organisation, however this will only be done with an appropriate confidentiality agreement in place.

All data will be handled securely, during all phases of the research, and in line with the University and data protection regulations (GDPR). Please see the next section “will my participation be confidential?” for further details.

Will my participation be confidential?

Your participation and the information we collect about you during the course of the research will be kept strictly confidential. Your place of work will not be informed whether you as an individual have decided to take part or not.

Only members of the research team (myself and my supervisors) and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

You will be given a participant identification number (your data will be pseudonymised), so that your data is identifiable only by this number (including the file name of the audio recording). The consent forms and list linking names to participant identification numbers will be kept separately to the rest of the study data. The interviews will be audio recorded and once transcribed, the recordings will be destroyed. The audio recording may be transcribed by a member of the study team or by an appropriate individual/organisation, however for any interviews not transcribed by the researcher in the study team, an appropriate confidentiality agreement will be in place. Any potentially identifiable information discussed in the interview will also be removed from the transcript. The study team (myself and my supervisors) will have access to the data for the purpose of the study.

Appendix C

All data will be kept in line with the university and data protection regulations (GDPR). All of your information will be kept in a secure, locked filing cabinet at the university or on a password protected university laptop or university computer.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to be able to take part in the interview.

What happens if I change my mind?

You have the right to change your mind and withdraw from the interview at any time without giving a reason and without your participant rights being affected.

What will happen to the results of the research?

Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent before. You may also receive a summary of the results if you wish.

Where can I get more information?

If you would like further information after reading this information sheet, please contact Samantha Hornsey by email (sh7g13@soton.ac.uk) or by telephone (023 8059 1747).

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions.

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

If you would like to contact the research team, please contact Samantha by email (sh7g13@soton.ac.uk) or telephone (023 8059 1747). Alternatively, you can contact Samantha's supervisor Professor Hazel Everitt (H.A.Everitt@soton.ac.uk).

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at <http://www.southampton.ac.uk/assets/sharepoint/intranet/Is/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf>

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

Appendix C

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Thank you for taking the time to read the information sheet and for considering taking part in this research.

C.3.5 Final Interview consent form

This is the final approved version used throughout most of the study. See appendix C.2 for details of minor amendments throughout the study.

Document footer: Consent form_qualitative interviews [11/10/2020] [Version 1.2] [ERGO: 53955 / IRAS: 277619]

CONSENT FORM (Qualitative interview)

Study title: Primary Care Providers' views, understanding and current practice regarding the management of paediatric chronic insomnia - a mixed methods study.

Researcher name: Samantha Hornsey

ERGO number: 53955

Participant Identification Number:

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (11/10/2020 version 1.3) and have had the opportunity to ask questions about the study.	
I agree to take part in this research project (interview) and agree for my data to be used for the purpose of this study.	
I understand that taking part in the study involves audio recording which will be transcribed and then destroyed for the purposes set out in the participation information sheet.	
I understand that my personal information collected about me such as my name or where I live will not be shared beyond the study team.	
I give permission to be quoted directly (from the interview) in reports of the research but understand that my details will be kept confidential and I will not be directly identified (e.g. that my name will not be used).	
I understand my participation is voluntary and I may withdraw at any time for any reason without my participation rights being affected.	
I understand that should I withdraw from the study then the information collected about me up to this point may still be used for the purposes of achieving the objectives of the study only.	
I understand that special category information will be collected about me to achieve the objectives of the study (gender and ethnicity)	
I give permission for this data to be held by the Department of Primary Care as described in the participant information sheet for the purposes of this research study.	

Appendix C

Name of participant (print name).....

Signature of participant.....

Date.....

Name of researcher (print name).....

Signature of researcher

Date.....

C.3.6 Final semi-structured interview schedule

QUALITATIVE INTERVIEW TOPIC GUIDE

Introduction

The researcher will first introduce herself, welcome the participant and describe the interview (including what is meant by behavioural sleep and in reference to young children (up to age 5). The researcher will give the participant the opportunity to read through the participant information sheet again (and go through it with the researcher if they wish). The researcher will give the participant opportunity to ask any questions.

The researcher will then take informed consent (or check informed consent with the participant, if they are taking part over the phone and gave informed consent prior to the phone call). The researcher will give the participant opportunity to ask any questions.

Demographics questions.

Repeat demographics questions from survey.

Interview questions (and prompts in italics):

Views and beliefs:

1. **Could you start by explaining to me what the meaning of chronic insomnia in children is to you?**

Thank you. Just for the purpose of this interview, we are referring to chronic insomnia as problems with otherwise healthy children initiating and maintaining sleep for behavioural reasons. For example, the questions in this interview will refer to children who have difficulty adhering to bedtime limits, difficulty getting to sleep or who wake frequently throughout the night and need a parent to resettle them. Please answer the questions throughout this survey, based on your beliefs, experiences, understanding and views of managing these types of sleep problems in otherwise healthy children up to and including the age of 5.

2. **Please could you describe your views about chronic insomnia in young children?**
 - a. How do you feel poor sleep impacts children?*
 - b. How does it impact the family?*
3. **How important, if at all, do you feel it is to address children's chronic insomnia in primary care?**
 - a. How important is this topic in relation to other aspects of children's healthcare?*
 - b. How much action do you think needs to be taken?*
4. **Could you describe what you believe your role is in managing children's chronic insomnia?**
5. **How do you think parents feel about coming to primary care to manage their children's chronic insomnia?**
 - a. Are there any other sources of support that you are aware of?*
6. **Could you describe your views of any management strategies that you are aware of (if any)?**
 - a. Are there any that you believe are effective or ineffective?*

Qualitative interview topic guide_v1_11-12-2019
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Current practice:

7. Please describe any particular experiences you have had with the management of chronic insomnia in young children.
 - a. Please could you describe a typical presentation and how you would usually manage it?
 - b. Could you describe any positive or negative experiences?
8. How (if at all) does the issue of chronic insomnia in children, come up in consultation?
 - a. Is there any particular person who tends to bring it up?
 - b. Who do you think ought to discuss this with them?
 - c. Are there any particular triggers for the conversation?
9. Could you tell me about what you would usually say if a parent came to you about their children's chronic insomnia?
 - a. How seriously would you take their concerns?
10. Could you tell me about how you usually manage chronic insomnia in children, if at all?
 - a. Could you describe a general process that you may follow?
 - b. Are there any particular recommendations that you make? If so, please explain.
 - c. Could you describe anything you may take into account?
11. Could you describe anything that would lead you to conclude whether a problem is a behavioural sleep problem?
12. Could you describe anything in particular that you would recommend for children experiencing chronic insomnia?
 - a. Could you describe anything you may take into account?
13. Could you describe to me how you feel when discussing management of chronic insomnia in consultation?
 - a. How does your experience feel?
 - b. Is there anything that makes it easier or more difficult?
14. Is there anything in particular that you would like to be able to use, that would help management of children's chronic insomnia in consultation?

Knowledge and understanding:

15. If applicable, could you describe any training regarding children's chronic insomnia that you may have had?
 - a. Could you describe any training specific to behavioural sleep?
 - b. Where did you receive the training?
 - c. How satisfied are you with the training that you have had?
 - d. Would you like more training in this area?
16. How much knowledge and understanding do you feel you have about managing children's chronic insomnia?
 - a. How sufficient do you feel your understanding is?

b. Would you like more training in this area?

17. Could you describe your level of confidence in managing children's chronic insomnia in consultation?

a. How confident do you feel in discussing or recommending management strategies in consultation?

Other:

18. Is there anything else that you wish to add?

General prompts:

1. Could you tell me a little bit more about that?
2. How does/did that make you feel?

Thank the interviewee for taking part, ask for their practice code and give them the debrief sheet. Also give them the £10 voucher.

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C.3.7 Final Interview debrief statement

Document footer: 04/12/2019 Version 1 [ERGO: 53955 / IRAS: 277619]

Debrief sheet (Qualitative Interview)

Study Title: Primary Care Providers' views, understanding and current practice regarding the management of paediatric chronic insomnia - a mixed methods study.

Researcher: Samantha Hornsey

ERGO number: 53955

Thank you very much for taking part in this survey. Taking part in this study will have provided valuable information and help improve current understanding of how children's chronic insomnia is managed in primary care.

If you would like any information resources about this topic, you can access these by reading the following article, and/or the references which are cited in it:

- Hill CM, Everitt H. Assessment and initial management of suspected behavioural insomnia in pre-adolescent children. *BMJ*. 2018;363.

If you would like to contact the research team, please contact Samantha by email (sh7g13@soton.ac.uk) or telephone (023 8059 1747). Alternatively, you can contact Samantha's supervisor Professor Hazel Everitt (H.A.Everitt@soton.ac.uk)

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions. If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk)

C.4 Interview analysis

C.4.1 Overview of themes and sub-themes

Over-arching theme	Sub-themes									
<p>1. Attitudes and Views about the Importance of Sleep Problems</p>	<p>1.1 View that sleep problems are common in children</p>	<p>1.2 Views about multiple impacts of poor sleep on the family</p>	<p>1.3 Perceptions about causal factors of sleep problems</p>	<p>1.4 Emphasis on the importance of sleep</p> <p>View that it's important to address sleep problems</p> <p>Not as important in general practice as other presenting problems</p>	<p>1.5 Subjectivity around defining sleep problems</p> <p>Views about societal and cultural influences on the perception of sleep problems</p> <p>Defining sleep as a problem based on it's perceived impact</p> <p>Reluctance to label it as a medical problem</p>	<p>1.6 Normalisation of some sleep problems</p>	<p>1.7 Viewing poor sleep as a complex issue</p> <p>Viewing poor sleep as a negative cycle</p> <p>Perceiving sleep as a complex issue</p>			

Over-arching theme	Sub-themes								
<p>2. Chronic Insomnia is Infrequently a Primary Reason for Consulting in General Practice</p>	<p>2.1 Perceptions of parents' reluctance to consult in general practice</p> <p>Perception that parents come to general practice out of desperation or last resort</p> <p>Perceived stigma for parents about consulting a GP for behavioural sleep problems</p>	<p>2.2 Chronic insomnia is rarely consulted as a single problem in general practice</p> <p>Frequency of sleep problems as a key concern in general practice</p> <p>Discussing sleep within other consultations</p> <p>Perceived as a common problem within health visiting</p>	<p>2.3 Views about missed opportunities to discuss sleep problems in primary care</p> <p>Differences in accessibility</p> <p>Perceived negative parental experiences of management</p> <p>Time limits in primary care</p>						

Over-arching theme	Sub-themes								
	Perception that parents do not think to come to general practice								
3. Views and Experiences of Advice and Recommendations	3.1 Signposting in general practice Signposting or referring to other professionals Signposting to resources	3.2 Basic advice, bedtime routines and other components of sleep hygiene Advising about basic/primary advice Advising about bedtime routines and other components of sleep hygiene	3.3 Assessing the situation Assessment General practice as a role to look for underlying causes	3.4 Beliefs supporting an individualised approach to management	3.5 Views and recommendations about specific strategies Suggesting behavioural interventions Perceptions of extinction methods Views about cosleeping Views about pharmacological treatment	3.6 Emotional support and management of the impact on parents Acknowledging the difficulties and being empathetic Management of the impact on the parents Encouraging parental acceptance or	3.7 Awareness of non-healthcare resources	3.8 Follow-ups in health visiting	3.9 Mixed views about referral and secondary care

Over-arching theme	Sub-themes								
		Advising on parental approach Parental education				managing expectations Providing reassurance or empowerment Importance of a good patient-doctor relationship and communication			
4. Views regarding roles of different PCPs in the management of chronic insomnia in children	4.1 Perception that primary care should address chronic insomnia	4.2 Perception that HVs or other community support are more suited to management Health visiting before general practice	4.3 Mixed views around the role of general practice Perception that GPs are not best placed for management Some views that GPs are						

Over-arching theme	Sub-themes								
		Perceptions that HVs or other community care have an important role in management	suited to manage chronic insomnia Some parents happy to go to GP						
5. Limited Professional Training and Knowledge Regarding Chronic Insomnia in Children	5.1 GPs receive minimal or no professional training about paediatric chronic insomnia	5.2 Specialised training options for HVs	5.3 GPs perceive limited or varied knowledge for management	5.4 Knowledge from practical experience	5.5 Interest for information resources	5.6 Interest in future professional training	5.7 Uncertainty in usefulness of further professional training		
6. Perceived Self-Efficacy for Managing Chronic	6.1 Mixed confidence levels	6.2 Perceived barriers to managing sleep	6.3 Positive feelings						

Over-arching theme	Sub-themes								
Insomnia in Children	Limited confidence Feeling confident for behavioural management Confident for basic advice, but unconfident for in depth management	problems in consultation Inability to solve the problem quickly Perceived pressure to solve the problem Influence of parental resistance, misunderstanding or readiness to discuss and change	towards the consultation						
7. The Influence of the Personal Experience of Being a Parent	7.1 Personal experiences influence feelings and attitudes	7.2 Knowledge acquired through personal experience rather than	7.3 Usefulness of discussing personal experience in consultation						

Over-arching theme	Sub-themes									
	Sense of empathy Impact on confidence	professional training								

C.4.2 Coding manual

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
1. ATTITUDES AND VIEWS ABOUT THE IMPORTANCE OF SLEEP PROBLEMS	1.1 View that sleep problems are common in children		Participants talk about their perceptions that sleep problems are common in children, though this is not necessarily described in a professional context.	<i>“I think – it’s a very common issue, certainly, both from my own personal experience and from – experiences of people in my family, as well as professionally, although, to be honest, I’ve come across it more outside of my work, I would say, than I have directly in work. So, yes, so I think it’s a very common issue and problem” – P91, GP</i>
	1.2 Views about multiple impacts of poor sleep on the family		All participants describe many different impacts of poor sleep on the children and/or family. In particular, they emphasise a big impact of poor sleep on the family or the impact of resulting adult insomnia. Some even	<i>“it can be quite – quite a big – a big deal, both for the children and for the family. So, yes, I think the impacts can be quite severe, in terms of behaviour issues as they get a bit older, how they – not only how they behave but how they - how they learn in pre-school and just starting school, as well and in terms of the family. I mean – it can be massive, in terms of – the knock on effects of chronic tiredness in the parents and I think there’s a lot of – there can be a lot of expectations felt by parents about – that they should be getting</i>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
			<p>mention the impact on parental mental health, such as depression.</p> <p>One participant discussed the feeling of empathy because of the impact it has on the family.</p>	<p><i>their children into a routine and so on. So there can be quite a lot of guilt and hang-ups in that department as well, which probably isn't very helpful. And – yes – generally or if the – the sleeping problems are affecting other children in the family and their own sleep as well, it can be a major issue. So, yes, I think it's certainly a big issue for children and parents and families" – P91, GP</i></p>
	<p>1.3 Perceptions about causal factors of sleep problems</p>		<p>Many participants talk about factors which they feel may impact on or contribute to sleep problems. For example, parent-driven factors, environmental factors, acute illnesses, social support etc. The impact of the Covid-19 pandemic was also discussed by some.</p>	<p><i>"I think a lot of support that parents gain, in terms of their parenting experiences and sleep management, actually comes from peer support and I think peer support has been massively impacted by reduced social contact of Covid-19" – P96, GP</i></p> <p><i>"I mean there aren't ... there aren't many other things really. It might be illness, you know, acute illness, but then it becomes behavioural" – P70, GP</i></p> <p><i>"I think – a lot of it is – parent-driven. So I think when a baby is born and kind of as they grow up and as they're a toddler and up to the age of 5, I think they rely quite heavily on parental and environmental cues to help them sleep. So when they are in the womb they sort of have no – I mean they have a vague understanding of what night and day is, based on the mother's routine, but when the baby's born, I think they – they rely quite heavily on parental routine, however strict or however lax they want that to be. And – I mean the reason that I think a lot of children have issues with sleeping is because – there's some dynamic that is not – xxx there's some ... discord, some kind of imbalanced dynamic in the bedtime or naptime routine of kind of getting the child ready to go to sleep" – P90, GP</i></p>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
	1.4 Emphasis on the importance of sleep		Participants describe that sleep is important	<i>“think – sleep is key – to so many things that we probably don’t even know the full extent. So I would say that it influences academic ability, relationships, mental health, the whole lot, everything, really. I think if we can improve sleep, then a lot of the other things improve; not always but, you know, I think it helps. But I think the same about adults, if I’m honest” – P83, GP</i>
		1.4.1 Views that it’s important to address sleep problems	Participants describe that it is important to address sleep problems.	<i>“I think if we can improve sleep, then a lot of the other things improve; not always but, you know, I think it helps. But I think the same about adults, if I’m honest” – P83, GP</i>
		1.4.2 Not as important in general practice as other presenting problems	Some GPs describe that in a GP setting, though managing sleep problems are important, they may need to be less prioritised than other problems. One HV described that in their practice, it is as important as everything else.	<i>“yes – it’s important as an issue, but as a healthcare problem, I’d probably put it lower down than – than some other – problems which I would consider to be more, strictly speaking, medical problems, if that makes sense” – P91, GP</i> <i>“I mean obviously there are – if we want to kind of rank, you know, this amongst other health problems, I’d probably put it quite low down, because obviously there are more important health issues if somebody has, that we need to treat. So, you know, I would put it lower down the list” – P99, GP</i>
		1.5.1 Views about societal and cultural	Some participants describe that the perception of a sleep problem by parents can often be influenced by	<i>“I think part of the reason it’s such a big problem is because – children don’t necessarily conform to society’s expectations and if you’ve got parents who are busy and they’ve got other things to do and they want their child to go to sleep and it’s interfering with their</i>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
	1.5 Subjectivity around defining sleep problems	influences on the perception of sleep problems	familial, societal or cultural norms. The influences could be under- or over- normalisation of sleep problems	<p><i>lives, then that's going to be a problem, whereas if you were in a culture where children slept with parents, alongside parents, then it actually probably wouldn't be so much of a problem. So I think the issue is more our expectations of – of what – how children's sleep should be may be a big issue; that probably applies more to the initial insomnia, whereas the frequent waking is probably different.” – P82, GP</i></p> <p><i>“I think it is – it is a little bit normalised, a bit more than it should be. So, you know, I've heard a lot of people say – oh – you know – kids have sleep issues, it's normal, it's normal. So I think parents tend to over normalise it and say fine, it'll be fine. And a lot of the cases, it is fine; most of the cases, but then it just makes it harder for them to kind of pinpoint which ones are not fine” – P94, GP</i></p>
		1.5.2 Defining sleep as a problem based on it's perceived impact	Participants describe their view that chronic insomnia in children exists if the parent and/or child experiences a perceived impact from the sleep problems. Two participants instead described it based on sleep factors such as waking or sleep duration.	<p><i>“I've also learned that what's a problem with one person, really isn't necessarily a problem for another one” – P93, GP</i></p> <p><i>“I'd say more than just the odd sleep disturbance in a child; something that's affecting the quality of life of the child but also the extended family and perhaps impacting their day-to-day life” – P92, GP</i></p> <p><i>“it would be – basically – either really interrupted sleep overnight, so sort of waking several times in the night for no particular reason, as such, you know, not being unwell, things like that or also really delayed sleep or waking up really early. So I guess not</i></p>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
				<i>getting the recommended, although that's not the right word, but recommended hours of sleep, that they should get, to be helping develop" – P88, HV</i>
		1.5.3 Reluctance to label it as a medical problem	Some GPs talk about how they would not medicalise sleep problems or how they would label them as behavioural instead. One participant talked about medicalising sleep problems if it's more extreme than normal sleep problems	<p><i>"I don't think it's a medical problem as such; I think it's more behavioural and it would be nice to have somewhere that we could signpost patients to" – P98, GP</i></p> <p><i>"I don't know that I would medicalise it in all situations." – P83, GP</i></p> <p><i>"I suppose I would think of it in a medical point of view, in that children that really have difficulty sleeping, probably for more than a few months, um that's beyond the – sleep challenges of having a young child, you know, like a baby or a toddler; that would be my impression" – P87, GP</i></p>
	1.6 Normalisation of some sleep problems		Some participants describe that it is normal for some children to struggle with sleep problems, and that some children sleep better than others. These are described with the impression that they still need to be addressed.	<i>"it's really common; lots of people struggle and, you know, some children naturally will sleep really well from early on, but others, it takes – it's like a learned behaviour and it will get better with time, but it's important to persist, I suppose. And it's not a failure on the parents as such, it's, you know, some children are more challenging than others in terms of sleep, that's probably what I'd say." – P87, GP</i>
		1.7.1 Viewing poor sleep as a negative cycle	Some participants talk about cyclical effects of poor sleep and other poor outcomes.	<i>"I think if a child doesn't have enough sleep, their behaviour is affected, which ultimately – is – is very detrimental to a family. I would also say that the same applies in reverse, so that if a parent hasn't had enough sleep because the child is waking, their tolerance to</i>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
	1.7 Viewing poor sleep as a complex issue			<i>behaviour – or their tolerance to anything really, is probably – well – mine is diminished, so therefore it’s – it’s a never-ending battle; it’s a cycle that you’ve got sleep deprived parents, sleep deprived children who are just – they’re probably not as tolerant to any [situation] – either of them is not as tolerant, so therefore it’s not very – I think it’s a really big – a really big deal, if I’m honest.” – P83, GP</i>
		1.7.2 Perceiving sleep as a complex issue	Some participants talk about the complexity of sleep and managing behavioural sleep problems.	<i>“The main thing I would say is that it’s almost always – a complex issue with multifactorial [elements]” – P85, GP</i>
2. CHRONIC INSOMNIA IS INFREQUENTLY A PRIMARY REASON FOR CONSULTING IN GENERAL PRACTICE	2.1 Perceptions of parent’s reluctance to consult in general practice	2.1.1 Perception that parents come to general practice out of desperation or last resort	Many GPs describe that they feel often when parents bring the problem to primary care, it is as a last resort or out of desperation.	<i>“I think for – for most parents, I think if they’re coming to you, I find that, you know, they would have already tried other options or most of them have already done all of the things that you might suggest, in terms of routines and things. So it’s often seen as sort of a cry for help really and trying to get somebody and something to try and help manage that and it’s just recognising that, I think, as well.” – P92, GP</i> <i>“I think they don’t like to present, so they leave it quite late and come when it’s really – they are at their wits’ end and then they’ll come” – P98, GP</i>
		2.1.2 Perceived stigma for parents about consulting a GP for	Some GPs describe the feeling that parents may be embarrassed to come to primary care, perhaps because they feel a sense of failure.	<i>“I think that’s possibly why I feel we perhaps only see the tip of the iceberg, because – I think there’s a lot of hidden – paediatric insomnia that doesn’t get voiced. I think people feel a little bit ashamed, perhaps, that they haven’t been able to foster good sleep patterns in their young child.” – P96, GP</i>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
		behavioural sleep problems		<i>"I think they probably feel a bit – like – well – I think there's different types: I think there's some people who are probably a bit embarrassed about it and probably don't come in and will seek people like sleep consultants rather than necessarily a GP" – P87, GP</i>
		2.1.3 Perception that parents do not think to come to general practice	Participants often describe that they believe many parents do not think of coming to general practice, either because they simply do not think about it, or because they think it is not something that the GP would/should deal with. Some participants related this to the covid-19 pandemic. Once, it was mentioned that parents may not think to come to HVs.	<i>"so I think it's actually a bit more common than – than – than most people believe it is. I don't think many – patients, many parents come to the GP with it, so actually I think it's viewed as not being a GP problem. I think a lot of people go to the health visitor; I think some people talk about it with nurses when they're doing immunisations, for example" – P94, GP</i>
	2.2 Chronic Insomnia is rarely consulted as a	2.2.1 Frequency of sleep problems as a key concern in general practice	Often GPs describe that it is rare for parents to come to GP consultation purely for chronic insomnia. Some said this is more common for those with young infants. Some participants	<i>"I think actual presenting to a GP with a sleep problem – to me – seems to be fairly infrequent; it would normally be, you know, alongside some other issue" – P96, GP</i> <i>"I would tend not to bring it up. I mean, like I say, I know from experience that we'll go through spells where the child maybe is a bit unsettled for a period of time and hopefully</i>

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Over-arching theme	Sub-theme	Codes	Description	Quote(s)
	single problem in general practice		say that they would rely on parents to bring up this issue, rather than proactively asking them, unless something else was going on that it may relate to.	<p><i>they nip it in the bud; so I would rely on the parent to raise it, if it was something that they're struggling with" – P99, GP</i></p> <p><i>"I think if you've got a small baby, then it's easy; parents often bring it up, you know, xxx or if they're presenting with postnatal depression, I definitely would bring up, you know, how's baby sleeping?" – P93, GP</i></p>
		2.2.2 Discussing sleep within other consultations	Many participants described either that sometimes parents may bring up sleep problems as an issue when consulting about another problem, or that they themselves will ask the parent about sleep when consulting about another issue. Some participants describe that it may be brought up in universal appointments, such as baby checks or during immunisations. Some HVs in particular described screening for sleep problems when they see the parents, regardless.	<p><i>"They may come for, you know, immunisations and have a question or something unrelated and say – while I'm here, I'm having this issue" – P99, GP</i></p> <p><i>"I don't think it comes very often as a presenting complaint. I think it often is discussed ... like I said; so the times that it tends to come up is either when you're talking to mum about mental health and, you know, parents kind of – it's usually mum, I have to say, but parents' – mental health and coping and that has really been a huge problem in the pandemic as well and I think that, you know, that's sort of part of it. And new mums and young – and, you know, parents with young children, at home with them and not sleeping and so on. So it kind of comes up in that context. And usually in the context is kind of behavioural issues or – fussy eaters, sometimes it kind of comes in with that. It's – I can't think of many examples, if any, where it's been the kind of primary reason to speak to a GP" – P95, GP</i></p> <p><i>"Often it's what they come about – or I guess sometimes they might come with a kid who's got an acute illness and they might mention that their sleep is terrible and you</i></p>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
				<i>might say, well – shall we talk about that another time or something and, you know, flag up that actually it is okay to talk about it and there might be things they can do” – P70, GP</i>
		2.2.3 Perceived as a common problem within health visiting	Some participants mentioned that it is a common presentation to HVs, or GPs described the view that it is probably a common presentation for HVs	<i>“in my experience it hasn’t come to me personally as a GP, but I can imagine it might present quite commonly to – say – health visitors and that sort of thing, as well.” – P91, GP</i> <i>“yes, it’s something that we come across a lot within health visiting” – P84, HV</i>
	2.3 Perceived limitations of health services	2.3.1 Differences in accessibility	Participants discuss differences in accessibility of health services. In particular, participants sometimes suspect that HV accessibility may be an issue, some describe particularly since the covid-19 pandemic.	<i>“Well I think ... GPs would probably be – so it depends whether the family has an accessible health visitor that they have a reasonable relationship with and sadly they – mostly won’t, because that’s – or they might find it hard to get hold of their health visitor, but they might have a really good health visitor who – who could be really, really helpful and sort lots of things out” – P70, GP</i>
	2.3.2 Perceived negative parental experiences of management	Some participants talk about health services (either general practice or health visiting) with view that parents sometimes get a negative experience.	<i>“I don’t often do anything except to refer them on and I just wish that I could just give them a little bit more support. Yes – probably – don’t do enough, at the moment to be able to help” – P97, GP</i> <i>“I don’t think currently we have much to offer families and there seems to be quite a sort of – a gap and that can leave families very hope – less really. So I do question whether</i>	

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
		2.3.3 Time limits in primary care	Some participants discuss the issue of time limits in primary care consultations, particularly GP consultations. E.g., with limited time they would prioritise addressing other issues, or they acknowledge that they cannot manage sleep problems in the limited time.	<p><i>we need to really review what – where we’re at with, you know, what the kind of scale of the problem is and what we could offer” – P71, HV</i></p> <p><i>“I also think it’s always so busy in primary care that – you know – it’s just another thing that – that can easily be brushed under the carpet and the same with the health visiting team in primary care – I think they’re so busy with child protection work, that sort of – the more minor end of it is often brushed under the carpet until it becomes a really major problem. And if it was sort of talked about earlier with parents, it would be much easier, but I just think the lack of time and ability to do that is really tough” – P93, GP</i></p> <p><i>“it can be quite a challenging thing to try and explore in a 10 minute consultation” – P87, GP</i></p>
	2.4 Views about missed opportunities to discuss sleep problems in primary care		Some participants, whilst describing that it is rarely brought up on its own in consultation, perceive that it is under recognised or underdiscussed, and that primary care would be a good place to address it if that was possible. One HV described that they were not sure all parents think to come to HVs.	<p><i>“I think it’s really important worth bearing in mind that it is something that we do need to know about and maybe it’s just something that is under – not asked about very often” – P90, GP</i></p> <p><i>“I think sometimes issues don’t get sort of mentioned and I fear that parents probably don’t understand – maybe – how vital it is to have good sleep hygiene and patterns for children, but also they just don’t know where to go to get support. So that would be my concern, that unless we, as professionals, really raise it, and the ASQ kind of makes us do that, but I think sometimes we are not very good at being proactive with parents” – P71, HV</i></p>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
<p>3. VIEWS AND EXPERIENCES ABOUT ADVICE AND RECOMMENDATIONS</p>	<p>3.1 signposting in general practice</p>	<p>3.1.1 Signposting or referring to other professionals</p>	<p>Most GPs discuss signposting patients on to the HV. Some talk about signposting to other professionals or about referring on to secondary care support. Some GPs describe that their signposting can be due to time pressures in general practice. Some participants say that they would not refer on to secondary care.</p>	<p><i>“I think – signposting to other professionals who can give more – sort of – detailed and ongoing support, like health visitors and children’s centres and the [parenting course] I’d also usually include in a management plan” – P96, GP</i></p> <p><i>“I think it’s something that could be worked on a lot. I think often it’s a case of – if I did come across something like that – referring on so – maybe referring to the community paediatrics team in the first instance or to health visitors or somebody else who might have more knowledge of the area or be able to help with managing these children” – P92, GP</i></p> <p><i>“You just kind of make sure they know where to get support; make sure that they know they can come back to discuss things with me, if they – feel like they need to or they feel like they want to” – P90, GP</i></p> <p><i>“as a GP, I think – I’d love to be able to spend more time on it but literally – because of the workload, it is very difficult to. So I suppose signposting patients and their parents to advice; in the early stages I think there’s very, very little support out there and so it becomes a really serious problem. And at that point probably there are referral pathways, but I think that there’s a lack of support and ability to signpost earlier. So I guess a sort of listening ear in an ideal world, signposting to something, but I’m not sure the facilities there exist. So I don’t think, as a GP, it’s my job to take it on or necessarily to</i></p>

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Over-arching theme	Sub-theme	Codes	Description	Quote(s)
				<p><i>advise the patients, but I think telling them what's out there and where they might find help is probably more my role" – P93, GP</i></p>
		3.1.2 Signposting to resources	Participants talk about directing families to other resources, such as support groups, books or websites.	<p><i>"locally, as well, there are – quite good support groups online, who are using social media, that I could direct parents to. And there are also some good, national websites as well, aren't there? I can't actually remember the names, but I'm sure there are some" – P90, GP</i></p> <p><i>"I know internet resources that can be helpful for it, and sort of signpost them to things that they can do themselves for self-help and management." – P93, GP</i></p> <p><i>"And then I may give them some resources or – it sort of depends if they are book reading type parents...or kind of websites or Facebook groups. And, you know, signpost them that way" – P95, GP</i></p>
	3.2 Basic advice, bedtime routines and other components of sleep hygiene	3.2.1 Advising about basic / primary advice	Participants describe giving initial advice	<p><i>"either offer – immediate sort of advice or knowing how to signpost them to ongoing support" – P89, GP</i></p> <p><i>"my role is very – very much supportive, obviously giving the usual routine information about how to – just really simple things – to try and help them combat the insomnia. And again, actually – I don't really mind discussing in depth with parents and if that's not working, move them on to the health visitor who can actually provide more contact support than I can" – P86, GP</i></p>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
		3.2.2 Advising about bedtime routines and other components of sleep hygiene	Most participants describe advising families about sleep hygiene and components of sleep hygiene, often bedtime routines. One GP mentions the use of a sleep hygiene map as a resource. A HV spoke of videos about sleep hygiene provided online by a Trust during the pandemic.	<p><i>"I mean – so – yes, just briefly – minimising screen time, making sure there's plenty of calm down time; making sure there's a good bedtime routine so the child knows what's happening, using calming lights, calming – music or CDs, relaxation CDs, that kind of thing and – a period of parental time to help them calm" – P82, GP</i></p> <p><i>"Sleep hygiene as well; so I think it's – talk about the kind of wind down routines and then putting children to bed when they feel naturally tired, rather than trying to force it, but also good routines, as well" – P89, GP</i></p> <p><i>"the main things are making sure that the parents have got some routine, which I guess is actually really difficult when you've got more than one child of different ages. Making sure that – that you actually also have some healthy habits yourself, you know, getting into routines. ... As I said, you know, bed time, not having too much television, reading a story before bed." – P86, GP</i></p>
		3.2.3 Advising on parental approach	Participants often describe the importance of a consistent parenting approach. They acknowledge that parenting approaches are different but emphasise consistency.	<p><i>"... and also, yes, I mean, you know, are there different elders in the home; are the parents trying to do a certain way and maybe if there's grandparents in the home, are they maybe, you know, following a different approach, which is then resulting in inconsistency, and really just trying to get a more – see if they can instil a more consistent approach between the adults in the home" – P99, GP</i></p> <p><i>"I think consistency is one thing that I try and impart as being important, so that the child, you know, does – you don't backtrack all of a sudden, if you get very, very tired one</i></p>

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Over-arching theme	Sub-theme	Codes	Description	Quote(s)
				<p><i>night and suddenly you're back to square one again, if you see what I mean (I: Uh huh)</i> <i>So trying to have consistent parenting and consistent behaviours that are helpful" – P96, GP</i></p>
		3.2.4 Parental education	<p>Some participants talk about giving parents information, for example what is and is not normal for their child, or about what might be worsening the sleep problem.</p>	<p><i>"The only thing that I do think is quite good to point out to parents is how much sleep children of different ages – ideally require, because I actually think that that is overlooked sometimes and I – I never appreciated how much sleep a baby, for example, actually does need – and techniques to facilitate achieving that" – P83, GP</i></p>
	3.3 Assessing the situation	3.3.1 Assessment	<p>All participants talk about their assessment of the families situation to build a picture of what is happening. E.g. how has the sleep changed, what are their routines at night, what have they already tried. Participants talk about using resources such as sleep diaries. One participant mentions a questionnaire that helps highlight sleep problems</p>	<p><i>"So I try and explore, you know, what's been going on; how has it changed, what other – try and take a bit of a history of what exactly is the pattern of sleep or the difficulty that they're having. What are the sleeping arrangements; what's the family arrangements: is the problem at home or is it elsewhere? Although at the moment it's always at home, isn't it, but – and – and just kind of get an idea of what the child's behaviour and things like – whatever childcare setting and things like that. And then, yes, and then also kind of – I'd normally discuss their – yes – their routine and their – like what's a normal day, what's a normal bedtime; what's a normal night" – P95, GP</i></p>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
		3.3.2 General practice as a role to look for underlying causes	Many participants talk about a GP role of excluding other conditions or causes to the sleep problem.	<i>“Another key thing I would see as my role, would be to sort of drill down for any sort of underlying conditions or associated disorders that might be going on and presenting in this way; so that sort of diagnostic sieve sort of approach of looking to see if it is just that on its own, as the problem or if it’s indicative of something else going on that might need some further investigation or treatment or what have you.” – P91, GP</i>
	3.4 Beliefs supporting an Individualised approach to management		Many participants talk about the necessity of an individualised approach to consultation and management. E.g. one approach might work for one family but not for another. Some participants seemed to talk about the impact of the age of the child or whether parents are new parents, either for making various management recommendations, discussing the issue with parents, or in signposting to other professionals	<p><i>“I would acknowledge though that there are many – there are many ways of – trying to promote change of sleep patterns and each individual family unit and child may well find an individual path that’s suitable for them” – P96, GP</i></p> <p><i>“I suppose it depends, it depends really on the child and the age of the child and on the parents and their view on parenting. Again, I think how people want to address insomnia in children, at the milder end, comes down very much on to their parenting philosophy. So I don’t think – there’s not one size fits all and what’s a problem to one person might not be to another. So I think I’d probably explore sort of what their parenting philosophy was and what their ideas on it were, before I direct them. If they were more of an attachment parenting – and didn’t believe in – making behavioural changes through leaving the child, then I think that’s perfectly understandable and I’d have a different approach to somebody who was keener to go down more of the sort of behavioural approach.” – P93, GP</i></p>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
	3.5 Views and recommendations about specific strategies	3.5.1 Suggesting behavioural interventions	Some participants (some GPs, all HVs) talk about recommending specific behavioural interventions, or state that they might recommend some behavioural techniques	<p><i>“So things like – when they’re really young, would be things like controlled crying ... and that’s the main one and then also – reward charts when the child is a little bit older; those are the two main ones” – P98, GP</i></p> <p><i>“And then as children are getting older, yes, trying to establish about routines and I probably have done about the gradual retreating – strategies too, because I think that’s probably what the health visitors would say, from about 6 months on.” – P89, GP</i></p>
		3.5.2 Perceptions of extinction methods	<p>Out of those who talk about their opinions on extinction techniques, most participants describe that they do not agree with cry-it-out techniques, or that they prefer gradual or graduated extinction to full cry-it out. Often the participants describe that they opinions are based on personal preference rather than a professional opinion.</p> <p>Some of the participants agree with controlled crying and believe it is effective</p>	<p><i>“I personally – I would never, ever suggest to leave a baby crying. What do they call that? Controlled crying. It’s something that ... I don’t know I think, from my understanding, I think it can really affect children in that, you know, going forward, and I don’t think that is necessarily a good kind of strategy to use. However, I think that – it sort of depends, doesn’t it; it depends on the situation. I think that in certain cases, to go away and have a breather is one thing, but to kind of leave your baby crying for an extended amount of time, I would definitely sort of advise not to” – P95, GP</i></p> <p><i>“I think another method that is encouraged is – let your children cry it out. So if the child wakes up to actually just leave them to self soothe in that way. I find that a bit extreme. I try not to judge people if they do choose to use that method; I’m aware that it does work for people. It’s not something I personally feel so comfortable with, particularly for very young children. I’m more moved towards the sort of – gradual withdrawal” – P96, GP</i></p>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
			HVs describe the belief of the effectiveness of gradual retreat	<i>"I mean ... the one that seems, in my experience personally and professionally – controlled crying is really effective...And just sort of talk through with people that – yes – it might be hard, but, actually, they won't come to any harm and everybody is coming to harm now, from not having a sleep" – P70, GP</i>
		3.5.3 Views about cosleeping	One participant discussed their view of cosleeping; understanding that it works for some families but emphasises the importance of adhering to safety guidelines.	<i>"With regards to things like co-sleeping. I would usually give kind of recommendations in terms of what the – is it the Lullaby Trust, suggest signposting parents to that, in terms of like are they risky, in terms of are they smokers and so on, but, and I would kind of stick to the guideline recommendations with regards to co-sleeping, but I wouldn't – I wouldn't dismiss it if it's right for that family and if the risks have been addressed" – P95, GP</i>
		3.5.4 Views about pharmacological treatment	Often GPs described that they would not prescribe pharmacological treatment. Some did, or thought it would be better to be able to. Some even said that they preferred behavioural treatment over pharmacological treatment. Some participants describe how parents will come to consultation looking for medication to solve the problem,	<p><i>"I mean I certainly wouldn't be medicating them, you know; I think that's the last resort for anybody, and certainly not a primary care role, so that would certainly come from the secondary care." – P93, GP</i></p> <p><i>"I think there's the pushing for medication – is always the problem and sort of trying to rationalise why I'm not going to start it" – P86, GP</i></p> <p><i>"So usually it's non - non-prescription, so non-pharmacological; it would be more, you know, behavioural techniques really" – P99, GP</i></p>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
			which is not something they would prescribe.	<p><i>"It usually doesn't involve a prescription, so that's quite nice, as well, and you might be sort of empowering the family to do something itself, which is kind of nice, that you're sort of giving them - I hate to say giving control – it sounds a bit Brexit-y – but you know what I mean; you're giving them more control over what's going on at home, which is good..." – P70, GP</i></p> <p><i>"occasionally ... people like to try like an antihistamine or something like that to – in a bigger toddler, for a short term, which can you know, or if this kid that's had a good pattern but got out of it after illness or some sort of change in the family or circumstances..., then that might be a way, just for a week, just to sort of try and get them back into the pattern, into the habit of sleeping okay. So it depends whether they've always had the problem or whether they've – something's happened to get them out of their routine" – P70, GP</i></p>
	3.6 Emotional support and management of the impact on parents	3.7.1 Acknowledging the difficulties and being empathetic	Often participants talk about the importance of acknowledging the problem for parents and acknowledging their struggles.	<p><i>"I think acknowledging the problem is a big step, so parents can, so having empathy for the fact that it is – if they're sleep deprived, the parents, that it is life is very tough, especially if they're working (I: Mmm) and the relentlessness of it and I think just supporting them and try to give them some strategies that may or may not help" – P83, GP</i></p> <p><i>"acknowledging – what they're experiencing: listening to the story" – P89, GP</i></p>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
		3.7.2 Management of the impact on parents	Some participants talk about their management of the parents, either for impact on the parents, or because they have mental health struggles	<i>"... actually in the end, I don't think I did anything about the baby and I just managed mum" – P97, GP</i>
		3.7.3 Encouraging parental acceptance or managing expectations	Some participants seem to reiterate to parents that poor sleep is sometimes normal and then and that it's important to persist. They sometimes reiterate that it's not quickly solved.	<i>"I think if a child was under 6 months, a lot of it is adjusting parental expectations to infants' sleep and I think particularly in first-time parents, there's a lot of talk out there and people ready to say their baby's sleeping through at 8 weeks, but I think sometimes a lot of what my role is – is just adjusting expectations that actually – that's probably not normal and it is perfectly normal to be up with a child of that age a couple of times a night" – P93, GP</i>
		3.7.4 Providing reassurance or empowerment	Reassuring parents about what is / is not normal, that it is ok to present to primary care, or that sleep problems can be managed	<i>"Perhaps also acknowledging if a sleep pattern isn't, you know, something that has to just be accepted, is something that could be influenced or changed or promoted in some way, rather than just accept it as that's the way it is, that's normal... I think sometimes – sort of – saying to a parent who is struggling with a sleep problem – it's okay to just sort of cope with this at the moment until we're at a point that you feel that you can actually purposefully intervene with it and give that sort of – yes – that sort of reassurance that it's okay to – you need to tackle it but it doesn't have to be tonight, if you like; you have to sort of gear yourself up for it and be ready to tackle these changes" – P96, GP</i>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
		3.7.5 Importance of a good patient-doctor relationship and communication	Participants discuss the importance of honest, non-judgemental communication from themselves to the patient. One participant talks about the impact of a good patient-doctor relationship	<p><i>"I think my role would be – a sort of supportive, signposting kind of role, I would imagine. So – so – yes, being supportive, listening, active listening, showing sympathy and empathy and taking seriously and validating the experience" – P91, GP</i></p> <p><i>"I think it all boils down to the relationship a practitioner has with the patient and the family. I mean that really is key because, you know, if you haven't got that, then patients will not declare these things going on in their lives" – P99, GP</i></p>
	3.8 Awareness of non-healthcare resources		Some participants are aware of non-healthcare resources that parents might also use, such as friends, family, online resources and books, and they have mixed opinions of them.	<p><i>"so you've got the informal sources of support, obviously extended family and friends who have been through this; usually that kind of helps with most cases of managing sleep problems. Of course there is the media, what's available out there, in terms of self help resources and TV etc" – P95, GP</i></p> <p><i>"I'm fairly sceptical about anything that I have come across, parenting manuals, because – because I've not really seen them [slight laughter] work. But – and also I'm not sure about whether there is really – sort of – often these are sort of sold as a one size fits all method and I'm not sure that's – I think that's selling a bit false hope, really and I'm not sure there is an easy answer often to these things." – P91, GP</i></p>
	3.9 Follow ups in health visiting		All HVs mentioned that they provide a follow-up (either for a more detailed assessment/management	<p><i>"If there's time – I tend to try and do a follow-up visit or a follow-up call, as well and I think those experiences work better then, because the parents have then got someone they can sort of turn to and relate to, you know, relate to and support them, as opposed to just kind of...having a 10 minute slot" – P84, HV</i></p>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
			consultation, or as a follow up to see how parents are getting on)	
	3.10 Mixed views about referral and secondary care		Few participants talked about sleep clinics or referral to secondary care. Some participants described either that there are no sleep clinics in the area or that there are no clear referral routes. Some other participants mentioned the use of sleep clinics or secondary care (either as a referral or to ask for advice).	<p><i>"I don't think I've ever done a referral purely for insomnia and largely because one there are no sleep clinics, and if there are, they don't – they don't seem to be able to do anything more than we can, so I don't think I've ever used them" – P81, GP</i></p> <p><i>"I had to refer them to the paediatrician because they'd tried everything" – P94, GP</i></p>
4. VIEWS REGARDING ROLES OF DIFFERENT PCPS IN THE MANAGEMENT OF	4.1 Perception that primary care should address chronic insomnia		Participants describe seeing primary care as important to address chronic insomnia. One participant described that experience is more important than type of PCP. Some described the importance of collaboration between professionals	<p><i>"I think we are well placed to give advice and reassure in a lot of cases; so, yes, I think we have quite an important role there" – P99, GP</i></p> <p><i>"I don't think it terribly matters like what the profession of the person is, more what their – what their level of experience and confidence is in that problem. So – you know – I don't think it could be – I don't think you could say that it should be a GP or it should be a health visitor or something like that; I think it would have to depend on the individual practitioner, as to what they can bring to that problem" – P91, GP</i></p>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
CHRONIC ISOMNIA IN CHILDREN				<i>"I think it's really important. I'm not sure if it's something that is just managed in primary care, because maybe it's a collaborative approach between different services" – P90, GP</i>
	4.2 Perception that HVs or other community support are suited to management	4.2.1 Health visiting before general practice	Often GPs describe that the problem should be taken to the HVs first, or they describe that they should signpost to health visitors. This is also impacted by age of the child.	<i>"I think it's – I think people – mums, dads – would probably turn to health visitors before their GP and/or nursery workers, you know, or childcare settings and probably the internet as well, before they speak to us" – P95, GP</i> <i>"I think it's a secondary role: I think primarily it should be addressed. If a child is under 5 by the health visitor and then if after that or if the child is older, then, of course, the child will come to me and also the practice nurse as well" – P98, GP</i>
		4.2.2 Perception that HVs or other community care have an important role in management	Often participants described that HVs or other community support (e.g., nursery nurse, parenting course, children's centres) would be approached by parents and/or better suited. This is sometimes described as due to more continuity, time or knowledge. sometimes participants thought HVs and GPs are equally suited. HVs described that they believed it is part of their role	<i>"I wonder whether it would be more up to health visiting or children's nursing teams to help" – P89, GP</i> <i>"I think it's something that could be worked on a lot. I think often it's a case of – if I did come across something like that – referring on so – maybe referring to the community paediatrics team in the first instance or to health visitors or somebody else who might have more knowledge of the area or be able to help with managing these children" – P92, GP</i> <i>"I suppose from nursery, or nursery nurses, or if the kids are at an educational setting or nursery setting; I expect they try to seek support from there, too" – P89, GP</i>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
	4.3 Mixed views around the role of general practice	4.3.1 Perception that GPs are not best placed for management	Some participants described that they specifically thought general practice wasn't the best place to manage sleep problems	<p><i>"I think it's important to address it, but whether in primary care, who it's delivered by I think is a – I'm not sure if GPs are the best place to do it." – P89, GP</i></p> <p><i>"I think in the consultation you can often feel that, you know, perhaps you're not necessarily the best placed person to be giving ongoing management for this" – P96, GP</i></p>
		4.3.2 Some views that GPs are suited to manage chronic insomnia	Some participants described that GPs are either more suited to management, or that they are suited alongside HVs.	<p><i>"GPs would probably be – so it depends whether the family has an accessible health visitor that they have a reasonable relationship with and sadly they – mostly won't, because that's – or they might find it hard to get hold of their health visitor, but they might have a really good health visitor who – who could be really, really helpful and sort lots of things out. But otherwise, they will often come to the GP first. And so it's about signposting them if there is a health visitor or just advise them. I mean a lot of the time it's – it's – it's a couple of conversations with them, really, that – that you need and direct them to some advice in a book or online or wherever" – P70, GP</i></p>
		4.3.3 Some parents happy to go to GP	Some participants describe that parents can come to the GP before the HV	<p><i>"I think ... parents feel that it's the right thing to do, to visit me. We all know that in primary care we are asked about a multitude of things. Actually it seems to be more of a default, isn't it, you know – to go to see your doctor about literally anything from, you know, help with blue badges to – something related to, you know, taxes and bills. So, yes, a default, I think, for many parents would be speak to a GP first and they would be quite happy to do so." – P86, GP</i></p>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
5. LIMITED PROFESSIONAL TRAINING AND KNOWLEDGE REGARDING CHRONIC INSOMNIA IN CHILDREN	5.1 GPs receive minimal or no professional training about paediatric chronic insomnia		Many GPs talk about having had no professional training on this topic at all. Some GPs talk about remembering some training but cannot clearly remember what the training was.	<i>“on a professional level, I’ve had zero training on it, to be honest” – P93, GP</i> <i>“I think I’m – the amount of actual teaching we get about this – is very, very small. I remember having one lecture about sleep and children’s sleep and – only one that springs to mind, now I think back. And that was probably postgraduate teaching; I’m sure as an undergraduate I did some but I can’t really remember” – P95, GP</i>
	5.2 Specialised training options for HVs		All HVs described training opportunities that (or HV colleagues) had been given. They all spoke positively about the training. Some described a training course that they had accessed which was not provided by their organisation, although sometimes funding is difficult. Some also described	(quotes not provided to ensure that the participants are not identifiable)
	5.3 GPs perceive limited or varied knowledge for management		Many GPs say that they have very little or limited knowledge about this topic. Some participants specify to say that they feel knowledgeable or	<i>“I feel I have sort of – general common sense knowledge about it but I wouldn’t say that I feel I have any additional medical knowledge about it” – P96, GP</i> <i>“I: how much knowledge and understanding do you feel that you have about managing children’s chronic insomnia? P89: Errr, errr – on a scale of 1 – 10, about 2 or 3”</i>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
			somewhat knowledge for basic management, but not for anything further. Some GPs describe feeling knowledgeable. All HVs described feeling knowledgeable, but some acknowledged they would like more knowledge.	“I: how much knowledge and understanding do you feel you have about managing children’s chronic insomnia? P: I’m not sure how to measure that. ... Some – enough, maybe.” – p70, GP
	5.4 Knowledge from practical experience		Some participants talk about gaining some knowledge from practice, or where cases have prompted them to research it themselves. All HVs and one GP mentioned that they use the knowledge of colleagues by discussion with them (either on a case-by-case basis or in supervision).	<p><i>“I think all of it is just what you pick up as you go along and then personal experience” – P93, GP</i></p> <p><i>“It’s basically whatever I’ve read about it, after that case” – P94, GP</i></p>
	5.5 Need for information resources		Many GPs discuss how it would be useful to know of specific evidence-based resources / official websites that they could signpost families to, or of information resources that they could use either themselves to	<p><i>“I know patients will often be engaging with other sort of web resources or web platforms that might be giving fairly conflicting advice or maybe giving confusing advice and, at the moment, I wouldn’t feel I would know any particular resource I could necessarily signpost them to, that I know will be able to give – legitimate advice, if you like, approved advice and so that might be helpful to be able to signpost somebody to.” – P96, GP</i></p>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
			improve their knowledge or use as a guideline/algorithm in consultation. One HV described not needing further resources and another described a wish for more objective sleep assessment measures	<i>"I think what could make it easier is – if I did know a little bit more or if there was a clear – primary care guideline that I was aware of, that would tell me, right, first of all, try this: next, do that, next do this; some such framework to plan on, that would be helpful." – P91, GP</i>
	5.6 Interest in future professional training		Many participants discuss that future professional training would be useful, however their views on the level and types of training differed.	<i>"I think – rather than having extensive training for GPs, I think having an overview would be helpful, of the sort of strategies that perhaps would be advocated and the sort of assessment and management that would be advocated" – P96, GP</i> <i>"I really think it should be part of – GP training, for sure" – P94, GP</i> <i>"probably like a little short webinar or – online – like an e-learning or ... even just – a leaflet, I don't know; anything. I'd be grateful for anything" – P97, GP</i>
	5.7 Uncertainty around usefulness of further professional training		Some participants talked about an interest in training but uncertainty in the need for it either due to the infrequency in consultations, the view that it should be managed elsewhere or due to time pressures. A HV described not needing extra training.	<i>"I don't know. I think it's one of those things that it's probably so individual from one family to another, that specific training might not be terribly helpful and I think if – you know – if you've got sort of quite a lot of basic advice you can give and they're not progressing, I think they probably do need specialist input really, because – yes – to individualise it." – P82, GP</i>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
6. PERCEIVED SELF-EFFICACY FOR MANAGING CHRONIC INSOMNIA IN CONSULTATION	6.1 Mixed confidence levels	6.1.1 Limited confidence	Some participants describe a lack of confidence	<p><i>“My level of confidence is not that good” – P98, GP</i></p> <p><i>“I would feel a bit out of my depth, I think it’s fair to say. So it’s one of those sort of issues that I would know that I don’t know a lot about or very superficial knowledge of, professionally. So I would – so it wouldn’t be a very comfortable discussion for me to have. I think I could explore it, no problem, and talk about it and listen to it, but I would be feeling that feeling of (a) pressure to do something and (b) knowing that I don’t know what to do” – P91, GP</i></p>
		6.1.2 Feeling confident for behavioural management	Some participants describe feeling confident (some GPs, all HVs)	<p><i>“Yes, I must say – I feel quite confident and capable to – to manage and I know when I need to maybe ask for outside help; so I feel quite confident” – P99, GP</i></p> <p><i>“Yes, I think I’m fairly confident” – P92, GP</i></p>
		6.2.3 Confident for basic advice, but unconfident for in depth management	Some participants specify their confidence is different in different situations. E.g. they are confident with basic advice/management, but their confidence is less with more in-depth management.	<p><i>“I’d say ... low to medium, in that if there are things that – that I’ve found that I can make suggestions and say let’s try that, or, you know, these are things to try, as though I was a listening ear, for you know a few weeks and then re-review them, I think, fine, I’ll probably be reasonably confident with that, but if – if I – you know – certain suggestions or ideas we get nowhere, I think I’d be – I think I’d reach my limit quite quickly, if that makes sense” – P87, GP</i></p> <p><i>“I think I’m fairly confident in – in having a basic discussion and, you know, finding out what’s going on and advising things that they can try and reassuring the parents but I</i></p>

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
				<i>think if they were still really struggling, I think I'd want to get somebody else to see them" – P82, GP</i>
	6.2 Perceived barriers to managing sleep problems in consultation	6.2.1 inability to solve the problem quickly	Some participants describe how this type of problem is not something that can be fixed easily. Some participants talk about perceived pressure from parents to be able to solve it quickly.	<p><i>"I also feel a bit lost because – what can you do? I can't just reach for my prescription pad like I would for everything else: not for everything else, but not for the problem." – P97, GP</i></p> <p><i>"It's just quite frustrating when – I suppose – I can think of the odd occasion when families – it's just not working, things aren't – are not – well I think, as families get more and more stressed, it's difficult to maintain the sort of – trying to keep it proportional, trying to keep it – rather than making it a very upsetting time and everyone dreading the kind of – the bedtime routine, because they just know it's going to be another battle" – P89, GP</i></p>
6.2.2 Perceived pressure to solve the problem		One participant talked about a perceived pressure from parents for GPs to solve the problem	<i>"I think we often feel a pressure on us to be seen to be doing something about it" – P91, GP</i>	
6.2.4 Influence of parental resistance, misunderstanding or readiness to		Participants talk about how sometimes it could be difficult if parents are unwilling to discuss it, change behaviours or try different strategies. One participant talked	<p><i>"I occasionally get a negative experience of somebody who – doesn't really want to do that and thinks that there must be a – pharmacological solution, although I have to say – that isn't that often that people want to do that" – P70, GP</i></p> <p><i>"I think when someone says – I've tried everything, it's really important to explore that a bit, rather than just take it at face value." – P87, GP</i></p>	

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
		discuss and change	about the influence of parental motivation	
	6.3 Positive feelings towards the consultation		Some participants talked positively about the consultations	<i>"I feel fine. [Laughter] It's ... it's not necessarily a particularly difficult consultation; it's quite nice, like I said, because actually there's stuff that you can do that might help and might make quite a long-lasting difference to the family's and the kid's life."</i> – P70, GP
7. THE INFLUENCE OF THE PERSONAL EXPERIENCE OF BEING A PARENT	7.1 Personal experiences Influence feelings and attitudes	7.1.1 Sense of empathy 7.1.2 Impact on confidence	Some participants describe that having their own children has influenced their understanding and attitudes towards paediatric insomnia or it helps them empathise. Some talk about how it has influenced their confidence in professional management, or how it has influenced their perception of health services such as health visiting.	<i>"I think my compassion is more, having had children myself and, you know, understanding struggles that parents go through, because I think until you've had children ... you know, you just think, oh, that's – you know – what were you expecting, that's normal. [Slight laughter] And to a degree, you know, being told that it's – that is normal – to an extent, you know, can help, but also having somebody who understands that it can make you feel – really – sometimes quite depressed or anxious or ... you know, like I said, it can affect your relationship and all of those things."</i> – P95, GP
	7.2 Knowledge acquired through personal experience rather		Many participants describe that most of their knowledge is acquired through personal experience, rather than through professional training.	<i>"it's something that I haven't – come across a lot, in terms of – as part of my training and as part of my career. So it's something that I think is – I've learnt most about probably, in terms of sleep routines and patterns with children, through having my own children, rather than actually through my – my training"</i> – P92, GP

Over-arching theme	Sub-theme	Codes	Description	Quote(s)
	than professional training			<i>"I feel like if I had kids, I would know more. So GPs who have kids definitely know more. So I was a bit unsure." – P94, GP</i>
	7.3 Discussing personal experience in consultation		Some GPs talk about how they might share their personal experiences in a consultation, either to recommend strategies or to improve the patient-doctor relationship.	<i>"you might be able to share a little bit about your own personal experience, which people – you know – as long as it's appropriate - people often quite like. And then you can say – I had this, it kind of makes them feel that you understand what they're talking about, at least, rather than just not having a clue." – P70, GP</i> <i>"if I felt it was appropriate, then I would give my own personal experience of managing my own child" – P90, GP</i>

C.5 Triangulation of the survey and interview findings

Research question	Contextual theme	Quantitative findings	Qualitative themes	Convergence code
Explore PCP views about chronic insomnia in children	Views about the impact of chronic insomnia in children	Impact of chronic insomnia on various domains (ratings average between 3.4 and 4.7 out of 5, from 1 no impact to 5 major impact)	Sub-theme 1.2: Views about multiple impacts of poor sleep on the family (common theme)	Agreement

		Agreement with impact on children and family: >86% agreed or strongly agreed		
	Views about whether it should be managed in primary care	>80% and >67% agreed or strongly agreed it should be managed in health care, and in primary care, respectively	Theme 4: Views about management roles within primary care Sub-theme 4.1: perception that primary care should address chronic insomnia	Agreement.
	Views about management roles within primary care	For managing children’s chronic insomnia, participants rated parents and PCPs from a rating from 1 (least important) to 6 (most important). The parents were most often selected as the most important (modal response of a rank of 6) and 51.9% of the sample ranked the parents as 5 or 6. Similarly, 51.2% of the participants ranked HVs as 5 or 6 (most or second most	Sub-theme 4.2: perception that HVs or community support are more suited to management Sub-theme 4.3: Mixed views around the role of general practice	Mostly agreement, though there is some disagreement where some survey participants reported that parents and HVs were less important

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		<p>important), although the modal response was a rank of 5.</p> <p>% who rated 5 or 6, and modal responses were lower and more varied for the other items.</p> <p>However, some participants ranked parents and HVs as less or least important: 29.3% of those who ranked parents ranked them as the least important. 25% of those who ranked HVs ranked them as the second least important.</p>		
	<p>Views about behavioural and pharmacological management of chronic insomnia in children</p>	<p>>90% agreed or strongly agreed it should be managed with behavioural interventions, compared to 21.5% for pharmacological approaches</p>	<p>Sub-theme 3.5: Views and recommendations about specific strategies (relevant codes within were ‘suggesting behavioural interventions’ and ‘views about pharmacological treatment’)</p>	<p>Agreement</p>

	Beliefs about frequency of sleep problems in children (independent to healthcare)		Sub-theme 1.1: Views that sleep problems are common in children	Silence – not explored in the survey
	Causal factors to sleep problems		Sub-theme 1.3: Perceptions about causal factors of sleep problems	Silence – not explored in the survey
	Beliefs about the importance of sleep		Sub-theme 1.4: Emphasis on the importance of sleep	Silence – not explored in the survey
	Labelling and defining sleep problems		Sub-theme 1.5: Subjectivity around defining sleep problems	Silence – not explored in the survey
	Normalisation of sleep problems	Advise the problems will resolve over time: 26.9% to 46.9% would recommend this most or all of the time	Sub-theme 1.6: Normalisation of some sleep problems	Agreement

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	Complexity of the problem		Sub-theme 1.7: Viewing poor sleep as a complex issue	Silence – not explored in the survey
	Feelings and attitudes		Sub-theme 7.1: Personal experience influences feelings and attitudes	Silence – personal experience sub-group analyses not explored in the survey
Understand what PCPs currently know about chronic insomnia in children, and how much formal education they	Experiences with professional training	<p>No teaching during professional training: 84.8%</p> <p>52% felt they should have had more</p> <p>No opportunity since qualifying: 79%</p> <p>Attendance for those who had opportunities since: 51.2%</p>	<p>5.1: GPs receive minimal or no professional training about paediatric chronic insomnia</p> <p>5.2: Specialised training options for HVs</p>	Agreement for GP data. Partial agreement for HVs

have received on the topic during (and since) training	Interest in further training	Given the chance, 80.3% would like access to further opportunities	5.7: Interest in future professional training 5.8 Uncertainty in usefulness of further professional training	Agreement, with further information in the interviews
	Knowledge	% of participants scoring correctly on individual items ranged from 24.3 to 77% Nearly 70% were not aware of other resources for parents	5.2 GPs perceive limited or varied professional knowledge for management 5.4 Knowledge from practical experience 7.3 Knowledge acquired through personal experience rather than professional training	Agreement, with further information in the interviews
Explore PCP's current practice regarding management of	Frequency of consultation	Rarely: 40.6% Sometimes: 42.5%	Sub-theme 2.1 Perceptions of parents' reluctance to consult in general practice Sub-theme 2.2: Chronic insomnia is rarely consulted as a single problem in general practice	Agreement with further information from the interviews

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children's chronic insomnia			Sub-theme 2.3: Perceived limitations of health services	
	Who brings up the discussion	58%, 73.2% and 80.2% reported the family, for 0-6 months, 6-12 months, and 1-5 years respectively	Brought up by family or by PCP in other consultations	Agreement
	Reasons for infrequency		Theme 2 (and sub-themes within): Chronic insomnia is infrequently a primary reason for consulting in general practice	Silence – not explored in the survey
	What PCPs use/do to help consultation	Most chosen (n=258): discussion about sleep history Followed by personal experience (n=174) Followed by sleep diary (n=145)	Theme 7: The influence of the personal experience of being a parent. Sub-theme 3.3: Assessing the situation	Agreement
	Recommendations/action	>85% recommend positive bedtime routines most or all of the time, in all age ranges	Sub-theme 3.2: Basic advice, bedtime routines and other components of sleep hygiene	Agreement

		Referral: 13.3% to 26.9% would recommend most or all of the time	Sub-theme 3.9: Mixed views about referral and secondary care	Agreement
		Extinction-based techniques. Softer techniques had higher %'s than unmodified extinction, however needs significance testing	Relevant codes within sub-theme 3.5 Views and recommendations about specific strategies	Partial agreement
		Scheduled awakenings: 25.1% to 31.6% would recommend most or all of the time		Silence
		Pharmacological: <10% would recommend most or all of the time	Relevant codes within sub-theme 3.5 Views and recommendations about specific strategies	Agreement
		Advise the problems will resolve over time: 26.9% to 46.9% most or all of the time	Some PCPs reported that for some children it gets better over time	Partial agreement – further information in interviews
		No recommendation: <10% would recommend most or all of the time		Silent

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		Other		
			Sub-theme 3.1: Signposting in general practice	Silence – not explored in the survey
			Sub-theme 3.4: Beliefs for an individualised approach to management	Silence – not explored in the survey
			Sub-theme 3.6: Emotional support and management of the impact on parents	Silence – not explored in the survey
		Nearly 70% not aware of other resources	Sub-theme 3.7 Awareness of non-healthcare resources (little evidence-based resources mentioned and little mention of signposting them)	Partial agreement – further information in interviews
			Sub-theme 3.8: Follow ups in health visiting	Silence – not explored in the survey

	Perceived self-efficacy	Confidence ratings most commonly 3 out of 5, from a scale of 1 (not confident) to 5 (very confident)	Sub-theme 6.1: Mixed confidence levels	Agreement, further information in interviews
			Sub-theme 6.2: Perceived barriers to managing sleep problems in consultation	Silence – not explored in the survey
				Sub-theme 6.3: Positive feelings towards the conversation
Explore PCP perceived unmet needs regarding managing children’s chronic insomnia	Unmet needs for training	52% felt they should have had more training during professional training	Reported minimal/no training previously. Interest in appropriate brief training opportunities.	Agreement, further information in interviews
	Unmet needs for resources		Sub-theme 5.5: Interest for information resources	Silence – not explored in the survey

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<p>Find out whether there are any particular types of support tool that PCPs would like</p>	<p>Training</p>	<p>Given the chance, 80.3% would like access to further opportunities</p>	<p>Sub-theme 5.7: Interest in future professional training Sub-theme 5.8: Uncertainty in usefulness of further professional training</p>	<p>Agreement, further information in interviews</p>
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