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TAILORED HYPNOSIS TREATMENT FOR PRIMARY NOCTURNAL ENURESIS IN CHILDREN AND YOUNG PEOPLE

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Declaration

I declare that the research reported is my own and not submitted for any other academic award.
Title: Tailored Hypnosis Treatment for Primary Nocturnal Enuresis in Children and Young People

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Abstract of the Portfolio

Section A examines the association between nocturnal enuresis (NE) and Quality of Life (QoL) in children and young people. This paper systematically reviews the research literature in this area considering relationships between NE and QoL across demographic variables such as gender and age. Future research avenues and implications for clinical practice are discussed.

Section B reports on a tailored hypnosis treatment for children and young people with NE. This used a prospective case series with multiple-case AB design with follow-up, and tested the hypothesis that this approach would increase number of dry nights. Changes in child and parent psychosocial variables were also examined. Results indicated that participants improved in nighttime dryness as predicted, and that improvements were sustained at follow up. Self-reported continence specific QoL showed improvement approaching significance from baseline to follow up. Mixed results were found as to changes in other psychosocial variables as a result of treatment. Limitations of the research and its implications are discussed.

Section C is a critical appraisal of the research process as a whole, covering issues such as choice of research and how this developed through clinical practice, training and previous research experiences. It explores issues across the research process at individual, team, systems and organisational levels. It provides a critique of the design and methodology, as well a reflection on personal and professional development.

Section D reports on the results of a local questionnaire based service evaluation examining young people’s views of their paediatric diabetes clinics; including examples of good practice valued by young people. It also reports young people’s opinions and ideas about possible future service provision. It makes clear recommendations as to the ways forward in service user led service development.
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Section B: Research Report
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Section A: Critical Literature Review
A Review of the Association of Quality of Life and Nocturnal Enuresis in Children and Young People

Word count: 6034
Abstract

Background: Nocturnal enuresis (NE) in children and young people has been found to be associated with psychosocial difficulties, including quality of life (QoL) deficits. This paper systematically reviews the research literature in this area.

Method: Electronic searches of most commonly used medical and psychological databases were undertaken using search terms describing the target condition and target population. Search terms were applied to title, abstract and full text of articles to ensure inclusivity. References lists of key papers were also searched exhaustively.

Inclusion and exclusion criteria were applied, resulting in 12 quantitative studies for inclusion. All measure QoL by questionnaire; some use general health related QoL measures, and some continence specific QoL measures. Five studies use healthy controls; two are treatment outcome studies.

Results: Findings suggest that QoL of children with NE is lower than that of healthy children, with some domains more affected. QoL in NE is similar to that of children with chronic health conditions. There appears to an association between increasing age and lower QoL. No clear QoL differences according to gender emerge.

Future research could use both qualitative and longitudinal designs to explore relationships between age, gender, ethnicity and QoL, and clarify direction of causality regarding lower QoL in children with NE compared to healthy peers.

Keywords: enuresis, QoL, children, young people
**Introduction**

The Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-5) (American Psychiatric Association, 2013), defines enuresis as either involuntary or intentional voiding of urine into the bed or clothes, occurring at least twice a week for at least the last three consecutive months, (or if not of this frequency then to be exerting a clinically significant impact on one or more areas of functioning). It is diagnosed only in those over age 5. Other criteria state that the enuresis should not be due to congenital or acquired defects of the central nervous system or the direct physiological effect of a substance (such as a diuretic). Nocturnal enuresis refers to urinary incontinence (UI) during the night only.

**Prevalence of Nocturnal Enuresis**

Prevalence rates of NE are problematic to establish with accuracy due to differences in terminology, definitions and sampling strategies in extant epidemiological research. The Avon longitudinal study (ALSPAC: Golding, Pembrey, & Jones, 2001) represents the best UK data. Joinson, Heron, Emond, and Butler (2007) used postal questionnaires with parents when children in the ALSPAC cohort were around 7.5 years of age. They found that the infrequent bedwetting (<2 nights per week) prevalence figure was 21% at 4 years, 6 months and 8% at 9 years, 7 months of age. Those evidencing night wetting 3 or more times a week had prevalence figures of 8% and 1.5% at these ages. Epidemiologic research demonstrates that prevalence rates of NE decline with increasing age. However, for some it continues into late childhood and beyond. Yeung, Sreedhar, Sihoe, Sit, and Lau (2006) in an epidemiological study in Hong Kong, identified that older children with NE tended to show more severe symptoms. Hirasing, van Leerdam, Bolk-Bennink, and Janknegt (1997) assessed the prevalence of NE in adults aged 18-64 as 0.5%.

**Psychosocial Impact**

Childhood NE is associated with a range of psychosocial issues. Studies generally look at the impact of NE on the child, the family or at associations between NE and other variables. Findings regarding the prevalence of internalising problems in children with NE are inconsistent. Van Hoecke , Hoebeke, Braet, and Walle (2004) using parent questionnaires, found no differences in a group of children with NE in comparison to healthy controls. Wolfe-Christensen, Veenstra, Kovacevic, Elder, and
Lakshmanan (2012), using a symptom checklist with parents of children accessing paediatric urology services, found that 15.2% evidenced significant psychosocial difficulties; those with NE being 2.5 times more likely to show these than other groups looked at (daytime wetters, those with genital or renal conditions, or complex conditions involving continence issues e.g. spina bifida). Joinson et al. (2007) using parent reports, found that children with NE were more likely to experience social fears as well as sadness and depression than other UI subgroups. Lui and Sun (2005), in a Chinese sample of older children using retrospective parental reports, found that NE after 3 years of age is associated with increased risk of adolescent suicidal behaviour.

Self-esteem and the related construct of self-concept have been examined in several studies and one review (Redsell & Collier, 2001). In this review, the authors looked at 15 relevant studies and found that available data was not sufficient to conclude that children with NE have lower self-esteem than the general population. However, later studies do find evidence for lower self-esteem in this group (e.g. Theunis, Van Hoecke, Paesbrugge, Hoebeke, & Vande Walle, 2002), with indications that there are certain groups for whom self-esteem is particularly affected: girls; adolescents and those with frequent NE (Kanaheswari, Poulsaeman, & Chandran, 2012). However, others find lack of evidence to suggest that children who are wet at night have lower self-esteem than children who are dry (Robinson, Butler, Holland, & Doherty-Williams, 2003; Van Hoecke et al., 2004).

Several studies have identified associations between conduct problems and NE. Chang, Ng, and Wong (2002) looked at group of children with NE and a group of age and gender-matched controls. Child Behaviour Checklist (CBCL) parent ratings indicated particular problems with aggression as well as lower social competence and school performance than controls. Van Hoecke et al. (2004), also using the CBCL, found significantly increased levels of problem behaviour including externalising and attentional problems in children with nocturnal and diurnal enuresis compared to controls. Other findings suggest more externalising issues are found in children with combined day and night wetting rather than in those who wet only at night, or do not wet at all (Van Hoecke, De Fruyt, De Clercq, Hoebeke, & Vande Walle, 2005; Theunis et al., 2002).

Wider psychosocial issues for children with NE include risk of being found out at school, limiting their ability to join in peer group activities (Butler, Redfern, & Holland, 1994). Over 18% of the ALSPAC cohort (Joinson et al., 2007) reported being
unhappy with friendships. Children who wet the bed can also experience teasing or bullying (Hagglof, Bergström, Marklund, & Wendelius, 1998; Morison, Tappin, & Staines, 2000).

There is evidence that within the family NE can lead to increasing intolerance and blame of the child by parents (Butler, Brewin, & Forsythe, 1986; Butler, 1998). When NE continues into adulthood, it can affect personal relationships, social life and employment (Hirasing et al., 1997). However, evidence indicates that successful NE treatment can result in positive changes in self-esteem and self-image (Hagglof et al., 1998; Theunis et al., 2002), as well as QoL (Naitoh, Kawauchi, Soh, Kamoi, & Miki, 2012).

Quality of Life

Quality of life in children with ongoing health issues is conceptualised by authors such as Christine Eiser as being less focussed on the impact of symptoms of the health condition, but looking in a more holistic way at the child’s or young person’s perspective on their life. Quality of life research has been focussed on children with chronic illness and life limiting diseases, rather than on those with less severe functional disorders (Gerharz, Esier, & Woodhouse, 2003). Over the last ten years however, there has been more interest in examining QoL in the NE population, but the research literature is quite sparse. Extant research has used existing measures of health related QoL in children to explore QoL in relation to incontinence (e.g. Gladh, Eldh, & Mattsson, 2006). Researchers have also developed condition specific QoL measures such as the Paediatric Incontinence Questionnaire (Pin-Q) (Bower, Wong, & Yeung, 2006a) and the Pediatric Enuresis Module Quality of Life (PEMQOL) (Landgraf et al., 2004). Several studies have focussed on validating newly developed continence specific QoL questionnaires in different languages across different cultures (e.g. Bower et al., 2006b; Bachmann et al., 2009a). These include some initial information as to the QoL of children with continence problems in these different populations. Some studies look at both QoL as reported solely by children (e.g. Deshpande, Craig, Smith, & Caldwell, 2011); some also look at proxy measures of children’s QoL as reported by parents (e.g. Bachmann et al., 2009a; 2009b); some look solely at proxy reports by parents; these mainly use the PEMQOL (Landgraf et al., 2004).
Method

Electronic searches of available online databases were carried out. Databases were: Wiley, PubMed, EBSCO (Psychinfo and Psycharticles), Science Direct, Medline (Ovid Sp), Springerlink, SAGE, Web of Science and Google Scholar. These were accessed to allow access to a range of peer reviewed medical and psychological information, and therefore of scientific quality. The Cochrane Database of Systematic Reviews was searched to identify whether any reviews in this area had been undertaken. Athens database for the NHS was accessed similarly. A search of the author’s NHS Trust and University of Kent libraries identified no relevant papers accessible in paper journals.

First search of the databases was comprehensive and did not exclude any type of publication, or any year, in order to include as many relevant publications as possible. The search terms initially used were ‘nocturnal enuresis’ and ‘quality of life’ in all text. Other terms were then applied which reflected different ways of describing the condition or the individuals of interest in the literature. Search terms included exact or near synonyms for NE used in the literature ‘enuresis nocturna’; ‘bladder dysfunction’; ‘bedwetting’; nighttime wetting’; and ‘urinary incontinence’. The term ‘QoL’ was also used as an often used abbreviation for ‘quality of life’. Search terms regarding the population were ‘children’; ‘young people’; ‘adolescents’ and ‘teenagers’. Also searched were ‘treatment’ and ‘intervention’ to find studies looking at QoL as an outcome measure. Search terms were applied to title, abstract and full text of articles to be as inclusive as possible in the search (see Appendix A for table of search terms).

Relevant professionals working in bladder and bowel teams and paediatrics were approached to request knowledge of any further published or unpublished papers, but none were found. Manual search of references sections produced no further relevant papers. The literature search was curtailed and considered exhaustive at the point at which same studies arose repeatedly.

No reviews were found. Sixty eight relevant articles were found, which included duplicates. These studies were then manually searched for information in the abstract of relevance and the inclusion and exclusion criteria applied.

Inclusion Criteria

Any studies which examined enuresis in children and young people and its relationship to child or young person self-reported QoL. Papers were included if they
had a large proportion of those with NE in the sample or looked at NE group separately as part of the analysis. Papers which looked at NE of primary or secondary type were included. Studies were not required to have been published in any particular timeframe, but were published in peer reviewed journals. These journals were English language, or studies were available in English language translations.

Exclusion Criteria

Any studies which looked solely at parent proxy reports of child’s QoL in relation to enuresis. Eiser and Kopel (1997) have found that children and their parents do not always share the perception of child’s QoL in relation to medical conditions, and thus papers solely using parent proxy reports were excluded. Also excluded were studies which focussed solely on the QoL of another member of a child’s family (where the child had enuresis). Also excluded were studies where QoL in enuresis was not the primary focus - one study focussed on QoL in skin disease and compared it to pre-existing QoL data in other conditions (one of which was enuresis). Also excluded were studies where the QoL data was minimal. For example one study sought to develop a symptom checklist for enuresis and had only one item relating to QoL, and so was excluded. Professional opinions in journal entries were excluded, as were letters.

In total 12 articles remained fitting inclusion and exclusion criteria for this review. The data extraction table (Appendix B) highlights relevant details of the studies including authors; participants and measures used. Each study has limitations highlighted as well as brief outline of results presented in the final column. The quality of each of the 12 studies was assessed in relation to various aspects of methodology. The results of the 12 studies are thus compared and themes synthesised, differences identified and discussed.

Results

The 12 studies included in this review are all of quantitative design. Three of these studies sought to validate and establish psychometric properties of a specific self-report QoL measurement tool (Pin-Q) in UI. Three studies use the Pin-Q to examine in QoL in relation to type of continence issue (day, night, faecal or urinary), and to examine factors associated with, or predictive of, lower QoL. Five studies examine UI in relation to QoL using non-continence specific validated QoL measures. One study uses a newly developed but non-validated QoL measure. Six studies use a self-report
QoL measure as well as the parallel parent proxy report measure. Five studies examine QoL of children with continence issues in relation to healthy children. There are two outcome studies in the group which look at changes in QoL after treatment for NE.

Due to the paucity of literature in the area, it was considered appropriate to include the validation studies. Some include limited information about associations of other variables with QoL such as age and gender, and some comment upon issues in assessing self-reported QoL in a paediatric population, such as differences between clinician perceptions and child self-reports that are pertinent to this review.

Studies Using the Paediatric Incontinence Questionnaire (Pin-Q)

Validation of Scales. The Pin-Q was the first tool developed specifically to assess QoL in UI, and is the only self-report scale for this group which has undergone reliability and validity testing. A group of studies use the Pin-Q in a range of ways: initial identification of items for inclusion in the scale (via consultation with professionals); psychometric evaluation; test-retest reliability; translation and international validation, and proxy measure comparison.

Bower et al. (2006a) developed and validated the Pin-Q using a mixed design in consultation with expert clinicians across 13 countries. It comprises six domains looking at impact of bladder dysfunction on children’s QoL: self-esteem; mental health; independence; family; social interaction, and body image. Norming data was collected from 10 countries and 156 children. Findings using this first continence specific tool indicated that the younger the child, the greater the impact of enuresis on some aspects of QoL. Professionals and parents were not always accurate in their understandings of QoL in children with enuresis. Authors conclude there is a need for a QoL measure in continence problems in children, citing benefits as an objective outcome measure to inform clinical practice as well as research.

Bower et al. (2006b) moved on to examine the reliability of the Pin-Q. They also examined the child self-report version in relation to those proxy-completed by parents. Forty children aged 6-15 years and their parents completed the measure at initial consultation and two weeks later, with no intervening treatment. Good reliability was established. Proxy Pin-Q scores indicated that parents were generally accurate in their understandings of QoL in children with bladder dysfunction. However, parents were found to show poor perception of the child’s point of view of parent concern about bladder problems. Parents also underestimated the impact on the child’s sense of self-
worth.

Bachmann et al. (2009a) translated and cross-culturally adapted the Pin-Q to assess reliability and validity of the German version. The study looked at self-report and parent-proxy report from 144 children aged 6-18 with UI. This study found significant agreement between children and their parents regarding impact of continence issues on QoL. Findings indicated good reliability and validity. Quality of life was similar in girls and boys, and was not associated with differences in age, sex and incontinence type or severity, except for a slight significant association between age and QoL. The authors discuss that this latter finding may be to do with the greater impact of incontinence on adolescents, highlighting social stigma and embarrassment as possible factors in elevation of scores.

**Non-Validation Studies.** Bower (2008) used data from the original validation study (Bower et al., 2006a) to focus on children’s perception of impact of incontinence on differing domains of QoL. This found greatest impact on self-esteem domain of QoL. No difference in QoL was found according to age. However younger children indicated bladder problems had greater impact on sleep than older children; and older children indicated more concerns regarding parents’ negative feelings about their bladder problems. This study revealed gender related differences: girls showing significantly better self-esteem and body image than boys. Boys showed greater impact on QoL when they experienced urinary tract symptoms (and bowel symptoms) than girls and this impact was greatest with both day and night symptoms. This study also highlights possible cultural differences in response to QoL impact of continence issues, with European cultures showing greater impact.

Deshpande et al. (2011) looked at QoL using the self-report Pin-Q in 138 children ages 6-16 with UI in outpatient clinics in Australia. They aimed to identify factors such as age and gender that may affect QoL in this group. A weighted summative QoL score with a range of 1.75 to 7 (7 being lowest quality of life) was generated, and patient characteristics identified as predictors of lowered QoL. Significant findings indicated lower QoL in girls when compared to boys; also that white children had higher QoL than a small mixed subsample of children of different ethnicities (including Middle Eastern, Chinese and Sri Lankan). Symptom severity and underlying chronic disease were not associated with decreased QoL. Older age, female gender and nonwhite ethnicity were found to be independent predictors of QoL in this group: QoL was found to decrease in girls with UI who were older and nonwhite.
Indications were that self-esteem and mental health were the highest impacted domains.

**Studies Using Other QoL Measures**

Gladh et al. (2006) looked at 120 clinic children aged 6-16 and 239 age-matched controls with daytime incontinence, mixed daytime and nighttime incontinence, and a therapy resistant NE group. Thirteen per cent of controls had previously undiagnosed UI, and these children were excluded from the control group and the base analysis; their QoL scores falling between the continent and incontinent children’s scores. A modified adult questionnaire was used to assess QoL (Hornqvist QoL Measure, (Hornqvist, 1990)). Statistical validation found differences in QoL between these two groups across most measured domains, and that these were due to incontinence. Reliability was not assessed. Quality of life was rated lower by all age groups with continence problems in comparison to healthy children. This pattern did not hold for older adolescents (>12 years), where QoL was lower than controls in terms of leisure time and overall QoL. Authors concluded that QoL is most impacted upon in the youngest children with enuresis.

Ertan et al. (2009) looked at QoL in children with NE, and how this might be mediated by sleep quality. They looked at 44 children (aged 6-15) with NE and 27 healthy controls. Quality of life and sleep difficulties did not differ between the two groups. The self-esteem component of QoL in children with NE was found to decrease with age, and in those who had wet for longest; authors highlighted the cumulative stress of NE on older children. For those with greater sleep difficulties and greater daytime dysfunction, there was a greater impact in terms of the friendship and physical well-being aspects of QoL. Some aspects of sleep efficiency were lower in those with NE.

Karnicnik, Koren, Kos, and Varda (2012) collected prospective epidemiologic data about NE and its influence on QoL in a Slovenian group of 1,248 primary school children who responded to a questionnaire regarding QoL Issues. This included 44 children and young people with NE (aged 6-21) who had been treated for NE. Findings indicated lower QoL in less than half of the enuretic group; about half reporting that enuresis caused no problems in their lives. Other significant concerns included worries that wetting will never go; and that others would discover the problem.

Ücer and Gümüş (2013) looked at 101 children (aged 8-16) with NE and 38 healthy controls. They looked at interactions between NE, mood and sleep quality. The
group with NE had lower QoL, lower mood and more sleep problems than controls. In the NE group, there was an association between increasing age and lower QoL. Authors suggested that early intervention is important due to increasing issues in QoL with age.

Bachmann et al. (2009b) consecutively evaluated 103 clinic patients aged 6 to 18 with night and/or day wetting (including 12 with NE) and their parents. They used self- and parent proxy report QoL measures. Authors also sought to compare QoL in their sample with that of those with other chronic childhood conditions. Findings indicated UI has a similar impact on QoL to other chronic conditions such as asthma, dermatitis and epilepsy, and on the self-report version is also similar to QoL in those with more severe conditions of arthritis, diabetes and cystic fibrosis. Findings indicated no differences between child and parent proxy report versions of the scale. Gender, age and incontinence subtype were not associated with differences in QoL on either self-report or parent proxy report.

Naitoh et al. (2012) examined how treatment for NE affected QoL of children and their mothers attending a Japanese urology clinic. 139 patients (mean age 9.7 years, mean number of enuresis episodes 12.6 per two weeks), were compared with 109 healthy age and gender matched controls. Pre-treatment children showed significantly lower QoL than controls in terms of family related QoL, but no differences to controls in other measured domains of social relationships with friends or school were found. After successful treatment of all the children, their QoL in terms of family related problems improved to levels of controls. The authors did not report children’s QoL scores in any detail, focussing more on that of their mothers, but findings included differences in reported QoL between children and their mothers’ proxy report in family domain: children reporting higher impact. Authors indicated this may be because NE is restricted to home at night and therefore may not impact on daytime activities outside of the home.

Equit, Hill, Hubner, and von Gontard (2014) examined children’s and parents’ QoL in relation to treatment for a group with mixed continence problems (aged 4.3-15.8) using the Pin-Q and the World Health Organisation Quality of Life Questionnaire–Brief version (WHOQOL-BREF, (Skevington, Lotfy, & O’Connell, 2004)), questionnaire for parents. Children with greater incontinence had lower QoL, but benefitted from therapy even over a short period. Successful treatment improved QoL. Treatment non-responders showed lower frequency of incontinence episodes pre-treatment, had better QoL initially and this didn’t change via treatment. The study
identified differences in QoL between children with different continence subtypes: QoL was found to be more impaired in children with combined UI subtypes or with faecal incontinence (FI) than in children with isolated subtypes or without FI. The emotional and social aspects of QoL were found to be most affected and the impairment of QoL in children with day and night wetting was similar to that of children with chronic disorders (e.g. asthma).

**Discussion**

The aim of this review was to identify, analyse and synthesise research which looks at the associations between NE and QoL in children and young people. Some points can be made as regards the relative scientific merit of the papers included in this review. A critical appraisal approach using tools within The Critical Appraisal Skills Programme (CASP, 2014), enables examination of elements of studies across design; methodology; analysis; results, and interpretation of findings, as well as the overall value of the research. Using this approach, some studies within this review emerge as having greater scientific quality than others.

Of the seven studies which are cross sectional in design; the strongest of these appear to be by Bachmann et al. (2009b), Deshpande et al. (2011), and Gladh et al. (2006). All show good methodological definitions around the sample under investigation (although the latter is not clear on the exact enuresis type of participants), and one (Deshpande et al., 2011) does not delineate the sampling time frame. All address the issue of power, which the other studies of this type in the review do not. Problems with generalisability is an issue for the studies by Deshpande et al. (2011) and Bachmann et al. (2009b), due to the nature of the samples (drawn from a tertiary service), but this is discussed well particularly by the authors of the latter study. However, both of these studies use the validated, continence-specific Pin-Q; whilst the study by Gladh et al. (2006) uses a weaker QoL measure, which is non-continence specific, validated on adults and the authors do not make clear how it was ‘adjusted for healthy children with incontinence problems’ (p1649).

The two weakest of the studies of cross sectional design appear to be those by Ücer and Gümüş (2013) and Karnicnik et al. (2012). The former shows significant methodological flaws, which includes lack of definition of enuresis group under investigation, and although a control group is used, it is identified as being recruited consecutively from children of hospital employees, but this process is not made clear.
They do not deal with the issue of power. Similarly, Karnicnik et al. (2012), although using a large sample, did not attempt to stratify the sample. They also use a clinic population, but are unclear as to the definition of clinic type; how they identified the sample, and the percentage that responded to their questionnaire. They also use an unvalidated questionnaire of their own design, with no clear description of how it was developed. Their clinic group is also aged 6-21 years with no clear rationale for including adults. They engage in no clear discussion of clinical implications or future research.

Of the two outcome evaluation studies, the paper by Equit et al. (2014) is clearly of greater scientific quality due to a well-defined methodology, including well-defined treatment content and duration, and the use of the validated continence-specific Pin-Q. This study does not have a control group, but the analysis included treatment non-responders. By contrast, the treatment study by Naitoh et al. (2012) has methodological flaws, which include no clear description of the sample under investigation. The study does use healthy volunteer control data, but does not examine the QoL of children who did not achieve night time dryness; most of them being lost to follow up.

The 3 validation studies appropriately follow standard procedures in assessing validity and reliability of the Pin-Q cross-culturally.

For the group of studies as a whole, methodological issues in the studies make comparison and conclusion problematic. Sample sizes in the studies range from 12 participants to over 1000. Most of the papers take no account of, and make no adjustment for, life events or socio-economic factors which may affect QoL. None of these studies involve British participants, limiting the generalisability of findings to British children with NE. Most of the studies use samples drawn from clinic paediatric services and specialist continence services. Two samples are drawn from ‘tertiary’ centres (Desphande et al., 2011; Bachmann et al., 2009b). It is noteworthy that most children with NE in the UK are not seen within specialist paediatric clinics, but by community based school nursing services or within general practice. Therefore the samples in this review might be expected to be comprised of individuals who had more severe NE, or on whom the impact of this NE would be more severe, thus resulting in active help seeking behaviours from services. If the service structure of these countries can be assumed to be similar to the UK, most of the children across these studies would be accessing services delivered to those with most severe, enduring and impactful problems of NE perhaps affecting QoL to a greater degree.
The papers included in the review use a range of questionnaires to assess QoL. One paper uses an unvalidated QoL questionnaire (Karnicnik et al., 2012). Some use generic health-related QoL measures, and some use the continence specific Pin-Q. Additionally some of these studies use child self-report only, and some use both child and parent proxy report. The composite construct of QoL is comprised of different sub-constructs in different questionnaires, which might be expected to produce different overall scores and different scoring profiles according to the questionnaire used. This means comparing findings across studies using different questionnaires is difficult.

Five of the studies use healthy controls. Of these studies, (Gladh et al., 2006) found that QoL was rated lower by all age groups with UI, in comparison to healthy children. This pattern did not hold for older adolescents (>12 years), where QoL was lower than controls in terms of leisure time and overall rated QoL, but otherwise similar to healthy controls. One issue in this study is that it uses a mixed group of those with UI, not using an NE subgroup for analysis. Üçer and Gümüs (2013) found that those with NE had lower QoL (and mood and sleep quality), scores than healthy controls. Naitoh et al. (2012) found that the family domain of QoL of children with NE was lower than that of healthy controls. Ertan et al. (2009) looked at QoL in relation to sleep quality and used a control group of healthy children and a group with NE (examining how this might be mediated by sleep quality). Self-reported QoL did not differ between the two groups. However as the age of the child and duration of NE increased, the self-esteem domain of QoL worsened. Greater daytime symptoms due to sleep dysfunction in the NE group also had a greater the impact on QoL, especially the physical well-being and friendship aspects.

Only two papers look at incontinent children in the general population in relation to clinic populations. Gladh et al. (2006) found the NE group showed low levels of QoL. Whilst Karnicnik et al. (2012) found less than half of children with NE have significant impact on their QoL compared to healthy controls, but that the aspect affected most by NE was social relationships. This study did not use a validated QoL questionnaire and may therefore be considered to be less valid than others using these and reporting scores.

Findings from this review identify some comparisons regarding impairment in QoL in children with NE compared to those with other chronic conditions. Bachmann et al. (2009b) found that children and adolescents with UI show similar impact on QoL as children with other chronic conditions, e.g. asthma, dermatitis or epilepsy, and self-
reports of children are lower, and have similar to QoL in those with more severe conditions of arthritis, diabetes and cystic fibrosis. Equit et al. (2014) also found the impairment of QoL in children with day and night wetting comparable to that in children with chronic disorders (e.g. asthma).

The studies in this review find that there are some aspects of QoL which appear to be more associated with NE than others. Bower et al. (2006a) identified some interesting issues in their initial validation paper, including that the social, family and body image domains of QoL (thought by clinicians to be important), were rated less important by children themselves. Similarly the domains of mental health and independence were rated of high importance by children, but rated least important by clinicians. However, there was general agreement in ranking between children and clinicians as to high import of self-esteem in QoL. Bower et al. (2006a) looked at the 6 domains of the Pin-Q: self-esteem; mental health; independence; family; social interaction, and body image. Mean domain scores revealed greater impact on QoL in that order i.e. greatest on self-esteem (57% of participants reported impact self-esteem; 39.5% of participants reported impact on body image. Authors indicate this is due to self-report rather than proxy report. Also Deshpande et al. (2011) similarly found that self-esteem and mental health were the two most affected domains of QoL in children with UI. Bower (2008) found that self-esteem and mental health issues correlated significantly with poor treatment outcomes. Equit et al. (2014), using a mixed UI group, found that the emotional and social impact of incontinence was greatest: children felt unhappy; avoided overnight stays with friends, and showed reduced social activities.

Evidence seems to be a emerging regarding the association of NE with the self-esteem and mental health aspects of QoL. Previous findings regarding self-esteem and the related construct of self-concept have been inconsistent. Redsell and Collier (2001) in their review were unable to conclude that children with NE have lower self-esteem than the general population. Later studies do find evidence for lower self-esteem in NE (Theunis et al., 2002), with indications that there are certain groups for whom self-esteem is particularly affected: girls; adolescents and those with frequent NE (Kanaheswari et al., 2012).

One area for further research is to examine QoL in relation to successful treatment for NE. Only two of the studies in this review look at QoL in relation to treatment outcome (Naitoh et al., 2012; Equit et al., 2014). The latter authors found that successful treatment improves QoL of children. Non-responders to treatment had less
impairment of QoL initially and this didn’t change via treatment. However the non-responders showed lower frequencies of UI initially. Authors concluded that children with lower symptom severity showed lower impairment of their QoL, but benefited less from treatment. Naitoh et al. (2012) also found that successful treatment improved QoL for children. However the study did not look at the QoL of children who received treatment that was not successful (they were mostly lost to follow up or did not cooperate with post treatment assessment).

The relationship between age and QoL tends to point to an association between older age and decreased QoL in NE. Bachmann et al. (2009b) found no associations of age with QoL using a generic QoL questionnaire, but with Pin-Q proxy report (Bachmann et al., 2009a) found older children had lower QoL. However this looked at a mixed UI group where data from those with NE was not analysed separately. Bower et al. (2006a), using the Pin-Q, found that younger children with mixed UI issues report more impact in some domains of QoL, though did not report figures. But a later paper Bower (2008) again using the Pin-Q, found that the effects of continence issues (including NE) on QoL were relatively independent of age. However younger children indicated bladder problems had greater impact on sleep than older children; and older children indicated more concerns regarding parents’ negative feelings about their bladder problems. Deshpande et al. (2011) using the Pin-Q, found the opposite in mixed group including those with NE: older children with UI showing lower QoL. Gladh et al. (2006); Ertan et al. (2009) and Ücer and Gümüş (2013) also reported lower QoL in older children with NE in some domains. Furthermore, this finding of lower QoL in older children with NE may involve interactions with other variables such as length of time child has been enuretic; Ertan et al. (2009) for example identified significant associations between NE, age and self-esteem: as age of the child and the duration of enuresis increase, the self-esteem domain of QoL worsens.

Several of the studies in this review have examined QoL in relation to other variables such as gender. In this review, 7 of the 12 papers examined gender differences; 5 finding no difference in QoL between boys or girls with enuresis. Bachmann et al. (2009a) using the Pin-Q and Bachmann et al. (2009b) using a generic QoL measure found no gender differences, as did Gladh et al. (2006), Ertan et al. (2009) and Ücer and Gümüş (2013). Bower (2008) was the first to identify associations between male gender, day and night UI and FI: boys showing greater impact on QoL than girls; the impact being greatest on boys with day and night wetting. However
Deshpande et al. (2011) again using the Pin-Q, found lower QoL in girls than boys. Ertan et al. (2009) identified some interactive effects: the greater the incidence of daytime symptoms, the greater the impact on QoL, especially the domains of physical well-being and friendships.

Despite the range of international data collected in the studies that comprise this review, only 2 studies look at cultural differences. (Bower, 2008) found that European children with UI have lower QoL than Asian children. The authors discuss this in light of research findings about the tendency of Asian cultures to avoid more extreme responses on Likert scales. In the Deshpande et al. (2011) study using an Australian sample, white children had higher QoL than a subgroup of children of mixed ethnic origins (mainly Middle Eastern). This study did control for socio-economic status, allowing the authors to conclude that lower QoL in this subgroup may reflect either English literacy difficulties in responding to the questionnaire, or cultural differences around incontinence.

**Implications for Research**

The National Institute of Health and Care Excellence (NICE) in its 2010 guidelines on the treatment of childhood enuresis, highlights the need to assess psychological impact including QoL, both with regard to how it is impacted upon by NE, but also how it might change in response to treatment. The picture has not changed significantly since 2010, with only 5 papers emerging in this area since that time. To this point, the Pin-Q, the only children’s continence specific questionnaire has not been validated on a British population, making its use in the UK somewhat problematic. Neither has the Pin-Q been subject to sensitivity testing. There is a need to assess its utility in detecting change in QoL post treatment both when treatment has been judged successful and when not.

There is also a need to identify other issues that may be causative of, as well as resulting from NE. Variables which are associated with NE include ADHD symptoms and externalising behaviours such as aggression. It may be these that are contributing in some measure to impaired QoL in the NE population, and there is a need to develop research designs which control for these.

To date, there are no published qualitative studies which explore QoL issues in children with NE. There is certainly scope for designs that utilise exploratory, qualitative methodologies to explore QoL in this population.
The findings of this review suggest that research will be needed to clarify a number of issues regarding QoL in NE. Longitudinal studies in particular would help clarify direction of causality in this relationship. Most of the papers reviewed herein take little account of co-occurring variables such as socio-economic status which would be expected to impact QoL, and designs which account for these would be useful.

**Implications for Clinical Practise**

Professionals could be more aware of the impact that NE has on QoL, and the importance of asking children to self-report on their QoL. Research has also highlighted some associations of other variables with QoL in children with NE such as gender, age and ethnicity. There is a need for clinicians need to be aware of the differential effect of NE in children of different ages and ethnic backgrounds, so as to administer and tailor treatment appropriately.

As regards the relative merits of self vs. proxy report, Bachmann et al. (2009a) and Bachmann et al. (2009b) found significant agreement between children and parents regarding impact of continence issues on QoL, as did Bower et al. (2006b). However, these latter authors also indicated that parents may show poor perception of the child’s point of view of parents’ concern about these problems, and underestimate impact on the child’s sense of self-worth. Naitoh et al. (2012) also found discrepancies between parent and child reports in some domains. Bower et al. (2006a) also highlighted a possible incongruence of clinician and parent opinion with that of child and young person which indicates the importance of using an objective self-report QoL measure with the child, rather than relying on clinician judgement and/or parent testimony. Using the Pin-Q or other general QoL measure and discussing the findings with the family, might help families understand the perspectives of others and thus generate greater mutual family support.

**Conclusions**

Overall the findings of this review point towards QoL in children with NE being lower than in healthy children and comparable to that of children with some chronic health conditions. This review finds that perhaps some domains of QoL are more greatly affected by NE (the family domain, self-worth, self-esteem, social relationships, and leisure time). In addition, QoL may be lower in those who seek help from specialist services, than those who don’t. Further evidence of a more causal relationship between
QoL and NE is provided by two treatment outcome studies finding QoL improvements in successful treatment for NE. Findings as regards age and impact of NE point towards an association between increasing age and lower QoL in this group. Findings as regards gender mostly find no differences in the association of NE with QoL between boys and girls; one paper indicating girls have lower and one that boys have lower QoL.
References


*Identifies references included in this review.*
## Appendix A: Search Terms and Rationale used in Critical Review

<table>
<thead>
<tr>
<th>Search Term</th>
<th>Rationale</th>
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<tbody>
<tr>
<td>Nocturnal enuresis</td>
<td>This was the target health condition of the target population</td>
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<tr>
<td>Enuresis nocturna</td>
<td>Near synonym of nocturnal enuresis sometimes used in the scientific literature</td>
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<tr>
<td>Bedwetting</td>
<td>Common name for nocturnal enuresis</td>
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<tr>
<td>Nighttime wetting</td>
<td>Common name for nocturnal enuresis</td>
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<tr>
<td>Urinary incontinence</td>
<td>Another term often used synonymously with enuresis</td>
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<tr>
<td>Bladder dysfunction</td>
<td>Another term often used synonymously with enuresis</td>
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<td>Children</td>
<td>Target population</td>
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<tr>
<td>Adolescents</td>
<td>Target population</td>
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<td>Young people</td>
<td>Common name for target population</td>
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<td>Teenagers</td>
<td>Common name for target population</td>
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<tr>
<td>Quality of life</td>
<td>Target variable of interest in target population</td>
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<td>QoL</td>
<td>Commonly used abbreviation for quality of life</td>
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<tr>
<td>Intervention</td>
<td>To access papers where QoL may have been used as treatment outcome variable</td>
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<tr>
<td>Treatment</td>
<td>To access papers where QoL may have been used as treatment outcome variable</td>
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Appendix B. Data Extraction Table of Studies Included in Critical Review

<table>
<thead>
<tr>
<th>Authors and years</th>
<th>Participants (age, sex, details)</th>
<th>Aims of study</th>
<th>Measures used</th>
<th>Study limitations</th>
<th>Results</th>
</tr>
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<tbody>
<tr>
<td>Bachmann, Lehr, Janhsen, Steuber, Gabel, Von Gontard, &amp; Bachmann (2009a)</td>
<td>German sample of 91 boys, 54 girls with non-neurogenic UI aged 6-18 years (mean age 9.3 years; SD 2.2 years).</td>
<td>To establish reliability and validity of German version of Pin-Q.</td>
<td>German self- and parent proxy report versions of Pin-Q which had been translated and cross culturally adapted from English version. German Pin-Q compared with DCGM-10/12 – German QoL questionnaire.</td>
<td>Small non-white sample. Use of postal questionnaire with families where English may not have been first language may have impacted results.</td>
<td>German Pin-Q found to be valid and reliable outcome measure to assess QoL in children and adolescents with UI. High levels of agreement between parent and child versions of Pin-Q. Age, gender, type and severity of UI did not show significant associations with total Pin-Q scores – with one exception: QoL found to be lower in older children.</td>
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<td>Bachmann, Lehr, Janhsen, Sambach, Muehlan, von Gontard, &amp; Bachmann (2009b)</td>
<td>German sample of children with UI attending 3 tertiary centres. 65 boys and 38 girls aged 6-16 (mean age 9.3yrs; SD 2.2yrs). 12 monosymptomatic enuresis, 79 non-monosymptomatic enuresis and 12 DE.</td>
<td>To evaluate QoL in patients with non-neurogenic UI and to identify factors influencing this, To compare QoL in UI group to QoL of in chronic childhood health conditions.</td>
<td>Self-report and parent proxy report versions of 10-item DISABKIDS - chronic generic measure, short version which is a QoL questionnaire with cross-cultural validity.</td>
<td>No control group. Only some NE subgroup analysis. Possibility of selection bias as participants were attending tertiary incontinence centres indicating higher level of persistence and severity of problem. 1 tertiary centre was child and adolescent psychiatry clinic. Likely that this group would have comorbid emotional and physical health issues.</td>
<td>QoL of children and adolescents with UI similar to children and young people with other chronic conditions, e.g. asthma and epilepsy. Parents and children in NE subgroup reporting very similarly about QoL. Age, sex and incontinence type showed no significant association with QoL.</td>
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<td>Bower, Wong, &amp; Yeung (2006a)</td>
<td>Scoping exercise consulted 33 experts from 13 countries. Validation involved 156 children in 10 countries: 54% European; 29% Asian; 17% North American or Australian. 6-17yrs of age (38% younger than 8yrs, 50% 9-12yrs, 12% older than 12yrs). 54.5% boys, 45.5% girls. Symptoms: 46% nighttime only, 13% daytime only, 41% day &amp; nighttime 82% urinary only, 18% bowel and bladder.</td>
<td>To develop and validate the Pin-Q - a cross cultural tool to measure the psychological impact of bladder dysfunction in children.</td>
<td>Pin-Q was developed in 3 stages involving expert consultation; design and administration and analysis, validity and reliability testing.</td>
<td>Acceptable levels of structural validity, internal validity and reliability. Two factors (extrinsic and intrinsic) were identified by factor analysis. Lack of agreement between clinician and child ratings. Areas expected to be more impacted on by clinicians were rated lower by children (social, family &amp; body image). Agreement between child and clinician ratings on self-esteem as most highly impacted domain of QoL. Younger children reporting lower QoL in some domains than older.</td>
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<td>156 children in 10 countries: 54% European 29% Asian 17% North American or Australian. 6-17yrs of age (38% younger than 8yrs, 50% 9-12yrs, 12% older than 12yrs). 54.5% boys, 45.5% girls. Symptoms: 46% nighttime only, 13% daytime only, 41% day &amp; nighttime 82% urinary only, 18% bowel &amp; bladder.</td>
<td>Factors which may have affected results. Participants identified as having ‘bladder dysfunction’ no attempt to classify subgroups such as those with NE.</td>
<td>Showed poor perception of the child’s point of view of parent concern about bladder problems. Parents underestimated the impact on the child’s sense of self-worth. Findings suggest that having bladder problems has a detrimental effect on children’s QoL, which may not be well understood by parents.</td>
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<td>To generate information regarding child’s understanding of impact of continence issues on QoL.</td>
<td>Pin-Q translated into several different languages.</td>
<td>Child’s understanding of questions may be affected by educational level. Low parent literacy may also affect responses. No data was collected on socioeconomic factors which may have affected results. Verbal administration of scale by treating Clinician. Translation of scale by treating clinician. Child responses may be subject to influence of parent present during questionnaire.</td>
<td>Effects of continence issues on QoL relatively independent of age. However younger children indicated bladder problems had greater impact on sleep than older children; and older children indicated more concerns regarding parents’ negative feelings about their bladder problems. Boys showed greater impact of incontinence issues on QoL than girls. Impact is greatest on</td>
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<td>Authors</td>
<td>Sample Description</td>
<td>Study Objective</td>
<td>Pin-Q</td>
<td>Findings</td>
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<td>Deshpande, Craig, Smith, &amp; Caldwell (2011)</td>
<td>Australian sample of 138 children - tertiary clinic outpatients with UI. 77 boys; 61 girls aged 6-16yrs (mean 10yrs).</td>
<td>To assess QoL in children with UI and identify factors that decrease QoL in this group. To compare QoL in this group to that with children with chronic health conditions.</td>
<td>Pin-Q</td>
<td>Possible sampling bias due to small nonwhite sample. Authors indicate self-completion of Pin-Q differs to other studies where it was clinician administered which may introduce bias. Lower QoL found in girls when compared to boys; also that white children had higher QoL than nonwhites. Symptom severity and underlying chronic disease were not associated with decreased QoL. Older age, female gender and nonwhite ethnicity were found to be independent predictors on QoL in this group. Self-esteem and mental health most impacted domains of QoL. Results suggest that there is no difference in QoL between children with continence issues and chronic health.</td>
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<td><strong>Equit Hill, Hübner, &amp; von Gontard (2014)</strong></td>
<td><strong>German sample of 70 children: 64.3% boys; Mean age 8.7 years, (SD 2.8, range 4.3-15.8 years). Consecutively treated clinic patients with diagnosis of night or day wetting or FI or combined types.</strong></td>
<td><strong>To see if standardised treatment was successful within 3 months. To assess if QoL is more impaired in children with combined wetting and soiling subtypes, than with one subtype. To assess if QoL of children and parents improves on treatment.</strong></td>
<td><strong>Pin-Q self-report and the WHO-Quality-Of-Life-BREF questionnaire.</strong></td>
<td><strong>Evaluation of outcome difficult due to range of continence conditions looked at. Some children had not finished treatment at time of study end. Short outcome period (3 months) therefore not possible to assess if treatment effects and QoL effects endured. Parental QoL questionnaire was suggested by authors to be too global. Lack of screen for other unrelated life events which could have affected QoL.</strong></td>
<td><strong>The impairment of QoL in children was similar to other studies. No differences in QoL between different subtypes. QoL found to be more impaired in children with combined subtypes and with FI than in children with isolated subtypes or without FI. Treatment produced significant improvements in wetting and soiling frequencies, and successful treatment improved QoL for all groups including those with NE. Treatment nonresponders showed less symptom severity, and less impairment in QoL, initially, both of which changed less than in treatment responders. Single item analysis of the PIN-Q showed the emotional and conditions even after adjusting for other variables.</strong></td>
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<tr>
<td>Study</td>
<td>Sample Description</td>
<td>Study Objectives</td>
<td>Instruments Used</td>
<td>Findings</td>
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<td>Ertan, Yilmaz, Caglayan, Sogut, Aslan &amp; Yuksel (2009)</td>
<td>44 children with Monosymptomatic NE (13 male; 31 female) in nephrology outpatient department in Turkey and 27 healthy controls (10 male; 17 female) aged 6–15 years.</td>
<td>To examine decrease in QoL and sleep quality and identify associations between these variables in children with monosymptomatic NE.</td>
<td>KINDL QoL and Pittsburgh Sleep Quality Index (PSQI)</td>
<td>Self-reported QoL did not differ between the two groups. However, as age of the child and duration of NE increase, self-esteem domain of QoL worsens. Greater the incidence of daytime sleep disorder symptoms the greater the impact on QoL in NE especially physical well-being and friendships.</td>
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<td>Gladh, Eldh, &amp; Mattsson (2006)</td>
<td>Swedish sample of 120 children (83 girls &amp; 37 boys: 6-16 yrs) referred to clinic due to day and/or nighttime incontinence, and group of 236 age matched controls children (118 each boys and girls).</td>
<td>To develop further knowledge about how UI affects child’s QoL</td>
<td>A modified adult questionnaire was used to assess QoL (Hornqvist) it contained 38 self-report universal items and 14 UI related items</td>
<td>QoL was rated lower by all age groups with continence problems in comparison to healthy children. This pattern did not hold for older adolescents (&gt;12), where QoL was lower than controls in terms of leisure time and overall QoL, but otherwise their QoL was rated as similar to healthy controls. No significant differences between boys</td>
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<tr>
<td>Authors</td>
<td>Study Population</td>
<td>Research Question</td>
<td>Methodology</td>
<td>Findings</td>
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<td>Karnicnik, Koren, Kos, &amp; Varda (2012)</td>
<td>Slovenian sample of 1248 primary school age children and 44 children, who have been treated for NE in nephrology units in paediatric services.</td>
<td>To generate epidemiologic data about NE and how it affects QoL of Slovenian children and adolescents. To assess knowledge about the NE among school children.</td>
<td>Authors developed a questionnaire which asks general questions about children’s lives, problems, as well as QoL. Use of non-validated QoL questionnaire. Information on sampling strategy of healthy sample not detailed enough, and doesn’t take account of socio-economic groupings.</td>
<td>Findings indicate prevalence of NE in Slovenia is comparable that of other countries. Findings indicated less than half of children with NE have significant impact on their QoL. NE affects social relationships most. Authors note lack of knowledge of NE in children.</td>
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<td>Naitoh, Kawauchi, Soh, Kamoi, &amp; Tsuneharu (2013)</td>
<td>Patients of Japanese urology clinic: 139 with NE (110 male; 29 female. Mean age 9.7 years. Mean number of NE episodes was 12.6 per 2 weeks), and their mothers. Healthy controls 81 male 28 female mean age 9.9 years age and gender matched.</td>
<td>To assess changes in QoL of children and mothers after successful treatment for NE.</td>
<td>Kid-KINDL protocol child and adult proxy report. Mothers’ QoL evaluated with the SF-36®, the SDS (Self-rated mood scale) and the STAI (State-Trait Anxiety Inventory). Did not use continence specific measure. Study did not evaluate QOL of families where children did not achieve lasting remission from enuresis.</td>
<td>Family domain of QoL of children with NE was lower than that of controls. Vitality aspect of QoL of mothers was lower than controls. Both state and trait anxiety in mothers enuretic children was higher than that of controls. After successful treatment for NE QoL improved for</td>
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<td>Ucer &amp; Gumus (2014)</td>
<td>Turkish sample of 101 children with NE and 38 healthy controls aged 8 - 16 years.</td>
<td>To compare group of children with NE with a healthy control group by looking at their mood, QoL and sleep quality.</td>
<td>Pediatric Quality of Life Inventory (PedsQL 4.0) Depression Scale for Children (CES-DC) and The Pittsburgh Sleep Quality Index (PSQI).</td>
<td>Reduced QoL may be due to factors such as age, gender, socioeconomic status or school issues – but study does no adjustment for these. NE group showed lower QoL, mood and sleep quality scores than controls. Older patients showed more impact of NE on QoL than younger ones. Authors conclude that treatment provision at younger ages is important. No difference according to gender, age and housing type between two groups. NE group evidenced poorer school performance, which may have been a factor impacting on QoL.</td>
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Section B: Tailored Hypnosis Treatment for Primary Nocturnal Enuresis in Children and Young People: A Case Series

Word count 13,764
Abstract

**Background:** The National Institute of Health and Care Excellence (NICE) guidelines (2010) on the management of enuresis, recommend investigation into alternative treatments for nocturnal enuresis, including hypnosis. Evidence suggests that hypnosis is a valuable therapeutic approach for a variety of psychological difficulties in children and young people (Milling & Costantino, 2000). A range of studies using hypnosis as a treatment for primary nocturnal enuresis (PNE) have demonstrated efficacy over the last 40 years.

**Aims:** This study investigated the efficacy of increasing nighttime dryness of a short, tailored hypnosis-based intervention for children and young people with PNE. It also examined whether this approach, if successful, was associated with change in psychosocial function.

**Method:** The study used a prospective case series with multiple-case AB design with 12 week follow-up. Ten children and young people with PNE were recruited via local continence services. Eight completed the treatment. Psychosocial questionnaire measures were collected at each phase. Data were analysed at group level and at individual level using simulation modelling analysis (Borckardt et al., 2008).

**Results:** A significant increase in dry nights was found at group level, which was maintained at follow up; both showing large effect sizes. This significant increase in dry nights was also found at individual level of analysis. A self-reported increase closely approaching significance (and with a large effect size), in continence-related QoL was found from baseline to follow up, but was not reported by parents. Individual reliable change analysis showed changes in some psychosocial variables across phases for some participants.

**Conclusion:** Results suggest hypnosis may be an effective treatment for PNE, persisting in its effects after treatment end. Improved continence may be associated with improved QoL. Future research could use controlled trial methodologies to further establish treatment efficacy. Evaluation of costs/benefits would also be useful in the current healthcare climate.

**Keywords:** enuresis, hypnosis, children, young people
Introduction

Definitions of Enuresis

The Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5) (American Psychiatric Association, 2013), defines enuresis as involuntary or intentional voiding of urine into bed or clothes, with a severity of at least twice a week for at least the last three months. If not at this frequency, then the enuresis must have an impact that is clinically significant on one or more areas of function (e.g. social or academic).

Enuresis is only diagnosed at developmental age 5 years and over. Exclusion criteria for this diagnosis include that the enuresis is not a result of congenital or acquired defects of the central nervous system, or due to the physiological effect of a substance (e.g. antipsychotic medication or diuretic), or due to a pre-existing medical condition.

DSM-5 identifies nocturnal (night-time) enuresis (NE) as one of three main subtypes of enuresis, which include diurnal enuresis (DE) - enuresis that occurs in daytime only- as well as a mixed presentation of both NE and DE. Nocturnal enuresis is termed ‘primary’ (PNE) if the child has never achieved lasting (>3months) dryness at night.

Prevalence Estimates

As regards prevalence of NE, the best UK estimate is probably that established by Joinson, Heron, Emond, and Butler (2007), as part of the Avon Longitudinal Study (ALSPAC), (Golding, Pembrey, and Jones (2001), who examined questionnaire data from parents of children aged 7.5 years. They found that the infrequent bedwetting (< 2 nights per week) prevalence figure was 21% at 4 years, 6 months and 8% at 9 years, 7 months of age; those evidencing night wetting 3 or more times a week had prevalence figures of 8% and 1.5% at these two ages.

Most up to date findings are in a paper by Doganer et al. (2015) in a Turkish study. Parent questionnaires were used with 2,314 participants aged 6-14 years, and a prevalence of 9.9% was found. This study identified a slight preponderance of boys (10.7%); 9.2% for girls. Other studies have also identified this greater ratio of boys to girls, albeit at lower prevalence levels. Shreeram, He, Kalaydjian, Brothers, and Merikangas (2009) found the prevalence in boys (6.21%) was significantly greater than that in girls (2.51%). Across cultures findings generally indicate that NE exists at a ratio of about 2:1 for boys to girls (Hazza & Tarawneh, 2002; Liu, Sun, Uchiyama, Li,
Okawa, 2000; Tai et al., 2007).

NE can persist into late childhood and adulthood, but generally prevalence rates decline with age (Yeung, Sreedhar, Sihoe, Sit, & Lau, 2006). Prevalence rates of NE in adults vary between 0.5% (Hirasing, van Leerdam, Bolk-Bennink, & Bosch, 1997), 2% (Yeung et al., 2004), to as high as 6% in a large community study (Buckley & Lapitan, 2009).

**Psychosocial Impact of Enuresis**

Nocturnal enuresis has been found to be associated with a range of psychosocial problems which include low self-esteem or self-concept; low mood; elevated anxiety; behavioural problems and impaired quality of life (QoL). Early studies (e.g. Hägglöf, Andren, Bergström, Marklund, & Wendelius, 1996, 1998) identified lower self-esteem in children with NE. Pugner and Holmes (1997) in a study primarily focussed on the costs of enuresis, also found that children with NE have lower than average self-esteem and described themselves in negative ways. Redsell and Collier (2001), in a review of 15 studies a few years later, were unable to conclude on available evidence that children with NE have lower self-esteem than the general population. Later studies also found lack of evidence to suggest that NE in children is associated with lower self-esteem than controls (Robinson, Butler, Holland, & Doherty-Williams, 2003; Van Hoecke, Hoebeke, Braet, & Walle, 2004). However other studies do find evidence for lower self-esteem in this group (e.g. Theunis, Van Hoecke, Paesbrugge, Hoebeke, & Walle, 2002).

There is evidence for internalising problems in children with NE. Joinson et al. (2007) using parent report data, found that children who wet the bed were more likely to experience low mood, depression and social fears than non-wetters (although these findings were not reflected in the child self-reports). De Bruyne et al. (2009) using the Child Behaviour Checklist (CBCL), found that mothers rated their children with NE as more withdrawn than mothers of control children. Using retrospective parental reports, Liu and Sun (2005) identified associations between age of attainment of nocturnal bladder control and adolescent suicidal behaviour in a Chinese sample of 11-16 year olds.

Several studies have identified associations between NE and externalising behaviours (De Bruyne et al., 2009; Erdogan et al., 2008; Joinson, et al., 2007; Van Hoecke et al., 2004). Wolfe-Christensen, Veenstra, Kovacevic, Elder, and Lakshmanan
(2012) using a symptom checklist with parents of children with NE, found that 15.2% evidenced significant externalizing problems. Problems with aggressive behaviour have been found by Chang, Ng, and Wong (2002) in a group of children with NE when compared to matched controls.

The findings of an unpublished critical review by the author indicate that QoL in children with NE may be lower than that of healthy children (Wood, 2016). This review finds that some domains of QoL are more strongly associated with NE (family function; self-worth: self-esteem; social relationships, and leisure time). Findings indicate that there may be an inverse relationship between QoL and age. There is evidence of a causal relationship between QoL and NE; two treatment outcome studies finding QoL gains resulting from successful NE treatment (Equit, Hill, Hübner, & von Gontard, 2014); Naitoh, Kawauchi, Soh, Kamoi, & Miki, 2012).

NE can be distressing especially for older children and teenagers. It can lead to problems of social isolation, stigmatisation, teasing or bullying (Butler, 1994; Hägglöf, Andren, Bergström, Marklund, & Wendelius, 1998; Morison, Tappin, & Staines, 2000). The Avon longitudinal study found over a third of children with NE reported being the victim of bullying; over 18% reported being unhappy with friendships (Joinson et al., 2007). Other authors have found that children with NE are concerned about the risk of their condition being found out at school, which can limit joining in peer group activities (Butler, Redfern, & Holland, 1994). The persistence of NE into adulthood has been found to impact on personal relationships, social life and employment ( Hirasing et al., 1997).

However, evidence suggests that successful intervention for NE can result in improvements in psychosocial functioning, including QoL (Naitoh et al., 2012); self-esteem and self-image (Hägglöf et al., 1998; Theunis et al., 2002).

**Family Impact**

Findings indicate that NE impacts not only on the child but also on parents and family. The relationship between NE and parenting stress has been explored by authors using the Parenting Stress Index (PSI). Parents of children with day and night wetting (De Bruyne et al., 2009), and those with PNE (Chang et al., 2002) reported significantly higher overall stress levels than parents of controls.

As regards parental QoL in children with NE: mothers of children with NE report significantly lower QoL than controls (Egemen, Akil, Canda, Ozyurt, & Eser
(2008); Meydan, Civilibal, Elevli, Duru, & Civilibal, 2012). Other areas of family impact include increased cost burden of laundry, cleaning, replacing soiled bedding and clothing as a result of NE (Pugner & Holmes, 1997). The majority of parents in a study by Chao, Yap, Tan, Ong, & Murugasu (1997) expressed a desire to have a break from this burden, as well as about half reporting sleep disruption as the reason for seeking NE treatment.

Chronic bedwetting within the family can lead to an increasing parental intolerance and blame (Butler, Brewin, & Forsythe, 1986), as well as verbal and physical aggression and punishment (Can, Topbas, Okten, & Kizil, 2004; Sapi, Vasconcelos, Silva, Damião, & da Silva, 2009), and neglect (Can et al., 2004).

**Treatments**

Children are generally expected to achieve lasting nighttime dryness by the age of 5 or the developmental age of 5, if they are chronologically older. Common clinical practice however usually considers treatment only for those aged 7 and over. NICE guidelines on the management of enuresis (2010) provide clear treatment recommendations for children and young people. First line treatment approaches to NE include general advice regarding optimising fluid intake, avoiding caffeine based drinks, eating well and regular toilet use. Rewards charts for helpful continence behaviours are also recommended (e.g. for appropriate drinking and toilet use). If these are unsuccessful, further treatment options include use of an enuresis alarm and/or use of desmopression (a synthetic form of vasopressin, a hormone that decreases production of urine). Treatment resistant cases may also access specialist paediatric bladder services for additional pharmacotherapy.

**Hypnosis Treatment for Primary Nocturnal Enuresis**

There is a body of evidence indicating that hypnosis is a valuable therapeutic approach in a variety of psychological difficulties in children and young people (Kohen & Olness, 2011). For hypnotic interventions with children, the evidence for hypnosis based interventions is amongst the best for enuresis (see review by Milling & Costantino, 2000). A range of studies using hypnosis as a treatment for PNE appear in the scientific literature. These are summarised below.

Baumann and Hinman (1974) were amongst the first to describe the use of hypnosis in treatment with children (aged 7-13) with continence problems. They used
anticholinergic medication and what they termed ‘positive suggestive therapy’ involving hypnosis. Around half of 62 children with NE (authors do not clarify if this was PNE or SNE), demonstrated an increase in dry nights at the end of therapy.

Olness (1975) used hypnosis as the primary treatment in a series of cases of 40 children aged 4.5-16, half with PNE (half SNE). Each child’s treatment was according to clinical need and the number of sessions and intervals between these were variable. Length of treatment ranged from 1-28 months; all interventions were tailored to a point to achieve dryness of only one wet night per month. Thirty one of 40 children achieved total nighttime dryness. This study used trance induction and suggestions to wake to use the toilet. The children were taught self-hypnosis (SH) and instructed to use this between appointments.

Stanton (1979) treated a series of 28 cases with NE (the author does not specify whether these had PNE or SNE), aged 7-18, using hypnosis. Seventy per cent became dry at night, after three sessions; 15 remained completely dry at two month follow. The five who did not get completely dry were the youngest end (aged 7-12). This study reported using trance induction through means of ego-enhancement suggestions and post-hypnotic suggestions about being dry at night.

Tilton (1980) described hypnosis with a child aged 8 with NE, (which via the author’s case vignette seems likely to have been PNE). The author described a TV screen technique for trance induction where the patient was instructed to co-pilot a space ship with the therapist who was the child’s favourite TV character, Buck Rogers. In-trance suggestions were made, following those made in waking state about holding onto urine (and faeces) as long as possible before toileting, to result in dry beds. Over the treatment, night wetting was eliminated and maintained at six month follow up.

Kohen, Olness, Colwell, and Heimel (1984) published data using SH for a variety of paediatric problems, including both primary and secondary NE. No precise specification of the SH protocol was given; authors describing that each case received hypnotic induction via ‘mental imagery and relaxation or slight variations thereof’ (pg.22). Forty five percent of the group of 257 with NE achieved dryness of 30 consecutive nights. This was maintained at 12 month follow up; 31% achieving dryness on 50% of nights or more.

Edwards and van der Spuy (1985) treated NE in 48 children aged 8-13 years, half of whom had PNE. Children received once a week hypnosis training sessions using pre-recorded general hypnosis audiotapes for six weeks, across three treatment
conditions: hypnosis plus suggestion; hypnosis alone, or suggestion alone plus no treatment control. The two treatment conditions (hypnosis plus suggestion and suggestion alone), resulted in significant improvements in the number of wet nights over baseline and during the treatment period. The hypnosis alone group and the controls showed no significant differences over the treatment period. However, the group that did best, and the only one that achieved statistically significant improvement in dryness over the follow up 6 month period over the no treatment group, was the waking suggestions only (no hypnosis) group. They describe in some detail their hypnosis which included trance induction (relaxation, eye heaviness and closure, and deepening sleepiness). Pre-recorded suggestions played via headphones involved general tension reduction, increasing self-confidence, with specific suggestions regarding increase in dry nights and benefits accruing because of these. They also included NE specific suggestions around increased bladder capacity, not drinking before bedtime, and waking to use the toilet in the night.

Banerjee, Srivastav, and Palan (1993) undertook a comparative study of medication (imipramine) and hypnosis with 50 children (44 with PNE, 6 SNE), aged 5-16. Participants received hypnosis intervention using favourite imagery, in-trance suggestions as regards the child’s competency in managing the NE, and specific suggestions regarding waking to use the toilet during the night. Participants were trained to use SH at bedtime each night. Outcomes showed similar levels of success (all dry beds) at 76% and 72% respectively. At 9 month follow-up, 68% of the hypnosis group maintained a positive response; only 24% of the medication group did so.

Gottesgen (2003) reported on four children with PNE aged 9-12, using hypnosis with each but in only one using conventional hypnotic trance induction accompanied by visualisation of brain-bladder connections. The others received only waking suggestion about dry beds. All became dry after one session. The author discusses the possibility that suggestion is the active therapeutic ingredient, rather than formal trance induction.

Diseth and Vandvik (2004) used hypnosis with 12 boys aged 8-16; eight with PNE, and four with mixed day and night wetting. At referral they had a median of 0 (range 0-3) dry nights per week. After a preliminary assessment of motivation, they underwent hypnotherapy over two to eight sessions. They were given training in SH which they used for median of one month after treatment end. Follow up was at 15 months, when 9 out of 12 patients had consistently achieved 6/7 or 7/7 dry nights per week.
Seabrook, Gorodzinsky, and Freedman (2005) compared hypnosis with alarm therapy in treatment of 96 children aged 7-12, all with PNE. Alarm therapy subjects were more likely than hypnotherapy subjects to achieve dryness (55.3% versus 19.4%). Alone amongst the studies they looked at psychological variables associated with PNE, but not as treatment outcomes. Identified reasons why hypnotherapy may not have been optimally effective, included inadequate establishment of therapeutic rapport. They report using a modified home SH protocol based on Kohen and Olness (1996).

Minosh, Schwartz, and Badalyan (2013) undertook a prospective long-term study of a group of 53 children, 17 of whom had NE (the authors do not make clear whether this was PNE or SNE). They were treated consecutively with hypnotherapy; 14 (82%) receiving >1 hypnotism sessions; mean number of sessions was 1.76. The authors developed their own rating system of success, finding that outcome of treatment using hypnosis was ‘good-to-excellent’ in 11 children (65%) and ‘poor-to-fair’ in 6 children (35%). As part of the hypnosis treatment protocol they taught participants SH. Only 3 participants (18%) undertook SH every day or a few times a week; 11 (64 %) never did. They detail the hypnosis as involving use of induction and relaxation, deep breathing techniques and visual imagery, with a deepening phase accompanied by hypnotic suggestion (no specific details are provided of this).

NICE guidelines (2010) on the management of NE make recommendations regarding the need for further investigation of the effectiveness of psychological treatments (e.g. Cognitive Behavioural Therapy) as well as ‘alternative’ therapies, with priority given hypnotherapy and acupuncture as areas of research. NICE highlight treatment outcomes of interest as: increase in number of dry nights; permanent or temporary nature of increased number of dry nights; self-esteem; QoL; costs, and social engagement. NICE also highlight the need to explore how NE impacts psychological functioning and QoL life of children and families, with particular regard to how these variables change post treatment.

Extant studies reveal an increasing body of evidence regarding the effectiveness of hypnosis as a treatment for PNE. Generally studies make some mention of content of hypnosis used, which include induction and deepening of trance state (the range of techniques is discussed in Kohen and Olness, 2011). Mention is made of post-hypnotic suggestions (suggestions made in-trance about actions to be performed when not in hypnosis) about having all dry nights; some use in-trance imagery of getting up and using the toilet (Banerjee et al., 1993; Stanton 1979; Tilton, 1980). Training in SH or
provision of audiofile for use between and after treatment is also a feature (Olness, 1975; Minosh, et al., 2013).

**The Present Study**

The present study aimed to explore the effects of a short, hypnosis-based intervention for children and young people with PNE. The primary hypothesis was that this approach would reduce bedwetting and increase number of dry nights. The study aimed to tailor the hypnosis approach according to the needs, imaginative capacity and interests of the child; to use suggestion and specific imagery regarding bladder control and waking in the night to use the toilet, as used in previous studies. It also used post-hypnotic suggestions.

Additional hypotheses were that this hypnosis based approach would, if successful, change psychosocial factors in children and young people thought to be impacted by bedwetting such as QoL, anxiety, mood and behavioural variables. Possible changes in psychosocial variables of parenting stress and QoL as reported by parents were also examined.

**Method**

**Participants**

Participants were recruited via a paediatrician with special interest in continence; the local children’s bladder and bowel service, and school nurse enuresis clinics. There was consecutive participant enrolment to minimise selection bias in the design: the first 10 families who contacted the study author to express interest in participating in the study, met inclusion criteria and were enroled. No potential participants were excluded. Ten children and young people (4 male, 6 female) agreed to participate ($M = 11.4$, $SD = 2.37$, range 8-16 years). All identified themselves as of white British ethnicity. All lived with one or more parents and attended mainstream schools. Eight attended for seven sessions (including five sessions of active hypnosis), and all of these attended follow up. \(^1\)Two dropped out after attending two and three sessions respectively. See Table 1 for participant details.

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\(^1\) See p.119 for further details of participants who dropped out.
### Table 1

**Participant Demographics, Medication, Health Issues and Referral Sources**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
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<th>Current NE Medication</th>
<th>Referral Source</th>
<th>Other issues</th>
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<tbody>
<tr>
<td>1</td>
<td>M</td>
<td>12</td>
<td>Detrusitol 2mg*</td>
<td>Bowel &amp; Bladder Team</td>
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<td>F</td>
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<tr>
<td>3</td>
<td>M</td>
<td>12</td>
<td>Desmopressin 240mcg</td>
<td>Bowel &amp; Bladder Team</td>
<td>N</td>
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<td>10</td>
<td>Desmopressin 240mcg</td>
<td>School Nurse</td>
<td>N</td>
</tr>
</tbody>
</table>

* Prescribed but not being taken.
<sup>1</sup>Vasovagal syncope with type 2 cardiac involvement with low blood pressure; main symptom is fainting (for p2 about four episodes of this a year). Management is drinking lots of fluid and salt supplements.
<sup>2</sup>Emotional difficulties including: anxiety; low self-esteem; anger and behavioural problems; self-harming behaviours; mild learning difficulties; victim of bullying. In follow-up period p5 was diagnosed with attention deficit disorder and mood disorder.
<sup>3</sup>Mild asthma; no regular medication.
<sup>4</sup>Migraines approximately every two months; no regular medication.

### Design

This study used a prospective case series with multiple-case AB design with follow-up (Barlow, Nock, & Hersen, 2008). The AB design enables observation of change in a variable (here dry nights) over time across a series of individual cases. This is a controlled pre-post design involving the collection of baseline (pre-treatment measures), in which each case acts as their own control (Yin, 2014). It looks at change across each individual case, rather than relying solely on group averages across phases of treatment. Each case had a series of dry night measures across time. These covered baseline, active hypnosis treatment, and 12-week follow-up phase. In order to examine secondary hypotheses, standardised measures of child and parent psychosocial function were collected at baseline; post-intervention (at last treatment appointment), and at 12-week follow-up.

### Measures

**Primary outcome measure.** This was a simple measure of dry nights achieved. Participants recorded dry nights for each night across all the phases of the study.
Secondary outcomes measures

Quality of life. The Paediatric Incontinence Questionnaire (Pin-Q) (Bower, Wong, & Yeung, 2006) is a QoL questionnaire for children and young people (aged 8-17) with enuresis. The Pin-Q has a child self-report version (Appendix A) as well as a parent/carer proxy report version (Appendix B); both were used. The questionnaire has 20 items which examine social relationships, self-esteem, family and home, body image, independence and mental health. Higher scores reflect greater impact of enuresis on QoL. The initial validation study (Bower et al., 2006) collected data from 10 countries, and found the Pin-Q to be free of item correlation, ceiling and floor effects. Rasch analyses showed the internal validity of both factor analysed subscales was ‘reasonably good’. Cronbach’s alphas for the intrinsic and extrinsic factors identified were 0.91 and 0.72 respectively. The only reliability and validity data of the shorter version of the Pin-Q (the form used here) is from a study using the German version. Cronbach’s alphas of 0.84 and 0.86 respectively were found for self-report and proxy report versions. As regards validity, the German version showed good correlation with another paediatric QoL measure (The 10-item DISABKIDS, a chronic illness generic measure, (Petersen et.al.2005)). Self-report and proxy-report version correlations were $r=0.71$ and 0.69 respectively, indicating good validity.

The World Health Organisation Quality of Life Questionnaire-Brief version (WHOQOL-BREF) (Appendix C) is a short (26 item) version of the WHOQOL-100 generic QoL scale for adults. It is widely used in health and psychological research. Its psychometric properties have been well established using cross-sectional data obtained from a survey of adults carried out in 23 countries (N = 11,830), (Skevington, Lotfy, & O’Connell, 2004).

Children’s emotional and behavioural functioning. The Beck Youth Inventories-Second Edition (BYI-II), (Beck, Beck, Jolly, & Steer, 2005), (Appendix D). This consists of five self-report inventories that can be used separately or in combination to assess symptoms of depression, anxiety, anger, disruptive behaviour and self-concept. They are designed for children and adolescents aged 7 to 18. The BYI-II subscales show good concurrent, convergent and divergent validity and test–retest reliability ($r_s$ varying between 0.69 and 0.93), and high internal consistency varying from 0.86 to 0.96 across subscales, gender and age.

The Strengths and Difficulties Questionnaire (SDQ), (Goodman, 1997), (Appendix E). This is a very widely used brief behavioural screening questionnaire
designed for children and young people aged 2-17. The version used here is the parent report version for 4-17 year olds including impact supplement. The SDQ has 25 questions which focus on behaviours across five subscales: emotional problems; conduct problems; hyperactivity/inattention; peer relationship problems as well as a prosocial behaviour subscale. The psychometric properties of the SDQ are well established and have been widely investigated cross culturally in several samples, with good UK data (Goodman, 2001).

**Parenting stress.** The Parenting Stress Index 4th Edition, Short Form (PSI-4-SF), (4th edition, Abdin, 2012), (Appendix F). This is a widely used parent report questionnaire designed to evaluate the types and degrees of stress in the parent-child system across child and parent domains. A total parenting stress score is also available. Internal consistency is high across both subscales varying from 0.75 to 0.88. Test–retest reliability is high for the total stress scores $r = 0.96$. The PSI-4-SF has been subject to extensive psychometric evaluation multi-nationally with good evidence of validity (Abdin, 2012).

**Other Measures**

**Hypnotisability.** The Stanford Hypnotic Clinical Scale for Children (SHCS-C), (Morgan & Hilgard, 1978), (Appendix G). This is a brief scale which measures hypnotisability and imaginative capabilities of children. The one used here is for children aged 6-16. The form is comprised of eye closure relaxation based induction, followed by six test items exploring hypnotisability across several different domains (e.g. sensory, kinaesthetic and auditory). The items are designed to be of interest to children and young people and be relevant to choice of hypnosis technique used in intervention.

In addition, some demographic information was collected to describe the participating group including child’s age and gender.

**Inclusion Criteria**

1. Children and young people were aged between 8 and 17. There is evidence for greater hypnotisability (and therefore greater chance of treatment success), in children aged 8 and over (Kohen & Olness, 2011). Most published studies in this area include children and young people aged over 8 for reasons of greater motivation of older children to engage in treatment, and therefore increased likelihood of treatment
compliance. For example, Banerjee et al., (1993) found that hypnosis was less effective in younger children (aged 5–7) compared to medication treatment for PNE, whereas for older children the response was similar across both treatments.

2. The child or young person had a diagnosis of PNE, and that this diagnosis had been made by a health professional.

**Exclusion Criteria**

1. The child or young person evidenced significant psychological difficulty which would contraindicate treatment with hypnosis, or significantly affect treatment engagement or compliance. This was assessed at initial appointment by the study author, an experienced clinical psychologist.

2. The child or young person had been diagnosed with a significant developmental disability such as autistic spectrum disorder, attention deficit hyperactivity disorder or global learning disability, which would have significantly affected engagement or compliance with hypnosis treatment. This was assessed at initial appointment by the study author.

3. Child's or young person’s first language was not English or child's understanding and use of English was not of a level where therapy using hypnosis would be considered to be likely to be effective. Case reports in the hypnosis literature discuss use of sign language interpretation of hypnosis for adults (Alderete, 1967) and children (Kohen, Mann-Rinehart, Schmitz, & Wills, 1998) who are deaf, but no papers examine language-based interpreter services for delivery of therapeutic hypnosis.

**Procedure**

Ethical approval was granted via NHS Research Ethics Committee (Appendix H). Local approvals were granted via the Research and Development Department of the host NHS trust (Appendix I) and neighbouring NHS trust acting as Patient Identification Centre (PIC) (Appendix J).

Potential participants were provided with an information pack given out by NHS staff in local continence services. In the pack was an introductory letter inviting the child and family to participate in the research (Appendix K), an information sheet for parents (Appendix L), as well as one of three age-differentiated information sheets for children and young people (Appendix M).

Families were asked to contact the study author if they wished to consider taking
part in the research or to discuss it further. When potential participants made contact, a brief telephone screening interview was undertaken by the study author to ascertain suitability for inclusion. If families wished to participate, an initial assessment appointment was arranged. At this appointment a comprehensive history of PNE was taken, as well as information about the child and family’s psychosocial circumstances. Informed consent was taken from parent and child at this first appointment (see Appendix N for parent consent form; Appendix O for child/young person consent form). Initial assessment included completion of psychosocial questionnaires by child and parent. The second appointment involved psychoeducation as regards bladder function and brain-bladder connections. A measure of the child’s hypnotisability (SHCS-C) was undertaken, and a hypnosis script was developed with the child.

Therapeutic hypnosis began in session three and continued over four subsequent sessions. Each session included therapist-delivered hypnosis. Participants were taught SH and/or received one or more individualised hypnosis audiofiles (based on in-session hypnosis), with instructions for daily use between sessions. Parents were advised how best to support treatment at home. Post-treatment questionnaires were administered to child and parent at the last treatment appointment. These were administered again at follow up; approximately 12 weeks after intervention end ($M= 88$, $SD = 10$ days, range 73-108 days).

Intervention

The treatment protocol was developed and implemented by the study author who is trained in hypnosis and has had four years ongoing supervised practise. The treatment intervention was comprised of five, 30-60 minute sessions. The intervention length was determined by evidence suggesting that if hypnosis is to be effective with PNE it will be so within the first three to four sessions (Kohen et al., 1984; Stanton, 1979). Locally, short interventions of up to six sessions have produced good outcomes. Most studies indicate up to three quarters of children achieve lasting night dryness within six or fewer appointments (Banerjee et al., 1993; Edwards & van der Spuy, 1985; Olness, 1975; Stanton, 1979). Intervals between treatment sessions varied ($M = 25.25$, $SD = 9.98$, range 14-62 days). This was dictated by the needs and commitments of the child and family (distance to travel, holidays etc), and therapist judgement. Participants were in active treatment phase for a mean of 97.13 days ($SD = 13.87$, range 84-123).

A tailored hypnosis script was developed for each participant. This was based on
their SHCS-C scores; personal preferences; strengths and difficulties (such as boredom threshold and distractibility), and interests. Standard induction, deepening and intensification techniques were used as described in the general children’s hypnosis literature (e.g. Kohen & Olness, 2011). Elements included in hypnosis scripts were those found by the author to have been clinically effective in NE treatment. These included specific in-trance visualisations to increase the size and strength of the bladder; the strength of the bladder gate/door; the bladder filling and needing to empty, as well as imagery to deliver a message from the bladder gate/door to the child’s brain to wake it up. Also included were visualisations of waking in the night (with accompanying emotional suggestions e.g. the child being pleased, happy or surprised by this) (Olness 1975; Stanton, 1979); getting up and using the toilet (Edwards & van der Spuy, 1985), and going back to bed and waking in the morning with a dry bed (Kohen & Olness, 2011).

Post-hypnotic suggestions were also made regarding the child being in control of his/her bladder and its door/gate; of these being strong enough to hold throughout the night (Edwards & van der Spuy, 1985; Stanton, 1979), but if needed, to be able to wake and use toilet (Banerjee et al., 1993; Edwards & van der Spuy, 1985; Olness, 1975). Also included were post-hypnotic suggestions that regular practise of SH or audiofile listening would result in more bladder and gate control, more waking and more dry nights.

Each intervention session proceeded in a similar way with review of dry nights since the previous session; discussion and alterations of the script with the child if any changes were required due to boredom or lack of engagement with imagery, as well as problem solving with child and parent if home practise was problematic.

Results

Eight of the 10 participants completed the intervention, and the results are based on these. Group level results are presented first. These are followed by detailed results for each participant. Table 2 shows the results of the SHCS-C questionnaire which are discussed later in the text detailing the tailoring of hypnosis for participants.
Table 2

Results of and Comments on SHCS-C Questionnaire

<table>
<thead>
<tr>
<th>Participant</th>
<th>SHS-C score</th>
<th>Time* Distortion</th>
<th>Highest Scoring Items</th>
<th>Psychomotor** Retardation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>7</td>
<td>Y</td>
<td>All</td>
<td>Y Voice low and slow</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>Y</td>
<td>Kinaesthetic</td>
<td>Y Delay in response to questions</td>
</tr>
<tr>
<td>3</td>
<td>6</td>
<td>Y</td>
<td>Most, poor auditory</td>
<td>Y Voice slow and quiet</td>
</tr>
<tr>
<td>4</td>
<td>6</td>
<td>Y</td>
<td>Most poor auditory</td>
<td>Y Relaxed posture</td>
</tr>
<tr>
<td>5</td>
<td>6</td>
<td>N</td>
<td>Most, memory good</td>
<td>N</td>
</tr>
<tr>
<td>6</td>
<td>4</td>
<td>Y</td>
<td>Memory, poor auditory</td>
<td>Y Relaxed, head to one side</td>
</tr>
<tr>
<td>7</td>
<td>4</td>
<td>N</td>
<td>Kinaesthetic, poor auditory</td>
<td>Y Didn’t notice baby crying in hall</td>
</tr>
<tr>
<td>8</td>
<td>7</td>
<td>Y</td>
<td>All</td>
<td>N</td>
</tr>
</tbody>
</table>

*Refers to inaccurate estimation by participant in of time in trance. This is associated with greater depth of trance, therefore is a guide to participants’ hypnotisability.

** Refers to slowing of motor and vocal responses in trance. This is associated with greater depth of trance, and therefore is a guide to participants’ hypnotisability.

Group Results

All outcome measures (dry nights and psychosocial measures) were subject to comparison between phases by undertaking Friedman’s tests (see Table 3).

Table 3

Child and Parent Psychosocial Measures at Baseline, Post-Intervention and Follow Up

<table>
<thead>
<tr>
<th>Measure</th>
<th>Baseline</th>
<th>Intervention</th>
<th>Follow up</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Md(IQR)</td>
<td>Md(IQR)</td>
</tr>
<tr>
<td>Percentage Dry Nights</td>
<td>8</td>
<td>11.92 (17.10)</td>
<td>46.94 (20.94)</td>
</tr>
<tr>
<td>Child/Young Person Pin-Q</td>
<td>7</td>
<td>38.00 (11.00)</td>
<td>32.00 (31.00)</td>
</tr>
<tr>
<td>BYI-II</td>
<td>7</td>
<td>36.00 (20.00)</td>
<td>37.00 (19.00)</td>
</tr>
<tr>
<td>Self-Concept</td>
<td>7</td>
<td>46.00 (19.00)</td>
<td>48.00 (16.00)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>7</td>
<td>46.00 (22.00)</td>
<td>47.00 (12.00)</td>
</tr>
<tr>
<td>Depression</td>
<td>7</td>
<td>51.00 (20.00)</td>
<td>40.00 (16.00)</td>
</tr>
<tr>
<td>Anger</td>
<td>7</td>
<td>45.00 (10.00)</td>
<td>45.00 (11.00)</td>
</tr>
<tr>
<td>Disruptive Behaviour</td>
<td>7</td>
<td>29.00 (20.00)</td>
<td>19.00 (13.00)</td>
</tr>
<tr>
<td>Parent Pin-Q</td>
<td>7</td>
<td>9.00 (19.00)</td>
<td>8.00 (15.00)</td>
</tr>
<tr>
<td>SDQ</td>
<td>7</td>
<td>52.00 (17.00)</td>
<td>48.00 (22.00)</td>
</tr>
<tr>
<td>PSI-4-SF</td>
<td>5</td>
<td>80.36 (25.00)</td>
<td>87.5 (14.29)</td>
</tr>
<tr>
<td>WHOQL-BREF</td>
<td>6</td>
<td>70.86 (16.67)</td>
<td>72.93 (8.33)</td>
</tr>
<tr>
<td>Physical Health</td>
<td>6</td>
<td>75.00 (16.66)</td>
<td>83.33 (16.67)</td>
</tr>
<tr>
<td>Psychological</td>
<td>6</td>
<td>76.57 (15.62)</td>
<td>73.44 (15.62)</td>
</tr>
</tbody>
</table>

* Significant at p < .05
Two-tailed Wilcoxon signed-rank tests were conducted post hoc on those variables in Table 3 showing significant change across phases; Bonferroni corrections were applied, and significance level was set at $p < 0.017$.

**Dry Nights.** Friedman’s test revealed a statistically significant difference in percentage of dry nights between phases (Table 3). There was a significant increase in percentage of dry nights between baseline and intervention phases ($Z = 2.52, p = 0.012$) with large effect size (ES) ($r = -0.630$); and also between baseline and follow up phases ($Z = 2.52, p = 0.012$) with large ES ($r = -0.630$). No significant increase in percentage of dry nights was found between intervention and follow up phases ($Z = 1.82, p = 0.069$), with medium ES ($r = -0.455$).

**Child and Parent Psychosocial Measures.** The child self-report Pin-Q showed no significant QoL change from baseline to end of intervention ($Z = 1.86, p = 0.063$), with medium-large ES ($r = 0.498$). However the decrease in scores (representing an increase in QoL), very closely approached corrected significance between baseline and follow up ($Z = 2.37, p = 0.018$) with large ES ($r = 0.632$). No significant change in QoL was found between end of intervention and follow up phases ($Z = 1.35, p = 0.176$), with medium ES ($r = 0.361$).

As regards the BYI-II Anger subscale; after Bonferroni corrections were applied no significant change in anger scores were found between baseline and end of intervention ($Z = 1.52, p = 0.128$), with medium-large ES ($r = 0.407$); between baseline and follow up phases ($Z = 2.20, p = 0.028$), with large ES ($r = 0.588$); or between end of intervention and follow up phases ($Z = 1.45, p = 0.149$), with medium ES ($r = 0.386$).

No significant changes in scores were found across the three phases of the study for the remainder of the psychosocial measures.

**Individual Results**

Table 4 shows percentage dry nights for each participant across each phase. Weekly dry nights for each participant across phases can be found in Figures 1-8.
Table 4  
*Percentage Dry Nights for all Participants across Phases*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Baseline</th>
<th>Intervention</th>
<th>Follow up</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% Dry nights (dry nights / Σ nights)</td>
<td>% Dry nights (dry nights / Σ nights)</td>
<td>% Dry nights (dry nights / Σ nights)</td>
</tr>
<tr>
<td>1</td>
<td>20 (5/25)</td>
<td>66 (81/123)</td>
<td>81 (68/84)</td>
</tr>
<tr>
<td>2</td>
<td>54 (15/28)</td>
<td>85 (71/84)</td>
<td>93 (85/91)</td>
</tr>
<tr>
<td>3</td>
<td>0 (0/30)</td>
<td>31 (31/101)</td>
<td>25 (27/108)</td>
</tr>
<tr>
<td>4</td>
<td>12 (3/25)</td>
<td>42 (38/90)</td>
<td>56 (41/73)</td>
</tr>
<tr>
<td>5</td>
<td>2 (1/50)</td>
<td>55 (61/111)</td>
<td>57 (48/84)</td>
</tr>
<tr>
<td>6</td>
<td>12 (11/93)</td>
<td>47 (40/86)</td>
<td>74 (62/84)</td>
</tr>
<tr>
<td>7</td>
<td>17 (13/78)</td>
<td>47 (45/95)</td>
<td>74 (62/84)</td>
</tr>
<tr>
<td>8</td>
<td>0 (0/54)</td>
<td>37 (29/79)</td>
<td>31 (24/77)</td>
</tr>
</tbody>
</table>

The time-series data for each case was also analysed individually using Simulation Modelling Analysis (SMA). This was developed by Borckardt et al. (2008) as an approach to the analysis of short, autocorrelated data streams found in clinical practice. Borckardt and Nash (2014) describe how for AB designs as used here, using time series data (~5 data points per phase), SMA can offer adequate control of type 1 and type 2 error rates and be powered to detect relatively small effect-sizes (adequate power, > .80, with five data points per phase with a $5SD$ effect size). The approach taken can use parametric calculations (Pearson’s $r$), but the assumption was made that the data was unlikely to be normally distributed and the non-parametric equivalent, Spearman’s $Rho$ was used.

Using the method defined by Jacobson and Truax (1991), the Reliable Change Index (RCI) was calculated across the standardised questionnaire data where psychometric data was available. Reliable change calculations were made for all questionnaire data apart from the Pin-Q, where reliability data is available for the German version only, which was not judged appropriate to use in this instance. Furthermore if a reliable change was identified, it could then be identified as a ‘reliable and clinically significant’ change if the magnitude of change meant that it crossed an identified clinical cut-off score. This was calculable only for the BYI-II, the only questionnaire used in the present study with available population means (and $SD$s) for clinical and non-clinical groups, needed to calculate whether a reliable change is also clinically significant. Table 5 shows the results of phase level changes in dry nights for
All participants.

Table 5

*Phase Level Change in Number of Dry Nights for Participants*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Baseline to Intervention</th>
<th>Intervention to follow up</th>
<th>Baseline to follow up</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Rho p</td>
<td>Rho p</td>
<td>Rho p</td>
</tr>
<tr>
<td>1*</td>
<td>0.55 0.0244*</td>
<td>0.21 0.140</td>
<td>0.67 0.0242*</td>
</tr>
<tr>
<td>2</td>
<td>0.67 0.0410*</td>
<td>0.36 0.160</td>
<td>0.76 0.0001**</td>
</tr>
<tr>
<td>3</td>
<td>0.74 0.0001**</td>
<td>-0.16 0.601</td>
<td>0.68 0.0100*</td>
</tr>
<tr>
<td>4*</td>
<td>0.71 0.0001**</td>
<td>0.49 0.063</td>
<td>0.76 0.0001**</td>
</tr>
<tr>
<td>5</td>
<td>0.83 0.0001**</td>
<td>-0.02 0.968</td>
<td>0.78 0.023*</td>
</tr>
<tr>
<td>6</td>
<td>0.88 0.0001**</td>
<td>0.67 0.034*</td>
<td>0.89 0.0001**</td>
</tr>
<tr>
<td>7</td>
<td>0.75 0.0422*</td>
<td>0.64 0.115</td>
<td>0.90 0.0001**</td>
</tr>
<tr>
<td>8</td>
<td>0.81 0.005*</td>
<td>-0.21 0.386</td>
<td>0.82 0.002*</td>
</tr>
</tbody>
</table>

* Significant at p <.05
** Significant at p <.001

+Findings should be considered cautiously as these cases have only 3 data points at baseline phase compared with 4 or more of other cases.

All participants showed significant increase in number of dry nights from baseline to intervention, maintaining this at follow up. Only participant 6 (“Dan”) showed significant increase in dry nights from intervention to follow up.

**Participant 1 (“Sam”).** Sam, 12, achieved daytime dryness within normal developmental timeframes, but had never been dry at night for more than about a week. He had no history of daytime continence issues. Both his parents were late to achieve night dryness. Sam had been known to bladder services since age 6. He had undertaken bladder training (drinking more during the day, and restricting drinking after 6pm). He still drank a lot during the day, but found it difficult to restrict drinking late at night as he did a lot of sport, and so needed to rehydrate later in the day. Sam had no bladder abnormalities. Sam had been prescribed medication previously but had discontinued this due to lack of effect. He had tried alarm therapy several times for periods of a few weeks at a time since age 9; but the family found this very disruptive to sleep, and so discontinued. Sam was described as ‘soaked’ most nights; he wore pull ups and the bed was protected. Sam was noted to be a very heavy sleeper and never woke in the night to use the toilet or when wet.
Elements of note in hypnosis. Sam scored 7 on the SHCS-C, indicating high levels of hypnotisability. He demonstrated good imaginative capacities across most items. Sam’s hypnosis script was straightforward to develop with him, due to his broad imaginative capacities and high suggestibility. Sam chose SH rather than use an audiofile between sessions. Sam worked hard with SH and was very determined, but at times because of his full schedule he struggled to do SH every day. Sam had an immediate response to the first session of hypnosis, for the first time ever that night he woke and used the toilet and had a dry night.

Sam’s images were sometimes a little uncontrollable in his SH. He reported a problem with imagining getting up and using his toilet in his house; often finding himself using a shed outside, which he found slightly disturbing. This was discussed and managed by implementing an audiofile with clear suggestions and imagery about which toilet to use. In his SH he developed an image of a message being taken to his brain by a person. This had been the fictional character ‘Willy Wonka’ but latterly in SH, this had been the comedy character ‘Mr Bean’, who had not been doing the job well. This was framed as perhaps him lacking confidence, and was addressed by discussing who might be more competent for this job, then incorporating the outcome (his father), into his hypnosis script. Sam maintained progress over the follow up period. He reported cutting down use of SH to once or twice a week with no impact on frequency of dry nights. He used SH for a couple of days after a wet night. He experienced some life events which impacted on dryness e.g. his pet died, and Sam was very wet all the following week. Figure 1 shows Sam’s change in dry nights per week across the three study phases.
Figure 1. Dry nights per week (Sam)

Table 6

Scores on the Standardised Measures (Sam)

<table>
<thead>
<tr>
<th>Measure</th>
<th>Baseline</th>
<th>Post-Intervention</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child/young person</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pin-Q</td>
<td>39</td>
<td>42</td>
<td>16</td>
</tr>
<tr>
<td>BYI-II -Self-Concept</td>
<td>52</td>
<td>54</td>
<td>61</td>
</tr>
<tr>
<td>BYI-II -Anxiety</td>
<td>56</td>
<td>48&lt;sup&gt;RCI&lt;/sup&gt;</td>
<td>42</td>
</tr>
<tr>
<td>BYI-II -Depression</td>
<td>52</td>
<td>44&lt;sup&gt;RCI&lt;/sup&gt;</td>
<td>37&lt;sup&gt;RI&lt;/sup&gt;</td>
</tr>
<tr>
<td>BYI-II -Anger</td>
<td>51</td>
<td>40&lt;sup&gt;RCI&lt;/sup&gt;</td>
<td>36</td>
</tr>
<tr>
<td>BYI-II -Disruptive Behaviour</td>
<td>45</td>
<td>41</td>
<td>35</td>
</tr>
<tr>
<td>Parent</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pin-Q</td>
<td>28</td>
<td>12</td>
<td>4</td>
</tr>
<tr>
<td>SDQ</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>PSI-4-SF</td>
<td>34</td>
<td>34</td>
<td>34</td>
</tr>
<tr>
<td>WHOQL-BREF</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Health</td>
<td>78.57</td>
<td>85.71&lt;sup&gt;RI&lt;/sup&gt;</td>
<td>85.71</td>
</tr>
<tr>
<td>Psychological</td>
<td>75</td>
<td>75</td>
<td>79.16</td>
</tr>
<tr>
<td>Social Relationships</td>
<td>91.67</td>
<td>91.67</td>
<td>100&lt;sup&gt;RI&lt;/sup&gt;</td>
</tr>
<tr>
<td>Environment</td>
<td>78.13</td>
<td>93.75&lt;sup&gt;RI&lt;/sup&gt;</td>
<td>100&lt;sup&gt;RI&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

<sup>RI</sup> Reliable improvement from previous time-point
<sup>RCI</sup> Reliable and clinically significant improvement from previous time-point

Sam showed reliable and clinically significant improvement in three BYI-II subscales levels (anxiety, anger and depression), from baseline to post-intervention; the latter subscale showing reliable improvement from post-intervention to follow up (Table 6). The majority of Sam’s levels on the BYI-II across the 3 phases fell within the average range, as did his mother’s rating of his emotions and behaviour (SDQ) which put him at within the normal range and at low risk of any disorder. Her parenting stress
levels all fell within the average range across phases. Sam’s mother’s QoL levels showed reliable improvements across several domains from baseline to post-intervention and then again from post-intervention to follow up.

**Participant 2 (“Emma”).** Emma, 16, struggled to achieve day and nighttime urinary continence. Her father wet at night until his teenage years. The family first sought help when Emma was age 4-5 and still wet every day and night. She had a lot of bladder infections in her early years for which she took antibiotics. Emma was first seen by continence services at age 5, and undertook bladder training and reward charts for day wetting with no improvement. Bladder function tests were normal. The family bought an alarm, and used it for about a year intermittently, but with no success, as Emma did not wake. Her mother used to lift Emma and take her to the toilet during the night when younger. Emma got dry in the day in secondary school. Aged 10, Emma was referred to paediatrician with special interest in bladder issues and was prescribed medications for both DE and NE which she took for a few years with little improvement. Emma discontinued her medications several months before enrolling in the study. On enrolment, Emma was wet 1-2 nights a week. She wore pull ups in bed; the bed was not protected.

Emma reported sleeping very deeply. She had never woken in night to use the toilet. Emma had a session of private hypnosis a few months before enrolling in the study which was short (five minutes), but improved NE a little. Her mother discontinued the input after one session, as she felt that the therapist was too insistent in trying to sell a wider package of treatment for emotions.

**Elements of note in hypnosis.** Emma scored 2 on the SHCS-C indicating low levels of hypnotisability. She demonstrated adequate imaginative capacities with the kinaesthetic items of the SHCS-C, but across other items found it very difficult to create images or sounds. She could summon emotional feelings of being somewhere; on the memory item of the SHCS-C she described the feeling of being relaxed while on a holiday, but could not ‘see’ the beach where she was. Her lack of visual imagery was characteristic of congenital aphantasia, recently proposed by Zeman, Dewar, and Della Sala (2015) to describe the condition of having little or absent voluntary visual imagery. This is similar to previously used terms such as ‘defective revisualisation’ (Botez, Olivier, Vezina, Botez, & Kaufman, 1985). Clinical impression on undertaking SHCS-C was that Emma was trying to create imagery, but found it difficult and this failure
caused her some anxiety. This was addressed in therapy via the adoption of a non-directive approach which involved focus on ‘sensing’ in hypnosis rather than ‘seeing’ or ‘hearing’. Hypnosis used Hammond’s (1990) suggested phrases such as ‘I wonder if you’ll decide to…’, and ‘One of the things you may become aware of…’ to enhance Emma’s creative finding of solutions as an alternative to generating images.

Emma’s hypnosis script focussed on helping her to sense the feeling, for example of moving down ladder in the deepening phase of hypnosis rather than ‘seeing’ an image, and of feeling emotions to do with place and time. She also read words on a screen (rather than seeing images), to deliver the message to her brain that her bladder was full, and she needed to wake up.

As therapy proceeded it became clear that engaging Emma verbally during hypnosis affected the depth of her trance, and so this was discontinued. Emma chose SH rather than audiofile and worked hard at this over the intervention period, cutting down to the point of cessation over the follow up, using only when needed. Over the five sessions there were no changes to the script as it was delivered each session. Emma had some life events; she changed school and got a different part-time job, both of which impacted somewhat for a short period on dryness at night. Figure 2 shows Emma’s change in dry nights per week across the three study phases.

*Figure 2. Dry nights per week (Emma)*
### Table 7

*Scores on the Standardised Measures (Emma)*

<table>
<thead>
<tr>
<th>Measure</th>
<th>Baseline</th>
<th>Post-Intervention</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child/young person</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pin-Q</td>
<td>38</td>
<td>25</td>
<td>33</td>
</tr>
<tr>
<td>BYI-II -Self-Concept</td>
<td>34</td>
<td>35</td>
<td>35</td>
</tr>
<tr>
<td>BYI-II -Anxiety</td>
<td>59</td>
<td>56</td>
<td>57</td>
</tr>
<tr>
<td>BYI-II -Depression</td>
<td>61</td>
<td>55&lt;sup&gt;RI&lt;/sup&gt;</td>
<td>56</td>
</tr>
<tr>
<td>BYI-II -Anger</td>
<td>58</td>
<td>53</td>
<td>50</td>
</tr>
<tr>
<td>BYI-II -Disruptive Behaviour</td>
<td>42</td>
<td>41</td>
<td>47</td>
</tr>
<tr>
<td><strong>Parent</strong></td>
<td></td>
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<td>Pin-Q</td>
<td>34</td>
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<td>SDQ</td>
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<td>Physical Health</td>
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<td>Psychological</td>
<td>-</td>
<td>58.33</td>
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<td>Social Relationships</td>
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<td>58.33</td>
<td>66.66&lt;sup&gt;RI&lt;/sup&gt;</td>
</tr>
<tr>
<td>Environment</td>
<td>-</td>
<td>65.63</td>
<td>-</td>
</tr>
</tbody>
</table>

<sup>RI</sup> Reliable improvement from previous time-point

* Questionnaire not completed as Emma was outside the age range on which it was normed.

Table 7 shows Emma had a mixed picture of BYI-II subscale scores at baseline: she showed much lower than average self-concept levels; as well as moderately elevated depression and mildly elevated anxiety levels. She showed reliable improvement in depression level from baseline to post-intervention. Her parent-report emotional and behavioural (SDQ) score put her at low risk of any disorder across phases, and her scores decreased from borderline abnormal levels across baseline and intervention phases to within normal range at follow up. Emma’s mother’s QoL measure was largely unscorable at baseline and follow up due to being incompletely filled in. However her Social Relationships dimension of QoL did show reliable improvement from post-intervention to follow-up.

**Participant 3 (“Ben”).** Ben, 12, was very slow to get dry in the day. Ben’s mother and sister were late to be dry at night. The family first sought help for DE when Ben was age 5. Ben did bladder training which was not very successful. He had medication and behavioural therapy for DE, which at the time of enrolment in the study had almost remitted. Ben was identified as having a small bladder, and was supposed to drink more to improve his bladder capacity, but found this challenging. Ben had previous soiling issues, but had never been constipated. Ben had taken desmopressin
for several years, but had very rarely had a dry night. He wore pull ups every night; the bed was also protected. Ben was a heavy sleeper, and did not wake to use the toilet at night. **Elements of note in hypnosis.** Ben scored 6 on the SHCS-C, indicating high levels of hypnotisability. He demonstrated good imaginative capacities across most items; apart from auditory items, which were then minimised during hypnosis. Ben’s script was developed with him electing to use images from electronic gaming, especially ‘Minecraft’. He was very enthusiastic about undertaking hypnosis and created quite intense and complex images with little suggestion. Due to Ben’s identified small bladder, suggestions were made which encouraged him to visualise his bladder as very stretchy, with strong walls and a strong gate holding urine in and being able to contain as much as it needed to in the night. He generated an idea of a line of marching ants (from the film ‘Antz’) marching up to his brain to deliver the message that he needed to wake up and use the toilet.

On presentation, Ben was verbally impulsive, fidgety, and inattentive. Ben chose SH, as he reported he would get bored with the same audiofile. Two audiofiles for back up were also produced, as Ben got bored with his own SH and tended to avoid it, often missing several nights a week practise during treatment phase. Ben did start to wake in the night to use the toilet after initial session of hypnosis. However he would wake up to four times a night, but both Ben and his mother were concerned regarding sleep disruption. Subsequent sessions focussed more on imagery of Ben’s bladder and gate on his bladder being big and strong, rather than waking in the night.

Ben lost motivation over the follow up period. Ben’s older sister left for university in follow up and he had two viral illnesses which impacted on his nighttime dryness. He stopped using his audiofiles and SH and did not want to continue, feeling his efforts had not been rewarded by a sufficient increase in dry nights. Figure 3 shows Ben’s dry nights per week across the three study phases.
Figure 3. Dry nights per week (Ben)

Table 8
Scores on the Standardised Measures (Ben)

<table>
<thead>
<tr>
<th>Measure</th>
<th>Baseline</th>
<th>Post-Intervention</th>
<th>Follow-up</th>
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<tr>
<td>Pin-Q</td>
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<td>BYI-II -Self-Concept</td>
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<td>BYI-II -Anxiety</td>
<td>55</td>
<td>-</td>
<td>39</td>
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<tr>
<td>BYI-II -Depression</td>
<td>37</td>
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<td>36</td>
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<tr>
<td>BYI-II -Anger</td>
<td>41</td>
<td>-</td>
<td>32</td>
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<tr>
<td>BYI-II -Disruptive Behaviour</td>
<td>38</td>
<td>-</td>
<td>37</td>
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<tr>
<td>Parent</td>
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</tr>
<tr>
<td>Pin-Q</td>
<td>51</td>
<td>-</td>
<td>40</td>
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<tr>
<td>SDQ</td>
<td>19</td>
<td>-</td>
<td>10</td>
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<td>PSI-4-SF</td>
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<td>37</td>
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<td>Social Relationships</td>
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<tr>
<td>Environment</td>
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<td>-</td>
<td>93.75</td>
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</tbody>
</table>

Little can be assessed regarding change in Ben’s psychosocial measures across phases as due to an administration error they were not collected at post-intervention.

Participant 4 (“Kay”). Kay, 11, was dry during the day at a developmentally appropriate time. There was an extensive family history of PNE on both sides: Kay’s father was wet intermittently till aged 9; both maternal uncles were wet at night until teenagers; maternal grandfather and his four brothers were all late to get dry, as was a
At time of enrolment, Kay had never been dry consistently at night; having perhaps one dry night a week. Kay had phases of dryness in past; with rare occasions of a whole week of dryness. Kay accessed continence services at age 6. She had an alarm for a few months at that age, but it didn’t wake her up, and the family discontinued. Kay had been identified as having a small bladder. She had never woken to use the toilet, and did not wake when she had wet the bed. Kay had taken medication in the past which reduced with the amount of urine she produced at night, but did not help achieve dryness. Medication was discontinued a few months before enrolment.

**Elements of note in hypnosis.** Kay was a very motivated participant with a good range of imaginative capacities across all sensory domains, scoring 6 on the SHCS-C, indicting high hypnotisability. Kay was well able to generate her own imagery with little suggestion. Due to Kay’s identified small bladder, hypnosis focussed on imagery which encouraged visualisation of her bladder as strong, stretchy with a strong gate and able to hold as much urine as it needed to in the night. Kay created an image of the message to her brain being delivered by lots of little people, rushing to her brain in an elevator and banging gongs to wake her up to use the toilet. Kay chose audiofiles over SH and practised every day. Short and long audiofiles were provided, and latterly Kay learnt SH as she reported the audiofiles were becoming boring; she used both interchangeably. Shortly into the treatment, Kay was seen by parents using toilet in the night, but was reported to be asleep and did not recall waking. Suggestions to this effect were incorporated: that Kay’s body would know what to do when she needed the toilet in the night, and included the imagery of ‘watching’ herself getting up out of her bed to use the toilet rather than ‘finding’ herself doing this; suggestions were made that she may or may not be awake, and that this was fine. Kay maintained her almost daily practise over the treatment and follow up phases. Figure 4 shows Kay’s dry nights per week across the three phases of the study.
**Figure 4.** Dry nights per week (Kay)

![Graph showing dry nights per week (Kay)](image)

**Table 9**

*Scores on the Standardised Measures (Kay)*

<table>
<thead>
<tr>
<th>Measure</th>
<th>Baseline</th>
<th>Post-Intervention</th>
<th>Follow-up</th>
</tr>
</thead>
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<tr>
<td><strong>Child/young person</strong></td>
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<td></td>
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<tr>
<td>Pin-Q</td>
<td>38</td>
<td>11</td>
<td>12</td>
</tr>
<tr>
<td>BYI-II -Self-Concept</td>
<td>36</td>
<td>37</td>
<td>34</td>
</tr>
<tr>
<td>BYI-II -Anxiety</td>
<td>38</td>
<td>44</td>
<td>45</td>
</tr>
<tr>
<td>BYI-II -Depression</td>
<td>39</td>
<td>37</td>
<td>35</td>
</tr>
<tr>
<td>BYI-II -Anger</td>
<td>41</td>
<td>38</td>
<td>36</td>
</tr>
<tr>
<td>BYI-II -Disruptive Behaviour</td>
<td>45</td>
<td>43</td>
<td>41</td>
</tr>
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<td><strong>Parent</strong></td>
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</tr>
<tr>
<td>Pin-Q</td>
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<td>10</td>
</tr>
<tr>
<td>SDQ</td>
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<td>8</td>
<td>4</td>
</tr>
<tr>
<td>PSI-4-SF</td>
<td>52</td>
<td>51</td>
<td>50</td>
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<tr>
<td><strong>WHOQL-BREF</strong></td>
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<tr>
<td>Physical Health</td>
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<td>92.86</td>
<td>78.58RW</td>
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<tr>
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<td>66.67</td>
<td>70.83</td>
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<tr>
<td>Social Relationships</td>
<td>58.53</td>
<td>66.67RI</td>
<td>75RI</td>
</tr>
<tr>
<td>Environment</td>
<td>81.25</td>
<td>71.88RW</td>
<td>71.88</td>
</tr>
</tbody>
</table>

RW: Reliable worsening from previous time-point
RI: Reliable improvement from previous time-point

Kay showed much lower than average BYI-II self-concept across the three phases (Table 9). Her remaining BYI-II levels all fell within the average range across the three phases of the study, and did not show any reliable change across phases. Kay’s father’s scores of Kay’s emotional and behavioural functioning (SDQ) showed low risk of any disorder across phases and all fell within the normal range. His parenting stress levels (PSI-4-SF) were within the average range across all phases. Kay’s father’s QoL
measures showed a mixed picture of reliable improvement in Social Relationships across phases, with reliable worsening of Environment aspect of QoL from baseline to post-intervention, and of Physical Health aspect of QoL from post-intervention to follow up.

Participant 5 (“Dee”). Dee, 12, was slow to be dry in the day and had one dry night about every two months. She woke very rarely to use toilet in the night, but if she did this she would have dry night. Dee had a paternal cousin who was not dry at night until her teens. Dee presented to continence services at age 6 and undertook bladder training. She was referred on to a specialist continence paediatrician who prescribed medication for DE and NE, which she was still taking. At time of enrolment she was mostly dry during the day. Dee had an identified overactive bladder. Alarm therapy was suggested by continence services, but parents didn’t try this as they thought it would not wake Dee. She was woken/and or lifted for while at night, but slept so deeply it was difficult to rouse her, so this was discontinued a few years ago; parents re-tried this approach intermittently with no success. Dee wore pull ups in bed, which were soaking most mornings.

Elements of note in hypnosis. Dee scored 6 on the SHCS-C indicating high levels of hypnotisability. Dee had an interesting imagination, quite whimsical and like that of a younger child. For example when instructed as part of the administration of the SHCS-C to visualise a heavy rock in her hand, Dee experienced a baby elephant in her hand rather than a rock. Dee had an atypical social presentation; showing non-typical conversational patterns and social skills. She presented as immature, impulsive, inattentive and had some oppositional tendencies, of which there was a need to be cognisant by being non-directive in hypnosis. This approach allowed her to control her own images and Dee was very precise, detailed and protracted about the contents of her imagination which included lots of sweets, animals, friends and parties. Dee’s difficulties with attentional focus and distractibility were managed in hypnosis by shortening the induction and deepening procedures, and moving quickly to elements of the hypnosis which she could control and was therefore more interested in. Hypnosis was also delivered with a high level of vocal novelty e.g. changing tone, volume and emphases throughout. The hypnosis script was different every session at Dee’s request. Hypnosis had some focus on calming and stillness in her bladder, due to its overactivity.

Several audiofiles were produced over the course of intervention to allow for
Dee’s preference for novelty. Self-hypnosis was not offered, as it was judged that Dee would not be able to focus sufficiently on the actively therapeutic elements. Hypnosis included an element of Dee seeing her mother’s face looking pleased after a dry night, as it was judged that Dee was very dependent on parental support and praise.

The intervention was protracted as sessions were cancelled and missed by the family. Dee had several life events impacting on attendance, her use of audiofiles and her NE and DE. During the active treatment period she had a period of viral illness like the flu; she experienced ongoing bullying at school, and during the 12 week follow up period was stabbed in the arm with a penknife at school. She was diagnosed privately by a psychiatrist with a mood disorder and Attention Deficit Disorder, but no therapy was started. Dee was inconsistent with her home hypnosis practise from initial stages, stopping completely at start of follow up phase, her mother reporting that life was quite stressful for Dee and motivation to practise was low. Figure 5 shows Dee’s dry nights per week across the three study phases.

Figure 5. Dry nights per week (Dee)
Table 10

*Scores on the Standardised Measures (Dee)*

<table>
<thead>
<tr>
<th>Measure</th>
<th>Baseline</th>
<th>Post-Intervention</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child/young person</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Pin-Q</td>
<td>58</td>
<td>46</td>
<td>40</td>
</tr>
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<td>BYI-II -Self-Concept</td>
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<td>30</td>
<td>30</td>
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<tr>
<td>BYI-II -Anxiety</td>
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<td>93</td>
<td>80&lt;sup&gt;RI&lt;/sup&gt;</td>
</tr>
<tr>
<td>BYI-II -Depression</td>
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<td>87&lt;sup&gt;RI&lt;/sup&gt;</td>
<td>75&lt;sup&gt;RI&lt;/sup&gt;</td>
</tr>
<tr>
<td>BYI-II -Anger</td>
<td>83&lt;sup&gt;RI&lt;/sup&gt;</td>
<td>82</td>
<td>79</td>
</tr>
<tr>
<td>BYI-II -Disruptive Behaviour</td>
<td>60&lt;sup&gt;RI&lt;/sup&gt;</td>
<td>58</td>
<td>63</td>
</tr>
<tr>
<td><strong>Parent</strong></td>
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</tr>
<tr>
<td>Pin-Q</td>
<td>54&lt;sup&gt;RI&lt;/sup&gt;</td>
<td>29</td>
<td>38</td>
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<td>SDQ</td>
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<td>PSI-4-SF</td>
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<tr>
<td>Physical Health</td>
<td>60.71</td>
<td>64.29</td>
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<td>71.88&lt;sup&gt;RI&lt;/sup&gt;</td>
<td>59.38&lt;sup&gt;RW&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

<sup>RI</sup> Reliable improvement from previous time-point  
<sup>RW</sup> Reliable worsening from previous time-point

Dee showed much lower than average BYI-II self-concept levels across the three phases (Table 10). Her remaining BYI-II subscale levels all fell within the moderately to extremely elevated ranges across the three phases, although her anxiety levels showed reliable improvement from post-intervention to follow up; and her depression levels showed reliable improvement from baseline to post-intervention and then again from post-intervention to follow up, although these changes were not clinically significant. Dee’s mother’s scores on child emotional and behavioural problems (SDQ) showed high risk of any disorder, with scores falling within the abnormal range across all phases, with parenting stress (PSI-4-SF) levels within mildly to moderately elevated range across all phases. Her mother’s QoL levels showed a mixed picture of reliable change: improving and worsening across domains and phases of the study.

**Participant 6 (“Dan”).** Dan, 14, was dry in the day well within a normal developmental timeframe. His father was late to achieve night dryness and was not dry until age 8. His brother was not dry at night till age 12. A male cousin was slow to get dry at night, as was this cousin’s son, who was not dry till age 9. Dan had never been consistently dry at night. During school holidays he could be dry up to 3 nights a week, but usually only 1-2 nights. Dan was always soaked in the morning and never woke to
use the toilet. The bed was protected.

Dan first accessed continence services at age 8 and undertook bladder training. He had no bladder abnormalities. He found it difficult to drink as much as he should and his mother reported this as a source of friction between them. He tried medications for NE age 8-9, which produced no improvements for the year he took them. Dan had alarm therapy at age 9 for a few weeks. This was discontinued as he did not wake. Dan’s parents woke him nightly for a few years at about 11pm to use the toilet, which made him a little drier in the morning, but still wet. This was discontinued as Dan became confused on being woken and resisted aggressively. He was noted to be a very heavy sleeper. Dan’s mother disclosed an experience of stage hypnosis when younger, describing this as ‘fun’ but ‘embarrassing’. Dan appeared to have a negative opinion of hypnosis in relation to this, feeling that only ‘gullible’ people were hypnotisable. This was gently challenged via psychoeducation, including delineation of how therapeutic hypnosis was different to stage hypnosis.

**Elements of note in hypnosis.** Dan scored 4 on the SHCS-C indicating moderate levels of hypnotisability, finding auditory items most difficult. The SHCS-C suggested his imaginative capacity for memory items was better than other aspects, so this was maximised in developing the hypnosis script. Dan found it difficult at times to generate images, so suggestions were made as to images being things he had experienced before. Dan struggled with less directive hypnosis approaches and appeared to become anxious when not able to generate images independently, but could also resist too much directiveness. Hence a careful balance was needed, suggesting that he *might* be able to see certain images, and if needed a suggestion as to what they *might* look like. Dan couldn’t find a way to get message to brain to wake up, so the suggestion was made that the cork (which was the image he had created to hold urine in his bladder), was glowing and he was able to add that this glow went up a very big thick red wire that then electrocuted his brain, made it ‘zap’ bright white and wake him up. Dan never woke to use the toilet throughout the first few sessions of active treatment, so this aspect of hypnotic suggestion and imagery was discontinued for the remaining sessions.

Dan liked the predictability and routine of using the same hypnosis script over the intervention period. Two audiofiles were produced; one short and one long to be used interchangeably. Dan did not wish to learn SH. He reported home practice most nights during treatment and follow up phases. Figure 6 shows Dan’s dry nights per
week across the three study phases.

*Figure 6. Dry nights per week (Dan)*

![Dry nights per week (Dan)](image-url)

**Table 11**

*Scores on the Standardised Measures (Dan)*

<table>
<thead>
<tr>
<th>Measure</th>
<th>Baseline</th>
<th>Post-Intervention</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child/young person</strong></td>
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<tr>
<td>Pin-Q</td>
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<tr>
<td>BYI-II -Self-Concept</td>
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<tr>
<td>BYI-II -Anxiety</td>
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<tr>
<td>BYI-II -Depression</td>
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<td>44</td>
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<tr>
<td>BYI-II -Anger</td>
<td>47</td>
<td>54&lt;sup&gt;RW&lt;/sup&gt;</td>
<td>44&lt;sup&gt;RCI&lt;/sup&gt;</td>
</tr>
<tr>
<td>BYI-II -Disruptive Behaviour</td>
<td>48</td>
<td>52</td>
<td>39&lt;sup&gt;RCI&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Parent</strong></td>
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<tr>
<td>Pin-Q</td>
<td>37</td>
<td>21</td>
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<td>SDQ</td>
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<td><strong>WHOQL-BREF</strong></td>
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<tr>
<td>Physical Health</td>
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<td>75&lt;sup&gt;RI&lt;/sup&gt;</td>
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<tr>
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<td>70.85</td>
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</tr>
<tr>
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<td>75&lt;sup&gt;RI&lt;/sup&gt;</td>
<td>68.75</td>
</tr>
<tr>
<td>Environment</td>
<td>65.63</td>
<td>65.63</td>
<td>58.33&lt;sup&gt;RW&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

<sup>RI</sup> Reliable improvement from previous time-point  
<sup>RW</sup> Reliable worsening from previous time-point  
<sup>RCI</sup> Reliable and clinically significant improvement from previous time-point  
* Questionnaire not completed as Dan was outside the age range on which it was normed.

Dan showed much lower than average BYI-II self-concept subscale levels across the study (Table 11). His remaining BYI-II subscale levels all fell within the average range across the three phases of the study, although his anger and disruptive behaviour
levels showed reliable and clinically significant improvement from post-intervention to follow up (his anger levels had previously shown reliable worsening from baseline to post-intervention). Dan’s mother’s scores of Dan’s emotional and behavioural problems (SDQ) were all within the normal range for all phases, with high risk of any disorder in baseline phase, but low risk of any disorder across latter two phases. His mother’s QoL measures showed some reliable improvement in the Physical Health and Social Relationships levels from baseline to post-intervention, but reliable worsening in the Environment subscale level from post-intervention to follow up.

Participant 7 (“Zoe”). Zoe, 9, was dry in the day from a developmentally appropriate age. Regarding family history, a second cousin was not dry at night till age 11. Zoe was sometimes dry at night, but only for a couple of nights in a row. The family accessed continence services when Zoe was 7. Zoe underwent bladder training which indicated her bladder may have been a bit small, but not outside the normal range. Zoe tried medication for one month aged 8 and was dry for five consecutive nights; her NE then returned to its previous frequency, so medication was discontinued after a few weeks. Zoe was lifted by parents at night to use the toilet when younger, but this was not habitual.

Elements of note in hypnosis. Zoe scored 4 on the SHCS-C indicating hypnotisability within the moderate range. She had poor auditory imagination, but very good kinaesthetic imagination. She was very good at experiencing feelings to do with time and place in hypnosis and described her most relaxed time as Saturday ‘lazy’ morning with all the family in pyjamas, and how good this felt to her, so this feeling was incorporated into the script. Zoe was very well able to generate images herself with high levels of detail. She volunteered more information about her images in hypnosis very easily without suggestion or prompting, and so this process was facilitated. Zoe liked a lot of variation in the way the session were conducted. Sometimes she liked to sit up, sometimes lie down, and sometimes have two chairs to sit on (one for her feet).

She came to every session with new ideas as to the content of hypnosis for that session. These ideas were incorporated and she was initially committed and enthusiastic about the treatment. Zoe never woke to use the toilet during intervention phase, so imagery and suggestions around this were discontinued after a few sessions. Zoe was very active and fidgety in hypnosis and in general. She had some mild challenging behaviour at home, was reported resist doing what she was asked and have
tantrums. She became bored very easily, which had implications for home hypnosis practise.

During the treatment, her mother discovered that Zoe has not been using the toilet at school at all for several months and was cutting back on her drinking during the day. Over time this may have reduced her bladder capacity. Her mother addressed this with the school and post hypnotic suggestions were made as to increasing toilet use and drinking in school.

Zoe learnt SH and also had a total of eight different audiofiles over the course of treatment, based on the different hypnosis scripts developed in sessions. Zoe became bored over time with what she considered to be lack of progress. It was agreed to reduce audiofile use to alternate nights. Zoe discontinued home practise almost immediately into the follow up phase. Figure 7 shows Zoe’s dry nights per week across the three phases of the study.

Figure 7. Dry nights per week (Zoe)
Table 12

Scores on the Standardised Measures (Zoe)

<table>
<thead>
<tr>
<th>Measure</th>
<th>Baseline</th>
<th>Post-Intervention</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child/young person</td>
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<td></td>
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<tr>
<td>Pin-Q</td>
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<tr>
<td>BYI-Self-Concept</td>
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<td>58</td>
<td>62</td>
</tr>
<tr>
<td>BYI-Anxiety</td>
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<td>38</td>
<td>31</td>
</tr>
<tr>
<td>BYI-Depression</td>
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<td>47</td>
<td>34RI</td>
</tr>
<tr>
<td>BYI-Anger</td>
<td>61</td>
<td>38RCI</td>
<td>36</td>
</tr>
<tr>
<td>BYI-Disruptive Behaviour</td>
<td>54</td>
<td>45RCI</td>
<td>51</td>
</tr>
<tr>
<td>Parent</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Pin-Q</td>
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<td>16</td>
<td>13</td>
</tr>
<tr>
<td>SDQ</td>
<td>22</td>
<td>20</td>
<td>17</td>
</tr>
<tr>
<td>PSI-4-SF</td>
<td>53</td>
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<td>48</td>
</tr>
<tr>
<td>WHOQL-BREF</td>
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<td></td>
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</tr>
<tr>
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<td>Psychological</td>
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<td>75RW</td>
<td>91.67RI</td>
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<tr>
<td>Social Relationships</td>
<td>75</td>
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<td>100RI</td>
</tr>
<tr>
<td>Environment</td>
<td>75</td>
<td>75</td>
<td>75</td>
</tr>
</tbody>
</table>

RI: Reliable improvement from previous time-point
RW: Reliable worsening from previous time-point
RCI: Reliable and clinically significant improvement from previous time-point

The majority of Zoe’s levels on the BYI-II across phases fell within the average range. However, Zoe showed average or above average self-concept levels across phases (Table 12). She also showed reliable and clinically significant improvement in two BYI-II subscales levels (anger and disruptive behaviour), from baseline to post-intervention; she also showed reliable improvement in her BYI-II depression level from post-intervention to follow up.

Her mother’s rating of Zoe’s emotions and behaviour (SDQ) levels fell within the abnormal/very high range, putting Zoe at high risk of any disorder; but fell within the borderline range at post-intervention. Her mother’s parenting stress levels fell within the average range across all phases. Zoe’s mother’s QoL levels showed reliable improvements in Social Relationships from baseline to post-intervention and then again from there to follow up. Her Psychological facet of QoL showed reliable worsening from baseline to post-intervention, followed by reliable improvement from there to follow up.

Participant 8 (“Fin”). Fin, 9, was dry in the day within the normal developmental timeframe. There was no family history of NE. Fin had had very few dry nights ever, and was always very wet in the morning. He wore pull ups; the bed was not protected. The family tried short periods without them every now and then, but this
produced no change. Parents tried lifting him to toilet at night a year previously, but this made no difference to his NE. Fin had been known to bladder services since age 8. He had done bladder training. He had no issues with the capacity of his bladder. Fin had been offered medication, but didn’t want to take it.

**Elements of note in hypnosis.** Fin scored 7 on the SHCS-C indicating high levels of hypnotisability. Fin preferred that he was not engaged verbally during hypnosis, reporting that this impaired his imaginative capacities and distracted him. The script was easily developed, which he preferred to stick to without variation over the weeks. Initially he requested audiofiles and was given short and long versions. Fin started to wake and use the toilet quite soon into the treatment. Over time, Fin’s use of audiofiles became inconsistent, as he reported finding them boring, so he was taught SH and it was agreed he could have two nights off a week from SH/audiofile, which helped his motivation. He stopped home practice completely in follow up period. Figure 8 shows Fin’s dry nights per week across the three phases of the study.

*Figure 8. Dry nights per week (Fin)*
Table 13

*Scores on the Standardised Measures (Fin)*

<table>
<thead>
<tr>
<th>Measure</th>
<th>Baseline</th>
<th>Post-Intervention</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child/young person</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Pin-Q</td>
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<td>18_RCW</td>
</tr>
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<td>BYI-Self-Concept</td>
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<td>52</td>
<td>42_RCI</td>
</tr>
<tr>
<td>BYI-Anxiety</td>
<td>41</td>
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<td>39_RW</td>
</tr>
<tr>
<td>BYI-Depression</td>
<td>39</td>
<td>56_RW</td>
<td>44_RCI</td>
</tr>
<tr>
<td>BYI-Anger</td>
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<td>40</td>
</tr>
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<td>BYI-Disruptive Behaviour</td>
<td>44</td>
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<td>45</td>
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<tr>
<td>Parent</td>
<td></td>
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</tr>
<tr>
<td>Pin-Q</td>
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</tr>
<tr>
<td>SDQ</td>
<td>4</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>PSI-4-SF</td>
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<td>Social Relationships</td>
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<td>91.67_RI</td>
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</tr>
<tr>
<td>Environment</td>
<td>84.38</td>
<td>87.5</td>
<td>90.63</td>
</tr>
</tbody>
</table>

\_RI Reliable improvement from previous time-point
\_RCI Reliable and clinically significant improvement from previous time-point
\_RW Reliable worsening from previous time-point
\_RCW Reliable and clinically significant worsening from previous time-point

The majority of Fin’s levels on the BYI-II across phases fell within the average range. However, Fin showed a reliable and clinically significant worsening of self-concept levels from post-intervention to follow up, where his score fell to below average (Table 13). He also showed reliable worsening of depression level from baseline to post-intervention which then showed reliable and clinically significant improvement to follow up. His father’s rating of Fin’s emotions and behaviour (SDQ) levels and parenting stress levels fell within the normal range across all phases. Fin’s father’s QoL levels showed reliable improvements in social relationships from baseline to post-intervention and then again from there to follow up. His Physical Health aspect of QoL showed reliable improvement from baseline to post-intervention.

**Discussion**

The aim of the present study was to examine the effectiveness of hypnosis intervention for PNE which was tailored according the needs, strengths and difficulties and imaginative capacities of the individual. Clear evidence was found that the intervention was associated with significant increase in the proportion of dry nights over the treatment period, which was maintained at follow up. Significant results were found
to support this at a group level and also at individual level. Findings are consistent with previous research using hypnosis for NE using hypnosis based treatment (Banerjee et al., 1993; Kohen et al., 1984; Minosh et al., 2013). Although a range of issues such as having a mixed primary and secondary NE group in some previous studies, different ways of recording increase in dry nights, and differing length of follow up, make it problematic to compare the findings of this study to others.

At a group level, participants did not evidence significant psychosocial change across phases as result of successful treatment. Participants’ self-reported QoL did closely approach significant improvement from baseline to follow up. This may indicate that it may take longer for improving dryness at night to translate into tangible QoL gains for young people. It may be that QoL improves over time as participants not only become drier, but remain drier at night, especially as some participants had reported periods of previous transient dryness. This continuing dryness then may lead to engagement in activities not previously enjoyed, such as sleepovers with friends and school trips, which had been avoided, until lasting faith in ongoing dryness had been achieved. It may be that with a longer follow up period, QoL may have shown significant improvement.

This is the first hypnosis study to look at QoL as an outcome of hypnosis-based PNE treatment, and findings can be considered as broadly consistent with other research which found QoL improvements attendant upon other successful treatment (Equit et al., 2014; Naitoh et al., 2012). Parent proxy-report in the current study showed no significant QoL gains over intervention and follow up, this may reflect findings of Naitoh et al. (2012) who identified differences between QoL as reported by parent and child reports in some domains, and Bower, Sit, Bluysen, Wong, & Yeung (2006) who indicated that parents may underestimate the impact of PNE on their child.

There were also improvements approaching significance from baseline to follow up in self-reported anger levels. A positive association between the NE severity and the impact on various areas of psychosocial function, including externalising behaviours has been found by several authors (Theunis et al., 2002; Van Hoecke, et al., 2006; Wolfe-Christensen et al., 2012). Therefore reducing the severity of NE may be effective in reducing anger associated with it.

At individual level, participants did show some changes in psychosocial function across phases. Both ‘reliable’ and ‘reliable and clinically significant’ changes in emotions and behaviour were self-reported across phases. It is notable that self-concept
levels for half of the participants was lower than average at baseline, consistent with findings from other studies showing lower self-esteem/self-concept of those with NE than controls or norms (Phung, Kelsberg, & Safranek, 2015; Theunis et al., 2002). This did not change for most over enrolment; showing reliable worsening for one participant (Fin, p8). This may be as he was one of 2 participants who were less dry (though not statistically so), at follow up than over intervention phase, and both he and his parents expressed a sense of failure and regret that he had not continued home hypnosis practice and therefore not maintained progress.

Individual self-reported psychosocial changes were mostly improvements across phases. Five participants showed ‘reliable’ or ‘reliable and clinically significant’ improvements in mood across phases; whilst two improved in anxiety levels and two in disruptive behaviour levels. Sam (p1), Emma (p2), Dee (p5), Zoe (p7) and Fin (p8) all showed reliable improvements in mood across phases. It is notable that the first three had significant life events that may have impacted on mood: Dee had multiple psychosocial difficulties some of which got worse or better, as did her ability to cope with them; Emma changed school and got a new job, and Sam’s mother changed career. Fin’s mood change was in the context of reliable worsening in mood at intervention end, returning perhaps to its more stable level at follow up. It remains problematic to draw conclusions regarding improvements in night dryness and the impact of this on these variables.

It is worth considering any impact of percentage increase in dryness across phases on individual change in emotional and behavioural functioning. Dee (p5), the participant who gained most (nearly 53%) in terms of dry nights from baseline to intervention, showed reliable improvement in mood levels. Sam (p1), the participant who gained second most in percentage dryness between baseline and intervention (increase of over 45%), showed most reliable improvement in his self-rated emotions over this time. However Dan (p6) and Fin (p8) both made gains of 34-36% over the same period and did not evidence gains, but showed reliable worsening in anger and depression scores respectively. It may be that psychosocial response to living with NE is highly individualised, as is the response to successful treatment. There will of course have been other issues and events in the lives of the participants, which were not the focus of this study, which will have impacted on psychosocial function.

As regards parent report of participants’ emotions and behaviour, these show an interesting mixed picture. Several participants had abnormally elevated reported
difficulties at baseline (Dee p5; Zoe p7; Ben p3), which may have been due to their co-morbid difficulties rather than those associated with PNE, as even with successful treatment there were no significant changes across phases of treatment either at group or individual level. Similarly, reported parenting stress levels were high at baseline for only one participant (Dee p5), who had significant co-morbid difficulties. No significant changes were found at group or individual level across phases in parenting stress levels. These findings were supported by testimony from parents reporting being largely unbothered by their child’s PNE in terms of the stress imposed upon them day to day. This is in contrast to findings suggesting that parenting stress levels are higher in parents of children with PNE (Chang et al., 2002). No previous studies have examined how parenting stress might change with treatment for PNE.

Parental QoL did not change at group level as result of successful NE treatment, consistent with findings of Equit et al. (2014). They also used the WHOQOL-BREF and found that QoL did not improve after 3 months’ treatment; even for parents of those for whom treatment was successful. At an individual level, parents’ QoL changed over phases, both worsening and improving reliably more than any of the other psychosocial measures. No attempt was made to screen for, and thus consider changes to parental QoL due to events in family and parents’ lives unconnected with PNE. As such it remains problematic to determine effects of this treatment on parents’ QoL. It may have been useful to consider using a continence specific QoL measure which looks at aspects of family QoL in relation to a child with NE within the family. The only one currently available is the PEMQOL (Landgraf et al., 2004) which looks at the family’s emotional and social well-being.

A strength of the present study was its formal assessment of hypnotisability; an area important in informing the hypnosis tailoring. Most studies in this area did not undertake standardised assessment of hypnotisability, apart from Banerjee et al. (1993) who also used the SHCS-C. In the present study, 3 participants evidenced less than optimal levels of hypnotisability (scores 4 and below on the SHCS-C), with one showing an unusual almost complete lack of ability to create visual imagery in hypnosis (Emma, p2). Several showed poor auditory imaginative ability in contrast with norms for children from SHCS-C (London & Copper, 1969), which identify auditory hallucinatory capacity as the easiest item for children and young people. Systematic and in depth assessment of these factors allowed for tailoring of hypnosis to individuals, instead of use of standard audiofile given to participants in some studies (Edwards &
van der Spuy, 1985; Seabrook et al., 2005).

It is unclear (due to lack of detail of hypnosis protocols in previous studies), if this is the first study which involves the elicitation of specific in-trance imagery around increasing the size and strength of the bladder; the strength of the bladder gate/door; the bladder filling and needing to empty, and then using specific imagery to send a message to the brain to alert it to wake. The range of idiosyncratic images generated by individual participants was broad and unpredictable, and suggest that enabling generation of participants’ own images was important, as well as the use of simple verbal post-hypnotic suggestion (to have more dry nights; to be able to wake and use the toilet), mainly used in previous studies. The helpfulness of in-trance suggestion differed between participants. For some being unable to visualise suggested images caused anxiety (Emma, p2) or was experienced as actively helpful (Dan, p6) who struggled to generate his own images without suggestion. There were some issues around the tailoring via suggestion. Some participants temperamentally resisted any control they perceived to be imposed on them during hypnosis. This was important with Zoe (p7) and Dan (p6), who resisted more directive suggestion. This was addressed by employing a less authoritarian style of language as suggested by Kohen and Olness (2011), who indicate that an authoritarian hypnosis style can negatively impact on the hypnotic experience of children. Ideas of pacing and leading involved in the delivery of the hypnosis with children (Wester & Sugarman, 2007) were adopted; offering empathic confirmatory sentences such as ‘It looks like this is a bit tricky’ and ‘You may find that you start to see.’, thus involving the language of possibility to encourage and prompt participants to explore new imagery, rather than instructing them directly to create images.

What also seemed important in the tailoring was the discontinuation of aspects of hypnosis that didn’t seem to be effective for some participants, such as imagery specifically around waking and using the toilet in the night. Zoe (p7) and Dan (p6) never woke to use the toilet during the treatment phase, and Ben (p3) was concerned (along with his mother), about the number of times he was waking to use the toilet, and the consequent disruption to his sleep. Imagery around using the toilet at night for Kay (p4) who didn’t recall, but clearly was half-waking and using the toilet, was tailored to incorporate ‘observing’ self-rather then ‘experiencing’ herself waking and using the toilet.

Choice as regards use of SH, audiofile or both was an important aspect of the
tailoring. SH has been identified as enabling and empowering for children to achieve dryness, and enforcing sense of responsibility, competency and self-esteem (Gottsegen, 2003; Kohen et al., 1984). Participants in the present study were given a choice as to audiofile, SH or both for home practice across the whole enrolment period. This differentiation of audiofiles and SH for all participants was done to counter the tendency identified by some authors for children to be reluctant practisers at home (e.g. Kohen & Olness, 2011). Participants did indeed report getting bored with audiofiles, and so more and different files were produced to deal with this. Short and long versions of audiofiles were also produced for some participants to facilitate practise for periods when motivation may have been low. Some participants did not want or were adjudged to be unsuitable (Dee, p5) to be taught SH. Half of participants used a mix of SH and audiofiles. Enrolment in this study was for a period of several months for all and finding ongoing motivation to sustain practise was reported as difficult by most participants and their families, with several of the participants showing clear issues with motivation, finding commitment to continued practise very challenging (Zoe, p7; Ben, p3; Fin, p8). The role of practise in maintenance of treatment effects needs to be considered. Most apart from Dan (p6) and Kay (p4) discontinued hypnosis practise during follow up, despite instruction to continue. However all maintained their level of dry nights at follow up from baseline period. Of note is that only Dan (p6) continued to make significant gains in night dryness from intervention to follow up; Kay (p4) approached significance in this too. Banerjee et al. (1993) attribute their finding of the superiority of hypnosis treatment over imipramine at nine month follow up to the use of hypnosis practise. The majority of participants in the present study reported reducing or completely stopping home practise in 12 week follow up, but did maintain dryness levels attained over intervention; perhaps more may have continued to improve from intervention to follow up with continued practise at home.

It is notable that the present study had a shorter follow up period than most of its type. Edwards and van der Spuy (1985); Diseth and Vandvik (2004), and Minosh et al. (2013) had follow up periods of 6, 15 and 25 months respectively, and thus the present study may not have achieved optimal outcomes at a shorter 12 week follow up.

Seabrook et al. (2005) identified possible lack of success of hypnotherapy may be due to lack of time to establish therapeutic rapport. This study had two drop outs. These may have been resistant to treatment or perhaps demonstrated just a lack of engagement with the therapist. The therapeutic alliance is undoubtedly important in
treatment efficacy, and Kohen and Olness (2011) discuss such ‘mismatches’ between therapist and child and recommend that in these instances, it may be worthwhile referring the child to another therapist with whom engagement may be better, rather than assuming that hypnosis will not be an effective treatment.

Most participants reported having tried another form of NE therapy (medication or alarm). However it was a feature of some families’ reports that medication did not work well enough to justify its continuance, and that alarm therapy was at best ineffective, at worst disruptive, to the family. Alarms also need to be supported to be used effectively in the home, which is not available in all health trusts in the UK. Non-compliance with or dropout from alarm therapy has also been found to be due to the alarm being too difficult or complicated to use (Moffatt, 1987), or may be due to the amount of support from parent and professionals needed for success (Perrin, Sayer, & While 2015). Cochrane Reviews of alarm treatments (Glazener, Evans, & Peto, 2005) and medication (Glazener, Evans, & Peto 2003) indicate around half of children (alarm), and the majority (medication), relapse after treatment cessation. Hypnosis appears to be minimally disruptive to the child and family, has few, if any, reported side effects, and may bring the benefit of increasing the sense of control and agency of children over their continence. It is also emerging as having superior treatment persistence effects.

Limitations of the Research

One area of weakness regarding case series is around enrolment of cases. Although cases were enrolled consecutively in this current study, there may be inherent bias in their enrolment. For example, it may have been the case that referrers firstly referred individuals they had had on their caseload for a long time, and/or who had been treatment resistant. This could have meant that the cases treated were a sample of more persistent and treatment resistant night wetters than would be representative of those in the general child NE population. This risk of bias in subject enrolment makes findings from the study difficult to generalise to the general child NE population. Larger studies with more systematic sampling strategies would permit of better generalisability. The lack of control participants makes it difficult to determine if the intervention was effective or a chance happening due to the natural evolution of the condition, although statistical analysis can go some way to evaluating this.

This design is able to give detailed information about change patterns in
symptoms across time. However, the limitations of this study include the relatively short time-series data. More baseline data points in the baseline phase would have been helpful to establish whether or not each case had a stable baseline. The shortest number of baseline data points herein is 3 (in two cases), which is somewhat shorter than the ~5 data points per phase identified by Borckardt and Nash (2014) as required to offer good control of type 1 error rates and adequate power to detect relatively small effect-sizes when using SMA.

This hypnosis intervention package involved some psychoeducational input as regards the anatomy and physiology of enuresis, delivered in session 2. This type of psychoeducational input in enuresis therapy covers a range of activities from simple information giving to parents and children about enuresis, to specific materials advising on use of treatments, such as alarms. This type of psychoeducation is a feature of some hypnosis interventions for enuresis (Banerjee et al., 1993; Gottesgen, 2003; Diseth & Vandvik, 2004; Seabrook et al., 2005). However, none of these authors make attempts to quantify the impact of this intervention strand on nighttime dryness. Available evidence examining the impact of educational information about enuresis (Cochrane Review; Glazener, Evans & Peto, 2004), concludes that evidence is insufficient to judge if this is effective in reducing enuresis, regardless of the method of delivery.

Additionally, the hypnosis intervention detailed herein involves perhaps more therapist contact time than in other forms of treatment, including the more standardised hypnosis used in some previous research. This contact may have a placebo effect and/or effects of general empathic psychological support may be experienced as motivating and therapeutic by participants. Some evidence exists regarding this direct involvement of therapists with families, and suggests that it can enhance the effects of other enuresis interventions (from simple behavioural packages to more complex interventions, such as dry bed training) (Glazener et al., 2004). The authors caution however, that these findings emerge from single trials only; further randomised controlled trial evidence is needed to further confirm this.

The impact on nighttime dryness due to the impact of negative life events has been discussed. However it may be that there is an impact on dryness of neutral or positive life events. For example baseline, treatment and follow up periods cut across both term time and school holidays, and these timings were different for different participants. One of the issues identified as relevant by participants in their NE was their sleep depth and sleep pattern. Most participants reported they slept so deeply that they
could not wake to use the toilet in the night. It was reported that when on school holidays, holidays or trips away from home, then sleep habits changed, with participants going to bed later and/or in unfamiliar surroundings. These could serve to change individuals’ depth of sleep such that they were more likely to have a dry night – either waking to use the toilet or being able to empty their bladder much later than usual before going to bed.

Future Research

PNE provides a highly objective and quantifiable measure of therapeutic success (dry nights), which makes it a suitable condition for testing of alternative therapies (Huang et al., 2011). Future research could involve more controlled trial methodologies with subjects being randomised to treatment arms, one of which would be hypnosis. Others might include medication treatment or no treatment controls, or different forms of hypnosis: clinically tailored versus a general hypnosis audiofile. Studies should be sufficiently powered to enable robust findings of the effectiveness of treatments. One of the major limitations of extant hypnosis research is the lack of treatment specification such as using a manual to ensure consistency of delivery (Milling & Costantino, 2000), future research should address this.

Avenues for further research could include identification of predictors of successful treatment outcomes such as socio-demographic characteristics of child or family, which might include optimum age for, and optimum length of, treatment.

This study adds to the body of evidence indicating the persistence of hypnosis treatment effects on nighttime dryness after active therapy cessation, which may be better than that of conventional treatments (alarm therapy and medication). In the current climate of economic constraints on costs of health care, hypnosis treatment for PNE should be subject to evaluation as to costs/benefits for health service providers and for families compared to conventional treatments.

Conclusion

The results of this study indicate that hypnosis may be an effective treatment for PNE, which endures in its effects after treatment end. Moreover, this improved continence may be associated with an improvement in participants’ reported QoL. Other aspects of individual participants’ psychosocial function changed as enuresis improved, but it was not clear as to the nature of this relationship and the effects of any concurrent
life events. Active tailoring of hypnosis to the strengths and difficulties of participants was identified as relevant. Further research is indicated to investigate effectiveness of tailored hypnosis with reference to accepted treatments in terms of outcomes, endurance of treatment effects and costs/benefits.
References


Appendix A. The Paediatric Incontinence Questionnaire (Pin-Q) Child Self-Report Version

Appendix B. The Paediatric Incontinence Questionnaire (Pin-Q) Parent Proxy Report Version

Appendix C. The World Health Organisation Quality of Life Questionnaire -Brief Version (WHOQL-BREF)

Appendix D. The Beck Youth Inventories -Second Edition (BYI-II)

Appendix E. The Strengths and Difficulties Questionnaire (SDQ)

Appendix F. Parenting Stress Index (Short Form) 4th Edition

Appendix G. Stanford Hypnotic Clinical Scale for Children

Measures subject to copyright have been removed from the electronic copy
Appendix H. Copy of Research Ethics Committee Approval

04 June 2014

Dear [Name],

Study title: Tailored Hypnosis Treatment for Primary Nocturnal Enuresis in Children and Young People: A Case Series

REC reference: 14/LO/0796
Protocol number: 2
IRAS project ID: 161053

Thank you for your letter of 02 June 2014, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chairman.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Miss Shehnaz Ishaq, nrescommittee.london-fulham@nhs.net

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list

A Research Ethics Committee established by the Health Research Authority
of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made.

Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

The Committee has not yet completed any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime no study procedures should be initiated at non-NHS sites.

A Research Ethics Committee established by the Health Research Authority
After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: [http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/](http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/)

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at [http://www.hra.nhs.uk/hra-training/](http://www.hra.nhs.uk/hra-training/)

| 14/LO/0796 | Please quote this number on all correspondence |

With the Committee's best wishes for the success of this project.

Yours sincerely

Signed on behalf of:
Dr Charles Mackworth-Young
Chairman

Email: nrescommittee.london-fulham@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: [Redacted]

A Research Ethics Committee established by the Health Research Authority
Appendix I. Copy of Research and Development Approval Host Trust

25/06/2014

Dear [Redacted]

Hypnosis for PNE: A Case Series

<table>
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</tr>
</thead>
<tbody>
<tr>
<td>REC Ref</td>
<td>14/LO/0796</td>
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Documents received

<table>
<thead>
<tr>
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</thead>
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<tr>
<td>Protocol – v. 3.0</td>
<td>17/04/2014</td>
</tr>
<tr>
<td>REC Favourable Opinion Letter</td>
<td>04/06/2014</td>
</tr>
<tr>
<td>Documents as listed on REC Favourable Opinion Letter</td>
<td>04/06/2014</td>
</tr>
</tbody>
</table>

Thank you for submitting the above referenced protocol to the R&D Department. I am pleased to confirm that your study has now been granted NHS Permission by the Trust provided that you comply with the conditions of Trust R&D NHS Permission which are attached.

You are advised to study this letter and the attached Conditions of Trust NHS Permission carefully.

NB - Commencement of the above trial is confirmation of your compliance to these Trust NHS Permission Conditions

All research undertaken within the NHS requires both management NHS Permission from R&D offices, NHS Research Ethics Committee favourable opinion and any other applicable regulatory approvals. Research may not commence at any NHS site until these have been obtained.

You must ensure that you are fully aware of your responsibilities and that your activities are conducted in line with the Local Research Governance Framework for Health and Social Care 2nd Edition, Research
Ethics Committee conditions, The Medicines for Human Use (Clinical Trial) Regulations 2004 and Amendment Regulations 2006.

Pharmaceutical clinical trials involving an investigational medicinal product shall be conducted in accordance with the conditions and principles of International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH GCP)

Investigators of other research should be conducting their activities to similar standards and good clinical practice systems.

Safety Reporting

Researchers should follow the safety reporting requirements of the protocol and study sponsor, Trust R&D SOPs, - Serious Adverse Event Reporting, and the Trust Policy for the Management of incidents http://www.ekhulf.nhs.uk/staff/systems/dealt-incident-reporting/. All staff are responsible for reporting adverse incidents, whether or not related to research in accordance with the above.

Amendments

The study sponsor is responsible for ensuring that amendments are submitted, as applicable, to the REC and the MHRA, and for ensuring that amendments are notified to PI's and the R&D Department. The sponsor is responsible for providing any updated documentation and regulatory approvals to the PI/research team.

Principal Investigators must ensure that amendments are not implemented until all applicable regulatory approvals and R&D acceptances are in place (unless an urgent safety measure).

Further guidance and examples of substantial and non-substantial amendments can be found on the NRES website www.nres.nhs.uk

Service Support Departments –
Medical Records, Radiology, Pathology, Pharmacy

Principal Investigators participating in a CTIMP are responsible for identifying trial patients in the study on all referral requests to service support departments such as Pathology, Radiology, Pharmacy and medical records are marked for retention. This will enable the necessary archiving in compliance with the Medicines for Human Use (Clinical Trials) Regulations [SI 2004 1031] & Amendment Regulations 2006 [SI 2006 1928].

Principal Investigators are required to regularly provide relevant support departments with a list of patients recruited into studies.

Service Support Departments (SSDs), (if supporting the study) should be notified immediately of any amendments to the study and provided with a current version of the protocol.

Monitoring

The sponsor is responsible for ensuring studies are appropriately monitored, particularly CTIMPs

The R&D Department may conduct on-site monitoring visits on a risk-based basis.

All Principal Investigators will have access to the R&D Database – Reda - to upload study documents and study information. As a condition of Trust NHS Permission Investigators are required to use the Reda database to provide regular updates to R&D on their studies,
Accrual
It is a condition of NHS Permission that PIs regularly provide accrual figures by uploading this information to Reda database. Failure to provide such information may result in the withdrawal of Trust NHS Permission.

End of Study Reports
Researchers must submit End of Study reports to R&D when all study activity, including recruitment, follow-up etc., has ended.

Training
For all interventional studies, including CTIMPs, medical devices etc., you agree to attend Good Clinical Practice training and updates. The PI is responsible for ensuring that the research team are competent and appropriately qualified to carry out their research roles, and have received appropriate GCP training. The PI is also responsible for ensuring the research team have trial specific training, particularly in completing CRFs and reporting of SAEs.

Delegation logs
Principal Investigators are responsible for ensuring that an up to date delegation log for the study is maintained detailing the roles and responsibilities delegated to research team members.

Breach of NHS Permission conditions
Failure to comply with these conditions or failure to provide the information when requested will result in the study being suspended and may lead to Trust approval being withdrawn.

Yours sincerely

Dr [redacted] (BSc, MSc, PhD, PG Dip, CBiol, MIItiol, CSci, FIBMS)
R&D Manager

Attached: Conditions of Trust NHS Permission
Appendix J. Copy of Research and Development Approval PIC Trust

Permission for research

I am writing to inform you that the NHS organisation listed below has granted permission for the following research project on the basis described in the application form, protocol and supporting documentation.

Study details:

<table>
<thead>
<tr>
<th>Study Title</th>
<th>Tailored Hypnosis Treatment for Primary Nocturnal Enuresis in Children and Young People: A Case Series</th>
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<td></td>
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<tr>
<td>Sponsor name</td>
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<td>K&amp;M CLRN study number</td>
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<tr>
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<tr>
<td>IRAS number</td>
<td>151053</td>
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<tr>
<td>REC number (REC name)</td>
<td>14/LO/0796 NRES Committee London – Fulham</td>
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NHS organisation(s) and location(s):

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<th>Organisation giving permission</th>
<th>Date of Permission</th>
<th>Sites to which permission applies</th>
</tr>
</thead>
<tbody>
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<td>20/06/2014</td>
<td></td>
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The documents reviewed were:

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<th>Version</th>
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<td>Current version of protocol</td>
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</tr>
<tr>
<td>REC letter of favourable opinion</td>
<td>14/LO/0796</td>
<td>04/06/2014</td>
</tr>
<tr>
<td>Supporting documents as listed in the REC letter</td>
<td>Various</td>
<td>Various</td>
</tr>
</tbody>
</table>

provides services to independent primary care contractors in NHS Trust, Ambulance NHS Trust.
Amendments to date | Amendment number (local ref) | Date
---|---|---
None to date | | |

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework, The Data Protection Act and NHS Trust policies and procedures. Permission is only granted for this NHS organisation to act as a participant identification centre (PIC) for your research study. Any other research activities at this NHS organisation, including the taking of consent, will require a further application for permission.

The following local conditions will apply:

1. **Sponsorship of study**
   
The research sponsor will be the organisation named above; the trust giving permission is not responsible for the management and design of the study.

2. **Confidentiality**
   
   You are required to ensure that all information regarding participants remains secure and strictly confidential at all times. You must ensure that you understand and comply with the requirements of the Data Protection Act (1998) and the NHS Confidentiality Code of Practice ([www.dh.gov.uk/assetRoot/04/06/92/54/04/06/9254.pdf](http://www.dh.gov.uk/assetRoot/04/06/92/54/04/06/9254.pdf)). Furthermore, you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

3. **Amendments**
   
   All amendments (including changes to the local research team) need to be submitted in accordance with guidance in IRAS. This office should be informed at the same time as REC is notified in order to avoid unnecessary delays.

4. **Study progression**
   
   You will inform us of any significant developments that occur as the study progresses. You will complete and return any report forms that we send you.

5. **Study completion**
   
   You will notify this office when the study has completed recruiting participants and when the study is finally finished at your site. You will complete and return the final report that we send you and inform us of any publications relating to the study.

Finally, I wish you every success with the study.

Yours sincerely,

[Signature]

Dr [Name]

RM&G Manager, [Name]

[Signature]

[Name]

Academic Supervisor

[Signature]

Dr [Name]

Sponsor's representative
Dear name of parent/carer

Re: Research Study: Hypnosis Treatment for Primary Nocturnal Enuresis in Children and Young People: A Case Series

XXX Services within Child Development locally have been providing treatment services for children who wet the bed for many years. We know that many children continue to experience bedwetting as they get older and may never have been dry at night. Bedwetting can be an upsetting for children and difficult for families to manage.

The National Institute of Health and Care Excellence (NICE), has produced guidelines about effective treatments for children and young people who wet at night. These guidelines suggest that more research is needed to look at therapies such as hypnosis as a treatment for bedwetting.

Hypnosis has been used to help children with emotional and behavioural problems for many years. The clinical psychologists working with children in East Kent have been using hypnosis for several years now to help children and young people with a range of problems, including bedwetting. However further research is needed to more clearly establish its effectiveness.

This research project aims to use hypnosis as a treatment for children and young people who wet the bed to look in more detail at its effectiveness. The enclosed information sheet tells you more about the research. If you and your child decide to take part, this would involve attending 6-8 appointments over several months at the Kent and Canterbury Hospital to treat your child’s bedwetting using hypnosis.

I very much hope you and your child would be interested in your child participating in the research. If you are interested and would like to find out more, or have any questions please either contact me directly on the telephone number or email above. Alternatively tear off the slip at the bottom of this letter and return it to me in the stamped addressed envelope provided, and I will contact you.

Yours sincerely

Name of Researcher
Job title

I am consenting for you to contact me regarding the research study: Hypnosis Treatment for Primary Nocturnal Enuresis in Children and Young People: A Case Series

My name______________________________
Child’s name __________________________
Telephone number(s)…………… Email……………………….

I would prefer to be contacted by phone / email / don’t mind (circle which applies)
Hypnosis Treatment for Primary Nocturnal Enuresis in Children and Young People: A Case Series

Name of Researcher: Job Title of Researcher

I would like to invite your child to take part in this research study. Before you decide, I would like you to understand why the research is being done and what it will involve for your child. Please read through the information provided. I am happy to answer any questions you may have. Also, feel free to talk to others about the study if you wish. Please ask if there is anything that is not clear.

What is the study about?
Many children experience bedwetting and have never been dry at night. Bedwetting can be upsetting and can be associated with being teased or bullied, with behavioural problems and poor self-esteem.

National guidelines (NICE 2010), on the management of bedwetting recommend a range of treatments for children and young people. However for some children and young people these treatments may not be wanted or may not work. The NICE guidelines suggest that we need to look at ‘alternative’ therapies including hypnotherapy as a treatment for bedwetting.

Hypnosis treatments have been used to help children with emotional and behavioural problems for many years, but there is not much research that looks at hypnosis as a treatment for bedwetting. However it is thought that hypnosis treatment for bedwetting can be effective and can work quite quickly. Locally the XXX team that works in Child Development has been successfully using hypnosis as a treatment for bedwetting for over two years.

Aims of the study
This study will use hypnosis to treat up to 10 children and young people (aged 8-17) with bedwetting. Each child or young person will receive up to 6 treatment sessions with a clinical psychologist, to see if treatment with hypnosis will work to help the bedwetting reduce. It will also look at whether other things change as a result of stopping bedwetting, such as child’s quality of life. This study will also contribute to obtaining a professional doctorate (PsyD) qualification for the XXXX undertaking the research.

How would I be involved?
The study would involve you and your child speaking to me on the phone to answer any questions you may have and to see whether your child would be suitable to take part in the study. If your child is suitable and both you and your child wish to take part, an assessment will be arranged to collect more information about your child, family and
bedwetting. You and your child will be asked to complete some questionnaires at this appointment which ask more about your child’s emotions, behaviour and quality of life, as well as some things about you as a parent/carer, such as your quality of life and stress levels.

**What would taking part in the study involve?**

After the initial assessment, you and your child will be asked to keep a simple diary for 2-3 weeks before treatment begins to record if and to what extent your child is wet at night. Hypnosis treatment will take place over 4-6 sessions, lasting about 35 minutes per session. Treatment sessions will take place every 2-3 weeks at your convenience and will be undertaken at the XXX Hospital. It is not anticipated that any expenses on your part would be incurred in taking part in the study; however, in the unlikely event of this, I would not be able to reimburse you.

**What if there is a problem or something goes wrong?**

If during your participation you have a concern about any aspect of this study, you should discuss these with me and I will do my best to answer your questions (Please see my contact details below). If you remain unhappy and wish to complain formally, you can do this by contacting the Patient Experience Team – details below.

Write to: Patient Experience Team, address (contact details of team).

**Will my child’s taking part in this study be kept confidential?**

Your child’s participation in this study is entirely voluntary and yours and your child’s consent will be obtained prior to any data being collected. You and your child will remain anonymous. I will follow ethical and legal practice and all information about you or the child will be handled in confidence. All information pertaining to yourself or your child will be stored on a password-protected NHS computer, and in a locked filing cabinet in my office at the Children’s Assessment Centre.

Your child will be allocated a study number at the beginning of the interview and this number is all that will appear on all information. Additionally, I will do my best to ensure that you and your child will not be identifiable in any report arising from this research. I will not reveal your name or your child’s name. However I will inform your child’s GP and your child’s school nurse enuresis clinic of your child’s participation in the research. If you and your child choose to participate in the research, you may at a later time withdraw your data from the research without giving a reason and with no effects on your child’s care. In addition to this, some basic demographic details such as your child’s age will be collected.

I appreciate your consideration of this study and will be happy to answer any additional questions that you may have. If you wish to participate, or would simply like to discuss the study further, please contact me on the number/email below. Alternatively, if you are happy for me contact you, please fill in the form enclosed in this letter to indicate this and send it back via the stamped, self-addressed envelope enclosed.

**Name and Job Title of Researcher**

Telephone and email
Information Sheet for Children aged 8-11 (Version 2 - 30.5.14)

This tells you about a project using hypnosis to help children who wet the bed

I am XXXX - this is me! I am a XXX and I work in a clinic. I help children with problems like worries, being sad and bedwetting.

I am doing a research project. I am asking if you would like to take part in this research project. Before you decide if you want to join in, it's important you understand what the project is about. You also need to know why it is being done and what it will mean if you take part. Please read the information here with your parents. If something doesn't make sense or you have questions about it, ask your family to call me so we can talk a bit more about it.

What is research?
Research is a good way to find out answers to questions.
What is this project about?
Many children wet the bed. Some children have never been dry at night. Bedwetting can be upsetting and children can be teased because of it. It can make children unhappy.

There are some treatments for bedwetting which can be helpful. You might have tried some treatments, but still wet the bed.

Hypnosis has been used to help children with lots of different problems for a long time. We think hypnosis might help children to stop wetting the bed. I want to do this project to find out.

Why have I been asked to take part?
The nurse who sees you at the bedwetting clinic thinks this treatment might help you.

Did anyone check the project is ok to do?
Before any research can happen it is checked by a group of people who make sure it is fair and safe.

Do I have to take part?
No you don’t. You can choose to take part if you want to. But if you change your mind at any time, you can stop taking part straight away.

How will taking part help me?
The hypnosis may help you to get dry at night.
What would happen to me if I do want to take part?
Once I have checked that you and your parents are happy for you to take part, you and your parent will come along and meet me at the Children’s Assessment Centre in XXX. You can ask questions and we will talk more about bedwetting, how hypnosis works and how it might help you.

We then arrange up to 6 more times for you to come and have hypnosis with me. There is a leaflet in the envelope you were given which tells you and your parents more about hypnosis and how it works.

You will be given a CD or a sound file to play which helps you practise hypnosis at home. I will also ask you and your parents to keep a diary of how many dry nights you have.

I would like to see you again a few months after you have finished the hypnosis treatment, to see if it continues to work.

What if there is a problem or something goes wrong?
If you have a worry at any time please talk to your parents about it or to me. I will do my best to answer your questions.

Will information about me be kept private?
All your information will be kept private. I will just let your family doctor and your nurse in the bedwetting clinic know you are joining in the project.
Information Sheet for Children and Young People aged 12-15
(Version 2 - 30.5.14)

These pages give you information about a research project using hypnosis to help children and young people with bedwetting

I am XXX. I am a XXX and I work in a clinic. My work involves helping children and young people with problems like worries, being sad and bedwetting.

I am doing a research project. I am writing to ask if you would like to take part in this research project. Before you decide if you want to take part, it’s important you understand what the research project is about, why it is being done and what it will mean if you take part. Please read this information sheet carefully and talk to your family or friends about it if you wish. If something doesn’t make sense or you have some questions about it, you or your family can call me to talk about it in more detail.

What is research?
Research is a good way to find out answers to questions. The question I want to answer in this project is ‘Can hypnosis help children and young
people with bedwetting?’

What is this project about?
Many children and young people wet the bed. Some children and young people have never been dry at night. Bedwetting can be upsetting and children and young people can be teased because of it. It can make children and young people unhappy. There are several treatments for bedwetting which can be helpful. You might have tried some treatments, but still wet the bed.

Hypnosis has been used to help children and young people with lots of different problems for a long time. Psychologists think it might be helpful for bedwetting and I am doing this research project to try and find out.

Why have I been asked to take part?
The nurse who sees you at the bedwetting clinic thinks this treatment might be effective to help you with bedwetting.

Did anyone check the project to make sure it is fair and safe?
Before any research can happen it is checked by a group of people who make sure it is fair and safe.

Do I have to take part?
No you don’t have to take part. You can choose to take part if you want to. But if you change your mind at any time, you can always stop taking part straight away.

How will taking part in the research help me?
The hypnosis may help you to get dry at night.
What would happen to me if I do want to take part?
Once I have checked that you and your parents are happy for you to take part, you and your parent will come along and meet with me at the Children’s Assessment Centre in XXXX. You can ask any more questions you have about the research project and we will talk more about bedwetting, how hypnosis works and how it might help you.

We then arrange up to 6 more times for you to come and have hypnosis with me. We can arrange these so you don’t miss much or any school or other things you might want to do. There is a leaflet in the envelope you were given which tells you and your parents more about hypnosis and how it works.

You will be given a CD or a sound file to play which helps you practise the hypnosis at home. I will also ask you and your parents to keep a diary of how many dry nights you have.

I would like to see you again a few months after you have finished the hypnosis treatment, to see if it continues to work.

What if there is a problem or something goes wrong?
If you have a worry at any time please talk to your parents about it or to me. I will do my best to answer your questions.

Will information about me be kept private?
All your information will be kept private. I will just let your family doctor and your nurse in the bedwetting clinic know you are taking part in this research project.
Information Sheet for Young People aged 16-17 (Version 2 - 30.5.14)

Hypnosis Treatment for Bedwetting in Children and Young People

Name of Researcher: Job Title of Researcher

I would like to invite you to take part in this research project. Before you decide, I would like you to understand why the research project is being done and what it would involve for you. Please read the information provided. I am happy to answer any questions you may have. Also talk to your family about the study if you wish. Please ask me if there is anything that is not clear.

What is the research project about?
Many young people still wet the bed. They may never have been dry at night. Bedwetting can be a upsetting and young people can be teased because of it. It can make young people unhappy.

National guidelines about treating bedwetting tell us there are several treatments for bedwetting for young people which can be helpful. Some young people have tried these treatments, but still wet the bed.

Hypnosis has been used to help young people with emotional and behavioural problems for many years. There is some information that tells us that hypnosis might be helpful for bedwetting and that it can work quite quickly. Locally we have helped some young people get dry at night by using hypnosis.

What is this research project trying to do?
I will use hypnosis to help children and young people who are aged 8-17 with bedwetting. Each child or young person will have up to 6 hypnosis treatment sessions. This will help me to see if treatment with hypnosis will work for bedwetting. I hope that the treatment will also help children and young people feel happier and better about themselves.
How would I be involved?
The study would involve you and your parent speaking to me on the phone to answer any questions you may have. If I think this treatment might be helpful for you, I will invite you and your parent to come and meet with me to get a bit more information about you and your family.

What would taking part in the study involve?
After the first appointment, you and your family will be asked to keep a diary to get some information about your wet and dry nights. The hypnosis treatment comes after this, and I will offer you 4 to 6 appointments for hypnosis, lasting about 35 minutes each time. These appointments would be once every 2-3 weeks at the Children's Assessment Centre, XXXX Hospital. We can arrange these appointments so you don't miss much or any school or other things you might want to do.

Will my taking part in this study be kept confidential?
Taking part in this research project is up to you. You can decide to stop taking part at any time. I will ask you for your consent in writing before we do any treatment. I will follow all the rules that are important when we do this kind of project. No one will know you are taking part except your family doctor and the nurse who gave you the information about this project. I will keep all the information I collect about you very safe in locked cabinets and I will use passwords on computer files.

Did anyone check the project to make sure it is fair and safe?
Before any research can happen it is checked by an ethics committee - a group of experienced people who make sure any research project is fair and safe to do.

I hope you will consider taking part in this research project. If you wish to take part or would like to talk about the research a bit more or ask questions, please contact me or ask your family to contact me on the number/email below.

Name and Job Title of Researcher
Telephone and email
Appendix N. Consent Form Parent of Carer

Trust Header

Consent Form for Parent or Carer (Version 1 - 7.3.14)

Hypnosis Treatment for Primary Nocturnal Enuresis in Children and Young People: A Case Series

Name of Researcher: Job title

Please initial box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my son’s/daughter’s and my participation is voluntary and that we are free to withdraw at any time without giving any reason, without my own or my child’s medical care or legal rights being affected.

3. I understand that relevant sections of my son’s/daughter’s medical notes and data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my son’s/daughter’s records.

4. I agree to my data being stored as outlined on the information sheet.

5. I agree for my son’s/daughter’s GP to be informed of their involvement in the study.

6. I agree for my son’s/daughter’s school nurse enuresis clinic to be told that they are taking part in the study.

7. I agree for my son/daughter to take part in the above study.

_________________   ________________   ____________ _________
Name of respondent   Date     Signature

_________________  ________________     _____________________
Name of person   Date     Signature taking consent

Name of child ____________________________
Appendix O. Consent Form for Child Young Person

Consent Form for Child or Young Person (Version 1 - 7.3.14)

Hypnosis Treatment for Primary Nocturnal Enuresis in Children and Young People: A Case Series

Name of Researcher: Job title

Please initial box

8. I have read the information sheet about this study. I understand it. I have asked any questions that I wanted to and these have been answered for me.

9. I understand that I am volunteering to take part. I can stop taking part any time they want to, and I don’t have to say why. Taking part will not affect any other health treatment I have.

10. I understand that parts of my medical notes and information collected during the research might be looked at by people who look at research or people from the NHS Trust. I give permission for these people to look at my medical records.

11. I agree to information about me being stored as I read it on the information sheet.

12. I agree for my family doctor to be told that I am taking part in the study.

13. I agree for my school nurse to be told that I am taking part in the study.

14. I agree that I will take part in the above study.

_________________   ________________   ____________ _____
Name of child or   Date    Signature
young person

_________________   ________________   __________________
Name of person     Date     Signature
taking consent
APPENDIX P. Instructions for Authors

1.1.1 Instructions to Authors

The Journal of Pediatric Psychology is an official publication of the Society of Pediatric Psychology, Division 54 of the American Psychological Association. JPP publishes articles related to theory, research, and professional practice in pediatric psychology.

1.1.2 Types of Manuscripts:

• Original research, including case studies
• Review articles
• Commentaries

1.1.3 Manuscript preparation: General Instructions

Full instructions for uploading data and files etc. are given on Manuscript Central at the website under Instructions for online submission: http://www.oxfordjournals.org/our_journals/jpepsy/for_authors/submission_online.html

1.1.4 Organization of manuscripts

Manuscript Central will guide authors through the submission steps, including: Abstract, Keyword selection, and the Manuscript. The manuscript must contain an Introduction, Methods, Results, Discussion, Acknowledgements and Reference List.

Length of manuscript: Original research articles should not exceed 25 pages, in total, including title page, references, figures, tables, etc. In the case of papers that report on multiple studies or those with methodologies that necessitate detailed explanation, the authors should justify longer manuscript length to the Editor in the cover letter. Case reports should not exceed 20 pages. Review articles should not exceed 30 pages. Commentaries should not exceed 4 pages. The Journal of Pediatric Psychology no longer accepts brief reports but will accept manuscripts that are shorter in length than the 25 page manuscripts.

Manuscripts (text, references, tables, figures, etc.) should be prepared in detailed accord with the Publication Manual of the American Psychological Association (6th ed.). There are two exceptions:

(a) The academic degrees of authors should be placed on the title page following their names, and
(b) a structured abstract of not more than 150 words should be included. The abstract should include the following parts:

(1) Objective (brief statement of the purpose of the study);
(2) Methods (summary of the participants, design, measures, procedure);
(3) Results (the primary findings of this work); and
(4) Conclusions (statement of implications of these data).

Key words should be included, consistent with APA style. Submissions should be double-spaced throughout, with margins of at least 1 inch and font size of 12 points (or 26 lines per page, 12-15 characters per inch). Authors should remove all identifying information from the body of the manuscript so that peer reviewers will be unable to recognize the authors and their affiliations. E-mail addresses, whenever possible, should be included in the author note.

Informed consent and ethical treatment of study participants. Authors should indicate in the Method section of relevant manuscripts how informed consent was obtained and report the approval of the study by the appropriate Institutional Review Board(s). Authors will also be asked to sign a statement, provided by the Editor that they have complied with the American Psychological Association Ethical Principles with regard to the treatment of their sample.

Clinical relevance of the research should be incorporated into the manuscripts. There is no special section on clinical implications, but authors should integrate implications for practice, as appropriate, into papers.

Terminology should be sensitive to the individual who has a disease or disability. The Editors endorse the concept of "people first, not their disability." Terminology should reflect the "person with a disability" (e.g., children with diabetes, persons with HIV infection, families of children with cancer) rather than the condition as an adjective (e.g., diabetic children, HIV patients, cancer families). Nonsexist language should be used.

1.1.5 Special instructions for types of manuscripts

(1) Treatment studies/Randomized controlled trials: If you are submitting a manuscript of a randomized clinical trial to JPP, you are required to submit a flowchart of your research
showing the steps found in the Consort E-Flowchart. This should be submitted as a figure. The Consort E-Flowchart and a checklist of items to be included when reporting a randomized trial can both be found on http://www.consort-statement.org Please clearly indicate the page numbers where each checklist item is reported in the manuscript. Please upload this checklist as supplementary material when you submit your manuscript for consideration.

(2) Case Studies: Although there may be some exceptions, most case studies should be sent to Clinical Practice in Pediatric Psychology (CPPP). Single-subject studies that employ rigorous A-B-A-B designs and/or statistical strategies can be sent to JPP. All others will probably fit better with CPPP. Case reports should not exceed 20 pages. Case reports are appropriate to document the efficacy of new treatment applications; to describe new clinical phenomena; to develop hypotheses; to illustrate methodological issues, difficult diagnoses, and novel treatment approaches; and to identify unmet clinical or research needs. Guidelines for case study submissions can be found in Drofatar, D. (2009). Editorial: Case Studies and Series: A Call for Action and Invitation for Submissions, Journal of Pediatric Psychology, 34, 795-802; Drofatar, D. (2011). Editorial: Guidance for Submitting and Reviewing Case Reports and Series in the Journal of Pediatric Psychology, 36, 951-958.


(4) Review articles: Please consult the recent editorial (New Guidelines for Publishing Review Articles in JPP) which describes new guidelines for review articles, and the Checklist for Preparing and Evaluating Review Articles.

   a) Topical reviews: Topical reviews summarize contemporary findings, suggest new conceptual models, or highlight noteworthy or controversial issues in pediatric psychology. They are limited to 2,000 words, contain no more than 2 tables or figures, and have an upper limit of 30 references. Supplementary online material (e.g., additional tables) may be considered on a case by case basis.

   b) Systematic reviews: Systematic reviews should not exceed 30 pages. Authors are required to attach the PRISMA checklist and flow diagram as supplementary material for each submission. Authors can find the PRISMA checklist and flow diagram in downloadable templates that can be reused at this URL, http://www.prisma-statement.org/statement.htm. Authors of systematic reviews that do not include a meta-analysis must provide a clear statement in the manuscript explaining why such an analysis is not included for all or relevant portions of the report.

(5) Commentaries: Commentaries are invited on all topics of interest in pediatric psychology, and should not exceed 4 pages, including references.

(6) Historical Analysis in Pediatric Psychology is a special series of papers devoted to the history of pediatric psychology. Authors interested in submitting a paper for this series should contact the Editor of JPP to discuss potential papers prior to submission. There is no deadline for these papers (they may be submitted anytime). All submissions will be peer reviewed and should comply fully with the JPP Instructions to Authors. Papers in this series should be tightly focused contributions that expand our understanding of the roots, evolution, and/or impact of pediatric psychology as a discipline. Manuscripts may focus on the influence of individuals, published works, organizations, conceptualizations, philosophies or approaches, or clinical and professional activities. Successful papers should articulate a clear purpose/question and develop a compelling argument for the topic. Contributions should include a breadth of coverage, such that contradictory data are included and potential biases acknowledged. Historical analysis is more than a recounting of the “facts” and should include a thoughtful and scholarly interpretation of the subject matter. Papers should rely on primary sources and must be clearly and appropriately referenced. Supplemental materials to accompany the article may be posted online.

1.1.6 Additional Guidance:
The following links provide additional guidance for authors and reviewers. Editorial Policy, Authors' Checklist, Guidelines for Reviews, Suggestions for Mentored Reviews, “People First,” NIH policy, Replication of research, Duplicate and redundant policies, Conflict of interest.

See the following articles for detailed guidance concerning preparation of manuscripts: Editorial: Thoughts in Improving the Quality of Manuscripts Submitted to the Journal of Pediatric Psychology; How to Write a Convincing Introduction; Methods: Editorial: How to Report Methods.
1.1.7 Funding
Details of all funding sources for the work in question should be given in a separate section entitled ‘Funding’. This should appear before the ‘Acknowledgements’ section.

The following rules should be followed:
• The sentence should begin: 'This work was supported by …'
• The full official funding agency name should be given, i.e. 'the National Cancer Institute at the National Institutes of Health' or simply 'National Institutes of Health', not 'NCI' (one of the 27 subinstitutions) or 'NCI at NIH' (full RIN-approved list of UK funding agencies)
• Grant numbers should be complete and accurate and provided in parentheses as follows: '(grant number xxxx)'
• Multiple grant numbers should be separated by a comma as follows: '(grant numbers xxxx, yyyy)'
• Agencies should be separated by a semi-colon (plus 'and' before the last funding agency)
• Where individuals need to be specified for certain sources of funding the following text should be added after the relevant agency or grant number 'to [author initials]'.

Oxford Journals will deposit all NIH-funded articles in PubMed Central. See http://www.oxfordjournals.org/for authors/repositories.html for details. Authors must ensure that manuscripts are clearly indicated as NIH-funded using the guidelines above

1.1.8 Permission for Illustrations and Figures
Permission to reproduce copyright material, for print and online publication in perpetuity, must be cleared and if necessary paid for by the author; this includes applications and payments to DACS, ARS, and similar licensing agencies where appropriate. Evidence in writing that such permissions have been secured from the rights-holder must be made available to the editors. It is also the author’s responsibility to include acknowledgements as stipulated by the particular institutions. Oxford Journals can offer information and documentation to assist authors in securing print and online permissions: please see the Guidelines for Authors section. Information on permissions contacts for a number of main galleries and museums can also be provided. Should you require copies of this, please contact the editorial office of the journal in question or the Oxford Journals Rights department.

Updated January 2013
Overview

The following section outlines reflections on the research process. It begins with exploration of my choice of project and how this grew out of clinical practice, combined with my evolving skills and activity in applied research. It explores my experiences of the stages and overall process of research; drawing on previous experiences and looking at the current research experience in relation to them. It examines the collaborative nature of research across agencies, departments and professions. It reviews skills and insights that have been developed via the process. Further critical reflection explores how the project might have evolved differently with the benefit of hindsight, and how the process and findings of this research has contributed to refining my clinical practice, as well as my thinking at management and strategic levels.

Choice of Project

The choice of the project emerged over time through the integrative process of provision of psychological services to children and young people with developmental conditions, and the ongoing need to implement innovative and effective interventions. My interest in using hypnosis was initially sparked by my use of simple imaginal techniques in my work - especially in pain management and anxiety related difficulties. I had experienced some measure of success using these, but felt I lacked both practical and theoretical knowledge regarding moving forward into integrating these into treatment packages.

I had developed a passing interest in hypnosis as part of my original training in clinical psychology at University College London (UCL), at that time also home to a hypnosis unit. This had provided me and my cohort with a couple of taster days’ tuition at that point. I had never developed this further, but had remained latently intrigued. Using imagery as part of my clinical work re-energised this interest, and I then undertook an accredited course in hypnosis to develop these skills. As part of this training course I also started to engage with the literature identifying the strong evidence base supporting the efficacy of hypnosis as a treatment for a variety of presenting problems in children. I was surprised by its utility in being applicable to a range of problems, and by the positive outcomes, identified for example in Milling and Costantino’s (2000) review of controlled studies on the efficacy of clinical hypnosis with children. Their findings also indicated that the evidence base for hypnosis is
strongest regarding its use in the management of acute pain, chemotherapy-related distress, and enuresis.

Within my clinical roles, I am required to provide services to children with wetting and soiling issues, and have always felt very comfortable using standard behavioural and cognitive behavioural therapy (CBT) techniques when the issues present in daytime, but found these less useful with nighttime presentations. There is some evidence that CBT is useful in treating nocturnal enuresis (NE) (e.g. Ronen, Woznera, & Rahava, 1992), but I had found this approach largely unhelpful and was looking for an effective psychological treatment to complement ongoing medical treatment, or to provide instead of medical treatment, where this had been unsuccessful or unacceptable to children and families. Hypnosis provided this, and I treated an initial case (12 year old girl) very successfully and quite quickly using a hypnosis-based intervention. I then wrote this up as a case report as part of my hypnosis training. This process meant further literature review and ongoing process of identifying evidence of effectiveness of hypnosis as an intervention in NE, all of which further engaged my interest and motivation to explore this treatment option in a more systematic way via the research process.

Around this time, new national guidelines (NICE, 2010) on the management of NE in children and young people were published. These recommend hypnosis treatment for NE as a therapeutic approach needing further research. This, coinciding with my successful treatment case was a very galvanising experience. Soon after this, I treated another two cases of NE successfully using hypnosis. As someone who has always been research active in my posts, I am always interested in and motivated to engage further in research that emerges from interesting clinical questions or novel and effective clinical interventions, of which this is a good example.

The issue as regards choice of project was also informed by balance of clinical roles and responsibilities and research. The children and families involved in this research project were children that I probably would have treated anyway as part of my clinical practice. I treated perhaps more of them in a shorter space of time than would usually be the case in routine clinical care, but certainly the research project fitted well with service demands, and therefore did not conflict with the commissioned clinical activity of the service I work in.
The Research Process

Literature Search

I’ve conducted systematic literature review several times in the course of my career for several pieces of research. However this was a different challenge to those I have previously undertaken. This current field of research is fairly small with few published studies; very few of these having level 1, grade A evidence (as adopted by NICE in examining the quality of evidence provided by treatment or management research studies). I had to be as inclusive as possible in accessing possible papers some of which dated back to the 1950s. A lot of these had to be accessed via the British Libraries Document Service, which I had never used before, and which my on-site NHS library service was very helpful in accessing for me. These were in fact a little disappointing when they arrived, being mainly single case reports of limited scientific value as regards informing this current research undertaking. This search presented different problems to previous searches where the skill has been to cut down the extant body of research to access most relevant papers. However this search, due to the paucity of published research in this area, meant being exhaustive and proceeded rather more like undertaking the critical review literature search process. I accessed the Cochrane Handbook for Systematic Review (Higgins & Green, 2011) which was helpful for its detailed guidelines on systematic search.

Ethics and Research & Development (R&D)

Before undertaking this professional doctorate, I had quite a lot of experience working in the field of clinically based research. This is been in research teams earlier in my career, and latterly in working jointly with other individuals and agencies, for example acting as a recruitment site or principal investigator for funded studies for organisations like the Tizard Centre for Disability, University of Kent, or around developing and supervising research/service evaluation projects for undergraduate placement students in my department. I had recently also collaborated successfully with the local NHS community trust in undertaking a project to develop a book resource to enhance participation in children with four limb cerebral palsy. This latter project was the largest I had developed, and had involved full R&D and research ethics approval. This was my first experience for several years of this process, and my first experience with the online IRAS application system. I found it pleasingly straightforward.
My pre-existing and ongoing relationship with my host trust’s R&D department and also that of the neighbouring NHS trust was also very helpful in knowing the systems, procedures and individuals to approach in developing and gaining approval for this piece of research. There was also obviously some knowledge about my skills and experience from their point of view, which I think contributed to expediting the process of getting relevant approvals of this research.

Hence through all these roles and experiences, I feel that I had developed my working knowledge of research methodology and the processes involved in undertaking research in NHS settings. And as importantly, I have continued to develop my knowledge of the local and national infrastructure and processes of research. All of which meant I was well placed to undertake more research and to be able to see the whole process through from conception of idea to write and dissemination of findings.

Choice of Design and Methodology

The process of research starts with an idea and questions that flow from that idea. The question for me as the research idea formed itself was ‘Is hypnosis an effective treatment for children and young people with enuresis?’ Secondary issues were around the best way to administer this treatment. I could of course have gone on and treated lots of cases and so refined the treatment myself in my clinical practice, rather than undertaking research. But the challenge in research is more systematic and involves answering questions of clinical efficacy to a higher level of evidence than that in clinical practice.

Issues that were considered in my decision making processes around the research included having a design which was strong enough to be able to address the primary question, whilst being at the same time being a good fit or at least a manageable option within the constraints of the service in which I work. This meant it needed to be manageable for me to undertake in terms of my time and resources, as well as financially viable. My level of experience as a researcher thus far meant that I was unlikely to have the profile and range of skills to be able apply successfully for an external grant to fund a more systematic trial with control group. Reading and discussion with psychological and medical colleagues identified that case series are relatively straightforward pieces of research to do within clinical practice. They are considered helpful in communicating clinical experience to a wider audience in a systematic way. They enable preliminary exploration of the usefulness and efficacy of
novel interventions and involve clinical methods that are cost effective (Virués-Ortega & Moreno-Rodríguez 2008).

The major issue with case series is the obvious lack of a control group, which means that it is difficult to draw definitive conclusions as to the efficacy of any treatment being looked at, as it may just be that change in the condition is due to the natural history of the condition (Carey & Boden, 2003).

AB designs are the simplest to undertake in this kind of case series research, and may constitute the only viable option within clinical practice due to cost and ethical concerns of instituting a second A phase (Virués-Ortega & Moreno-Rodríguez 2008).

Recruitment and Enrolment

This was a surprisingly straightforward process, and was well-balanced in terms of my research timeline. I had not explicitly planned for this intake of cases at intervals, but I suspect it resulted from initially meeting with the individuals and teams who were recruiting to the project at fairly widely spaced of intervals of about four to six weeks apart. This meant active recruitment started at different time points in different locations, resulting in steady and well-spaced recruitment of participants.

Very few children came through to me for possible enrolment who were not suitable, which I hope had been due the process of consulting closely with recruiting parties and giving clear guidance as to the project’s inclusion and exclusion criteria. There were some issues around the project seeking to enrol only 10 children, one of these being that with such as small number, I had to be aware to tell sites that the study was fully recruited to, so as to prompt them to cease giving information to potential participants.

There is a general point here that I have found in previous research activity, that the research process did also generate some different work, which I had anticipated. Once recruiting parties knew of my existence and interests and how to access my service, they were keen to use me as a source of consultation about, or referral of cases for other presenting problems, even if there were other more easily accessible and/or appropriate services to take those referrals. There was a need for me to be clear about service specification, referral pathways and boundaries of child development services, but signposting to other services was also an important role here.

Points to address with hindsight as regards assessment and enrolment in the study, would have been around motivation of children and young people to engage in
the process. Further assessment of motivational factors has been clearly identified in this study to be important, as lack of motivation contributed to treatment drop outs. There were two dropouts, one of which I had been unsure about enrolling initially - a girl with emotional and behavioral issues, fostered and adopted latterly in a stable care environment. Another girl, I did not identify as a possible dropout and who initially seemed very suitable; her mother indicating that her daughter hadn’t realised the degree of effort involved in practising the self-hypnosis (SH) every night. Perhaps I might have been clearer about the degree of effort on part of the child or young person to practise SH for the duration of the study, or for as long as it took to consolidate dryness at night. I hadn’t systematically assessed motivation at the point of enrolment, but with hindsight, I think perhaps this could have been more robustly assessed by use of techniques of Motivational Interviewing (Miller & Rollnick, 2012), or by use of a standardised motivational questionnaire.

Analysis

I understood the importance of having an overview of the research process including analysis strategy before developing and implementing the study. However I would have paid more attention gathering more time point data in the baseline period to establish rather better if I had a stable baseline period.

I have done quite a bit of large population data analysis using parametric statistics, and I have had experience of handling qualitative interview and focus group data, but this data was quite different. It was interesting to learn new statistical procedures including Simulation Modelling Analysis (SMA) (Borckardt et al., 2008) and to understand the theoretical underpinnings, uses and limitations of this mode of analysis. This took my reading into the fields of psychiatry and neuropsychology, as this method of analysis has been developed and used in these areas. I developed my knowledge about key assumptions regarding the data before it was subjected to analysis, and also more about interpreting statistical findings. Consulting with the NHS Trust statistician was challenging, but ultimately very useful in helping me understand the limitations of my data set, what could be achieved in terms of analysis and the boundaries of interpretation, which are always much clearer with larger data sets, robustly sampled, well-powered and using parametric analysis.

It was also interesting to enter into discussions with the statistician and to follow up with reading about the use of non-parametric statistics versus parametric statistics in
looking at group differences across time. I recalled as part of my training being required to do these analyses by hand, which I explored again with this data set. This really proved to be a worthwhile undertaking – allowing me to really explore the data and explore and understand in more detail exactly what I was doing in analysis.

**Organisational Issues or Obstacles Encountered During the Research**

**Balance of Clinical and Research Roles**

There was some negotiation with my manager around competing demands on my time and the need to continue to fulfil my management and leadership roles, as well as clinical roles within my current NHS post, in addition to the demands of undertaking research. I suspect that the research track record of the clinical psychology service within helped somewhat here. Over the last four years we have produced several pieces of service evaluation, audit and research without any compromise to clinical roles or job performance. However this negotiation was helped by my having developed a detailed plan and timeline for the research. This delineated how much of my time was going to be needed to fulfil the demands of the research, and how I was proposing to get this time, and not fall short in my other commitments.

**Grant Application**

I had also applied to the annual internal project grant scheme, which grants up to £50,000 to one or more projects within the trust to support the Trust’s employees in undertaking research. This was an exacting and detailed process which involved detailed costing in collaboration with the finance department of the Trust. This was a very helpful process to engage with in developing and expressing my research ideas clearly at an early stage, as well as developing a deeper understanding of funding issues for different aspects of research activity. I didn’t get this grant, however I was then able to use the developed research protocol and detailed costings to apply for a smaller grant from the Trust charity which, with the support of the R&D department, was granted. This helpfully provided for some backfill monies for my post.

**Navigating Organisations and Developing Relationships**

The matrix of systems, teams, processes and individuals within which research occurs was also interesting to observe, explore and be part of – not always happily. My
research project involved recruiting both from my host trust, as well as from the
neighbouring Community Trust, as children and young people with NE are first seen by
school nurse clinics based in this trust rather than in the acute Hospitals Trust. There
was a lengthy process of developing connections and relationships with the Community
Trust. Navigating the way around as regards service organisation and management was
tricky. There were several layers of management of school nurse teams that needed be
involved in understanding the value of the project, the scientific quality, the workload
implications for their nurse practitioners as well as the implications for their patients.
Strategic meetings with various involved parties took some time to arrange. The
Community Trust and the individuals I met with were clearly not involved in research
within their clinical and management roles. This meant I met with some resistance
initially followed by protracted requests for documented evidence that I had gone
through the correct channels (R&D, ethics etc) in developing my research to ensure that
I could access patients within the Community Trust.

I also found that it was important to allow time for discussion of the research
design with others. Nurses, as medical professionals, I suspect were used to the RCT as
the dominant study design. Therefore explaining and justifying why I was seeing only
10 cases in my research was a challenge.

The issue that the project used hypnosis also had an interesting impact on
individuals and organisations I was collaborating with in recruiting to the project. This
was beneficial for my purposes at times; people were naturally interested in and
intrigued by its use, and some disclosed having seen stage hypnosis, hypnosis on
television or indeed having experienced hypnosis themselves as part of entertainment or
as therapy. This natural curiosity meant that some individuals were interested to talk to
me and hear what I was hoping to undertake. At other times this pre-existing
knowledge and/or beliefs about hypnosis were a hindrance, with individuals expressing
scepticism about its status as a clinical treatment, I think basing their opinions on the
use of hypnosis as an entertainment, not appreciating its use and effectiveness in clinical
practice.

It was therefore at times a challenge to explain the scientific background and
usefulness of the project in the face of uninformed opinion. The challenge was to
succinctly and usefully present the process by which I had arrived at the current project:
integrating my knowledge of the evidence base for hypnosis in clinical work; the fact I
was using it habitually (as were others in my NHS service), for effectively treating a
variety of difficulties, whilst giving others an insight into the process and means by which it works. Citing research evidence and recent NICE guideline recommendations (NICE, 2010) as regards he need for further research using hypnosis with NE were helpful in changing the perceptions of nursing staff as to the integrity of the research.

Communicating with nurse managers was quite tricky. There were definite issues regarding defensiveness around the potential for incursion of clinical psychology roles and responsibilities into those of nurse practitioners. I keenly felt the need to open these issues for discussion and clarification. Communicating my understanding of and valuing the of nursing input for children with NE was vital in reassurance that I was in no way seeking to replace their roles in this area. Further communicating that I felt I could offer something complementary or as an alternative to medication options when standard nurse delivered treatment had not succeeded or had not been optimal in its effects.

I was minded to make sure that I was offering something in return for nurse practitioner teams helping to recruit to my project, and I committed to present the research findings at a later date, and also provide some training on behavioural management methods in continence which they might usefully apply in their work. However, it transpired that nurse practitioners were actually very keen to have somewhere to send children on to when their NE treatment options had exhausted themselves, with limited progress. Additionally nurse practitioner teams were enthusiastic about the possibility of collaborating to provide a manualised treatment protocol and CD/audiofile of general hypnosis script for enuresis (which has been used in previous studies (e.g. Seabrook, Gorodzinsky, & Freedman, 2005) as part of their clinics at some point in the future.

**What I Would do Differently in Clinical Practise as a Result of Undertaking this Research**

The research process has been really useful in refining my clinical practice. I have learnt a lot about differentiating hypnosis according to the temperament, developmental phase and imaginative capacities of the child. It has been invaluable to treat a series of cases to help identify for which children and young people this intervention will be most effective and which are the most effective ‘active’ treatment strands. Evidence of the importance of the visualisation within SH of waking, using the toilet and returning to a dry bed happy and proud seems to have been helpful to some
participants, but only a couple of participants actually woke in the night to use the toilet. The more effective strategies seemed to be to include imagery regarding increasing size and strength of bladder and strength of bladder gate to keep dry night.

The role of life events during treatment also seems to have been important. PNE in contrast to secondary nocturnal enuresis (SNE) has not been much investigated as regards the role of life events in contributing to or maintaining the problem. However there did appear to be a clear impact of life events of the nighttime dryness of the participants. Even small events such as a pet dying, to bigger events such as moving school, caused perceptible changes to nighttime continence for a time. Asking about these was important as not all participants thought it relevant to disclose these events. Providing some input for this in the course of usual clinical casework would seem to be useful e.g. stress management or friend making strategies for children who moved school or bereavement work for the loss of a pet. Although I did not do this as part of the research treatment protocol, concurrent intervention of these types may have meant that progress towards nighttime dryness was more consistent. Although over time these children and young people did regain and maintain progress after the life event had passed.

It was interesting within my role as head of service to consider the positive outcomes from the research in the light of service organisation and health economics. These may point to integrating an approach using hypnosis into the local paediatric continence service, where it may be an effective treatment option, where other more strongly evidence based treatments have not succeeded. The intervention was relatively brief and could conceivably be somewhat shorter in terms of face to face sessions, with the child or young person consolidating treatment effects by use of SH/audiofile at home.

**Reflections on Personal and Professional Development**

The undertaking of this piece of research was really gratifying in terms of seeing the development of my skills as a clinician and as a researcher and how the two roles inform each other. The development and undertaking of this project and the process by which it came about has also been useful in supervision and teaching I undertake to illustrate the process of being a scientist practitioner: how a good clinician develops and evolves treatments based on research evidence within clinical practise, but then remains aware of and attuned to the opportunities to refine research ideas and to subject good
clinical practice to a research methodology in order to add to the extant body of research in a particular area.
References


National Institute for Health and Care Excellence (2010). Nocturnal enuresis: The management of bedwetting in children and young People. Received from https://www.nice.org.uk/guidance/cg111


## Appendix A. Chronology of the Research Process

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Section D: Service Evaluation
Young People’s Views of Their Diabetes Service

Word count: 6057
Executive Summary

The prevalence of type 1 diabetes in those below age 19 years in the UK is one in 430-530 individuals; somewhat higher than in other countries (Diabetes UK, 2014). There are long term health implications for those with diabetes type 1 including a significant reduction in life expectancy (Bryden, Dunger, Mayou, Peveler, & Neil, 2003). For adolescents particularly, diabetes can impact on school attendance, social and family function, as well as psychological wellbeing (Christie, Romano, Thompson, Viner, & Hindmarsh, 2008). The National Paediatric Diabetes Service Improvement Delivery Plan (2013-2018), discusses the importance of diabetes services improving the care they deliver. Whilst the Department of Health’s (2007) ‘Making Every Young Person with Diabetes Matter’ report recommends that diabetes services should be informed by local need and be developed in partnership with children and young people.

An evaluation of the paediatric diabetes service within an NHS Trust was conducted. Aims of the evaluation were to elicit young people's opinions about aspects of the service including clinic appointments, the professionals with whom they came into contact and issues of importance to them around their diabetes. They were also asked about possible service developments.

Fifty service users aged 11-18 completed a self-report questionnaire while attending a routine diabetes hospital clinic appointment. This collected mainly quantitative data, with some qualitative data. Findings suggest that most of the young people found all parts of the service helpful: they felt listened to; received enough information, and said everything they wanted to in their appointments. However, young people also indicated some negative experiences, such as the practical difficulties of attending appointments.

Recommendations included increasing the flexibility of the service as regards provision of appointments out of school hours; considering the length of appointments, as well as continuing to improve waiting times at clinic. Out of clinic hours contact should be considered as should development of a web–based group for service users. A shared decision making approach should be used where possible with young people. Other recommendations include addressing how best to support young people with the social impact of diabetes. The report and its recommendations have been discussed with the diabetes team and circulated to service managers.

Limitations of the service evaluation include lack of generalisability or
comparison of the service to national standards. Additionally the study did not access the opinions of those not attending clinic, and those who may have poor attendance. Routine non-attendees may have reported different, and perhaps a more negative view of services, than those who participated.

Introduction

National Context

Diabetes UK (2014) reported the prevalence of diabetes type 1 in children and young people, below the age of 19 years in the UK, to be one in 430-530 individuals. This is high relative to other countries; the UK having the fifth largest population of children and young people with type 1 diabetes (International Diabetes Federation, 2013). The National Paediatric Diabetes Audit (NPDA) 2013/14 identified 31,500 children and young people with diabetes, (aged 0-18) living in the UK; about 95% of those having type 1 diabetes (NPDA, 2015).

The number of adults and children being diagnosed with diabetes is increasing. The World Health Organisation has called this a ‘global pandemic’ which impacts upon the lives and well-being of hundreds of millions of individuals with diabetes and their families (EURODIAB ACE Study Group, 2000). There are many long term medical consequences of diabetes, such as microvascular and macrovascular disease; and an average reduction in life expectancy of 23 years for people with type 1 diabetes (Bryden et al., 2003).

Health complications of diabetes are frequently first detected in childhood and adolescence. Evidence strongly suggests that if metabolic control is improved during childhood, then the incidence and progression of microvascular complications can be reduced (Diabetes Control and Complications Trial Research Group, 1993). Moreover, Hampson et al. (2001) found that small improvements in diabetes control can generate significant improvements in long term health and reductions in health care expenditure. Despite this, diabetes is frequently poorly managed during adolescence (Morris et al., 1997). Only 14-20% of children and young people with diabetes type 1 meet the recommended HbA1c threshold of <7.5% (Diabetes UK, 2005). Furthermore, over 30% of children and young people with diabetes type 1 had HbA1c levels of >9.5% and were therefore categorised in the ‘at risk’ group. Evidence from the National Paediatric Diabetes Audit 2010/11 found that in England and Wales, children with diabetes have poor glycaemic control in comparison to other European countries (NPDA, 2012).
Adjusting to diabetes alongside the developmental changes of adolescence can be particularly challenging. Self-care behaviours necessary for good metabolic control can conflict with social norms for this age group. Wolpert and Anderson (2001) suggested that medical teams tend to focus on biomedical outcomes to the neglect of adolescents’ greater concerns about how to integrate the demands of treatment into their daily lives. They suggest that this professional-adolescent mismatch in treatment goals can lead to frustration, conflict and poor management of diabetes.

The social stigma of diabetes impacts upon young people’s success in managing their diabetes. Schabert, Browne, Mosely, and Speight (2013) proposed that attitudes of blame and feelings of fear or disgust lead to young people with diabetes being judged, rejected and discriminated against. Consequently, the experience of diabetes related stigma has a negative impact on psychological well-being and may have a negative impact on diabetes management. However, when young people control and manage how and to whom they disclose information about their diabetes, then peer relationships can have a positive impact upon their adjustment to diabetes (Dovey Pearce, Doherty, & May, 2007).

It is clear that there are a number of personal and social challenges and barriers contributing to the poor health and psychosocial outcomes of young people with diabetes. In recent years UK guidelines have focused on improving care for children and young people with diabetes (NICE, 2004; 2015).

Gosden et al. (2010) assessed changes in the provision of UK paediatric diabetes services between 2002 and 2009. They found improvements in staffing: 98% of consultants had a special interest in diabetes, compared to 89% in 2002, and 88% of services had a diabetes specialist nurse who worked solely in paediatric diabetes, compared to 53% in 2002. However, only 21% of clinics had a psychological professional integrated within the diabetes team, compared to 20% in 2002. More recently the NPDA report 2012-13 concluded that significant improvements had been made in the delivery of care to children and young people (NPDA, 2014). However, it also highlighted that large variations remain in the quality of care received and the outcomes experienced by children and young people with diabetes.

The National Paediatric Diabetes Service Improvement Delivery Plan (2013-2018) aims to significantly improve care outcomes for children and young people with diabetes (NHS Diabetes, 2013). Primary desired outcomes are identified around metabolic control and reduction in hospital admissions for complications of diabetes.
Desired secondary outcomes include seeing evidence of listening, communicating and collaborating with children and young people, families, carers and health care professionals in all disciplines. These can be addressed through engaging young service users in initiatives to discuss and shape the diabetes services they use. The NHS Centre for Patient Involvement emphasises the importance of patient involvement in shaping and redesigning services. In addition, the Children's Charter for Diabetes produced by Diabetes UK, a national diabetes charity, advocates involving young people with service design and evaluation with the aim of creating services better tailored to their needs. In a 2007 report, Diabetes UK surveyed children and young people about their access to and quality of care. Some deficits in care were noted; such as difficulties accessing psychological support; a lack of courses to help learn about managing diabetes; limited information prior to transition to adult services, and poor access to insulin pump therapy.

The National Paediatric Diabetes Service Improvement Delivery Plan (2013-2018) highlights the importance of individual teams generating evidence, putting into practice and strengthening the teams that deliver care (NHS Diabetes, 2013). In addition, the Department of Health’s (2007) 'Making Every Young Person with Diabetes Matter' report, stated that 'services will need to be designed in response to local needs assessments, in partnership with children and young people, ensuring that they can meet the specific needs of the local population' (pg. 2).

Local Context – The Trust’s Paediatric Diabetes Service

The Trust covers a population of 760,000 people, which includes 123,000 children and young people. The Trust’s Paediatric Diabetes Team (PDT) currently provides for approximately 300 patients. The team runs the service across five hospitals across a wide geographical area.

The PDT includes three whole time equivalent (WTE) consultant paediatricians, with expertise in paediatric diabetes. Each of the three paediatricians is responsible for a different geographical area across the hospital sites. The PDT also includes 5.8 WTE paediatric diabetes specialist nurses (PDSNs); 2.5 WTE paediatric dietitians, and 0.02 WTE clinical psychologist input is provided across the service.

The National Paediatric Diabetes (NPD) Peer Review is a national quality assurance programme for NHS paediatric diabetes services, and part of the Clinical Network Assurance Programme run by NHS England. The Trust’s Peer Review report,
produced in 2014, gave details of the present strengths, areas for development and overall effectiveness of the Trust's paediatric diabetes service. Examples of good practice identified by the reviewers included the use of technology in aiding communication, good relationships with local schools, and data analysis at weekly meetings. Concerns raised by the peer review included variability in provision and quality of transition services and a lack of access to psychological support for patients at an intermediate level of need.

Aims

The present evaluation aimed to gather information from the young people using the service about the Trust's paediatric diabetes service. The evaluation sought to elicit opinions across several areas including:

- young people's opinions regarding their clinic appointments;
- their opinions of the professionals in the diabetes team;
- their sources of information about diabetes;
- issues that they feel are important for them around their diabetes, and
- the ways in which their diabetes service might be improved.

Method

Participants

Participants were children and young people with type 1 diabetes aged 11-18, and users of the paediatric diabetes service provided by the Trust. Fifty nine families were approached across 11 clinic sessions. Fifty (85%) of these children and young people participated. Three of these 11 clinics were transition clinics (clinics held jointly by paediatric and adult diabetes professionals), and attended by 13 of the participants. Figure 1 shows the number of participants across each of the Trust’s hospital sites.
Twenty two of the participants were male (Mage = 14.75, range 11-18 years); 28 female (Mage = 14.57, range 11-18 years). Mean reported age of diagnosis was 8.94, range 0-6 years.

**Materials**

An anonymised self-report questionnaire (Appendix A) was developed by the author. A draft copy was piloted and refined in collaboration with the young people’s service user representative within the Trust’s PDT.

The questionnaire included a range of fixed choice and Likert scale questions to generate quantitative data, as well as some open-ended questions to generate qualitative data. Areas covered by the questionnaire included demographic information such as participant age and gender. It also asked about satisfaction with clinic services, relationships with clinic staff and ways of improving existing services.

**Procedure**

Local approval was granted via the Research and Development Department of the host NHS Trust (Appendix B). Clinic lists were consulted to identify children and young people, within the specified age range, who were due to attend a clinic appointment at any one of the five hospitals in the coming months. Families were sent a letter and information sheet (Appendices C and D) by post. The purpose of the service evaluation was explained and they were informed that a researcher was likely to
approach them at their next clinic appointment. The letter indicated that children and young people could elect not to be approached at clinics by contacting the research team by email or telephone, or by telling their diabetes team at their next appointment. No one opted out in this way.

At each clinic, the researcher approached each child or young person who had been contacted by letter. Each individual was approached in the waiting room either before or after their appointment, depending on whether the clinic was running on or behind schedule.

After a brief verbal explanation of the purpose of the service evaluation and the content of the questionnaire, parents were again given the information sheet to read (Appendix D), and young people were given one of two age-differentiated information sheets to read (Appendices E and F). Nine individuals elected not to participate, mostly due to time constraints, such as needing to return to school after the appointment. Those who agreed to participate were asked to complete signed consent (see Appendix G for parent/carer consent form; Appendix H for consent form for young people aged 16 and over). Participants were told that their data would remain confidential and were reminded of their right to withdraw at any time.

Participants were then given the questionnaire to complete. The researcher remained nearby in case the young person or their parent had further questions or needed clarification.

Analysis

Quantitative data were collated and descriptive statistics generated in order to identify frequencies and means to questionnaire responses where appropriate. In some cases the Likert scale data was transformed into categorical data to better present the data. Qualitative data were transcribed from interview sheets and collated into MS Excel in order to aid analysis. Responses were categorised to summarise participants’ comments and opinions.

Results

The questionnaire asked a number of questions to elicit the children and young people’s experiences and opinions of four key parts of the service.
Clinic Appointments

Figure 2 displays the percentages of answers to fixed response questions regarding young people’s experiences of their clinic appointments.

Figure 2. Bar graph showing percentage of ‘Yes’ and ‘No’ responses to clinic appointment experience questions

A follow up question asked participants to report reasons why they missed appointments. Responses included a range of reasons such as school and exams, inconvenient times, family problems or illness.

Participants clearly indicated that they received enough information about diabetes from their clinic team. This was mirrored in the response to the question ‘Where or who would you go to get more information about diabetes?’ where 62.0% of respondents cited their diabetes team as their primary source of information. Twenty two per cent reported the internet as being their main source of information and a few participants reported this being another person with diabetes, books or school.

There was a low response rate to the request ‘Please tell us if there is anything else you need information about’. The few suggestions participants gave included: insulin pumps; controlling insulin levels; reasons for dizziness; puberty; drinking and
Figures 3-6 display percentages of responses to questions asking for young people’s opinion of their diabetes clinics.

**Figure 3.** Pie Chart showing percentages of responses to overall helpfulness of clinic appointments

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**Figure 4.** Pie chart showing percentages of responses regarding being listened to at clinic appointments

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<td>10.0%</td>
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Figure 5. Pie chart showing percentages of responses regarding feeling comfortable at clinic appointments

![Pie chart showing comfort levels](image)

Figure 6. Pie chart showing percentages of responses about feeling understood at clinic appointments

![Pie chart showing understanding levels](image)

Other questions asked young people to qualitatively describe the good or helpful things about clinic appointments, as well as the bad or unhelpful things. Participants were also asked what they would like to change about their clinic appointments. Table 1 displays themes that were generated from their responses to these questions and the frequencies of different responses.
The themes that emerged reflect the value young people place on the practical advice, information and help they receive from their diabetes team at clinic appointments. Encouragingly, 14 young people reported that there was nothing bad or unhelpful about their clinic appointments, and 10 young people reported nothing needed to change about their appointments. When bad or unhelpful things were reported, these

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</tr>
<tr>
<td></td>
<td></td>
<td>Not a lot of support/ solutions</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Being sent back to hospital</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Repetitive/ boring</td>
<td>4</td>
</tr>
<tr>
<td>What are the bad/unhelpful things about clinic appointments?</td>
<td>Nothing Negative</td>
<td>None</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Practical Difficulties</td>
<td>Time</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Waiting</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hard to get to appointment</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Don’t like going</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Judgemental/ patronising</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Not a lot of support/ solutions</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Being sent back to hospital</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Repetitive/ boring</td>
<td>4</td>
</tr>
<tr>
<td>If you could change things about clinic appointments what would they be?</td>
<td>No Changes</td>
<td>Nothing</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Organisation of service</td>
<td>Less Frequent</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Shorter Length</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>More convenient times</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Less waiting time</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Closer to home</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Teenage ‘toys’/ magazines</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Fewer professionals in the room</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Less patronising</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Option to talk to doctor alone</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Delivery of Service</td>
<td>Nothing</td>
<td>10</td>
</tr>
</tbody>
</table>

The themes that emerged reflect the value young people place on the practical advice, information and help they receive from their diabetes team at clinic appointments. Encouragingly, 14 young people reported that there was nothing bad or unhelpful about their clinic appointments, and 10 young people reported nothing needed to change about their appointments. When bad or unhelpful things were reported, these
tended to be concerning practical difficulties with the length and convenience of appointments. Negative experiences reported included feeling judged or patronised by clinic staff, not receiving the desired support or solutions, and feeling the appointments are repetitive and boring. Suggested changes to the service were mostly focused on the organisation of the services, including the length, frequency and convenience of appointments.

**Diabetes Nurses**

Over three quarters (77.1%) of respondents reported they had seen their diabetes nurse outside of the clinic. Table 2 displays the frequencies (and percentages) of responses to the question regarding opinions of out of clinic meetings with diabetes nurses.

Table 2

*Frequencies (and Percentages) of Responses to Diabetes Nurse Opinion Question*

<table>
<thead>
<tr>
<th>Question</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Very Unhelpful</td>
</tr>
<tr>
<td>How helpful do you find meetings with your diabetes nurse?</td>
<td>1 (2.6)</td>
</tr>
</tbody>
</table>

Other questions asked young people to qualitatively describe what the good or helpful things about out of clinic appointments with their diabetes nurse were and what the bad or unhelpful things were. Many examples of positive experiences were reported regarding out of clinic meetings with diabetes nurses. Thirteen participants reported nothing negative about their meetings with their diabetes nurse. When something bad/unhelpful was reported it was likely to concern the inconvenience of timing of the meeting. Table 3 displays themes that were generated from responses to these questions and the frequencies of different responses.
Table 3

**Diabetes Nurse Meetings Themes**

<table>
<thead>
<tr>
<th>Question</th>
<th>Theme</th>
<th>Responses</th>
<th>Frequency of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good/helpful things about</td>
<td>Positive Experience</td>
<td>More personal/ trusting/ open</td>
<td>11</td>
</tr>
<tr>
<td>meetings with diabetes nurse</td>
<td>Practical Advantages</td>
<td>Advice/ practical support</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Discussions and questions</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>More convenient</td>
<td>3</td>
</tr>
<tr>
<td>Bad/unhelpful things meetings</td>
<td>Nothing Negative</td>
<td>Nothing</td>
<td>13</td>
</tr>
<tr>
<td>with diabetes nurse</td>
<td>Practical Difficulties</td>
<td>Inconvenient time (lessons/lunch)</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Negative Experience</td>
<td>Travelling</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>They don’t understand</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Moaned at</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Boring</td>
<td>1</td>
</tr>
</tbody>
</table>

**Psychologists**

About a quarter (24.5%) of young people said they had seen a psychologist about their diabetes. Table 4 displays the frequencies (and percentages) of responses to the question regarding opinions of appointments with the psychologist.

Table 4

**Frequencies (and Percentages) of Participant Responses to Psychologist Opinion**

<table>
<thead>
<tr>
<th>Question</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How helpful do you find your appointments with the psychologist?</td>
<td>Very Unhelpful</td>
</tr>
<tr>
<td></td>
<td>1 (9.1)</td>
</tr>
</tbody>
</table>

Other questions asked young people to qualitatively describe good or helpful things about appointments with the psychologist, and about the bad or unhelpful things. Young people identified positive emotional and coping outcomes of these appointments, although a few negative experiences were noted. Table 5 displays themes generated from responses to these questions and the frequencies of different responses.
Table 5

*Psychologist Appointment Themes*

<table>
<thead>
<tr>
<th>Question</th>
<th>Theme</th>
<th>Responses</th>
<th>Frequency of Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good/helpful things about psychologist</td>
<td>Positive outcomes</td>
<td>About to talk/ express how feel about it Helps me cope</td>
<td>4</td>
</tr>
<tr>
<td>appointments</td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Bad/unhelpful things about psychologist</td>
<td>Nothing Negative</td>
<td>None</td>
<td>5</td>
</tr>
<tr>
<td>appointments</td>
<td>Unnecessary</td>
<td>Not necessary</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Negative Experience</td>
<td>Upsetting</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Told me everything I’m doing wrong</td>
<td>1</td>
</tr>
</tbody>
</table>

**Dietitians**

The majority (89.9%) of young people said they had seen a dietitian about their diabetes. Table 6 displays the frequencies (and percentages) of responses to question regarding opinions of meetings with the dietitian.

Table 6

*Frequencies (and Percentages) of Participant Responses to Dietitian Opinion Question*

<table>
<thead>
<tr>
<th>Question</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Very Unhelpful</td>
</tr>
<tr>
<td>How helpful do you find your appointments</td>
<td>1 (2.3)</td>
</tr>
<tr>
<td>with the dietitian?</td>
<td></td>
</tr>
</tbody>
</table>

Participants’ qualitative descriptions of good and helpful things about meetings with their dietitian reflect the value they place on the useful information and advice they receive. Fifteen participants had no bad or unhelpful things to report about meetings with dietitians. Table 7 displays themes that were generated from their responses to these questions and the frequencies of different responses.
Table 7

Dietitian Appointment Themes

<table>
<thead>
<tr>
<th>Question</th>
<th>Themes</th>
<th>Responses</th>
<th>Frequencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good/helpful things about dietitian appointments</td>
<td>Information and advice</td>
<td>Knowing what to eat</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Learning carb counting</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Advice and support</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Knowledge</td>
<td>5</td>
</tr>
<tr>
<td>Bad/unhelpful things about dietitian appointments</td>
<td>Nothing negative</td>
<td>None</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Negative Experience</td>
<td>Lacked understanding of my situation</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Practicalities</td>
<td>Not focused on real life</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unnecessary</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Infrequent</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Long</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Learning about foods you can’t have</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Carb Counting is difficult</td>
<td>1</td>
</tr>
</tbody>
</table>

Improving the Paediatric Diabetes Service

The questionnaire also asked what else young people think could be helpful for them. It also asked about what young people would like to spend more time talking to their diabetes team about.

Useful Additions to Services

Young people were asked the following: ‘There are some things that young people with diabetes have told us might be helpful to them. Please give each one a number from 0 to 10 as to how helpful or useful they might be to you (10 is extremely helpful; 0 is not helpful at all).’ Figure 7 displays the mean ratings of helpfulness of these suggested topics of discussion.
Figure 7. Bar graph showing participants’ mean rated helpfulness of suggested service improvements

Table 8 summarises participants’ ratings of how helpful the suggested improvements could be to them.
Table 8  
*Helpfulness Ratings of Suggested Improvements*

<table>
<thead>
<tr>
<th>Suggested Improvements</th>
<th>Frequency (%)</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>0-3</td>
<td>4-7</td>
<td>8-10</td>
</tr>
<tr>
<td>Being able to contact someone from your diabetes team for advice on weekends/evenings</td>
<td>5 (11.4)</td>
<td>15 (34.1)</td>
<td>24 (54.5)</td>
<td></td>
</tr>
<tr>
<td>A member of your diabetes team coming into school to talk to a group of people (chosen by you) about diabetes</td>
<td>12 (27.9)</td>
<td>8 (18.6)</td>
<td>23 (53.0)</td>
<td></td>
</tr>
<tr>
<td>Being able to meet other young people with diabetes</td>
<td>6 (13.6)</td>
<td>21 (47.7)</td>
<td>17 (38.6)</td>
<td></td>
</tr>
<tr>
<td>A member of your diabetes team talking to your year group or whole school about diabetes</td>
<td>14 (31.8)</td>
<td>13 (29.5)</td>
<td>17 (38.6)</td>
<td></td>
</tr>
<tr>
<td>Being a diabetes mentor to another child/teenager at some point</td>
<td>14 (31.8)</td>
<td>11 (25.0)</td>
<td>19 (43.2)</td>
<td></td>
</tr>
<tr>
<td>Having a diabetes mentor to talk to - an older teenager or young adult with diabetes</td>
<td>12 (27.3)</td>
<td>20 (45.5)</td>
<td>12 (27.3)</td>
<td></td>
</tr>
</tbody>
</table>

The mean ratings in figure 7 show that ‘Being able to contact someone from your diabetes team for advice on weekends/evenings’ is the improvement that young people felt would be most helpful. ‘A member of your diabetes team coming into school to talk to a group of people (chosen by you) about diabetes’ and ‘Being able to meet other young people with diabetes’ were also rated highly. There was quite a large variation amongst participants’ ratings as to the helpfulness for each suggested initiative. For instance, ‘A member of your diabetes team talking to your year group or whole school about diabetes’, generated a fairly equal number of low (0-3), medium (4-7) and high (8+) ratings of helpfulness.

The majority (95.7%) of respondents told us they already knew someone with diabetes. This person was most likely to be a friend. A number of questions asked participants under what circumstances they might like to meet other young people with diabetes. The highest number of respondents chose ‘A fun event like a daytrip’ for these meetings and ‘A few times a year’ for the frequency of these meetings. Several questions were also asked to elicit the views on meeting other young people with
diabetes via social networking. Over half (59.1%) of participants thought that having access to a Facebook or other web group, where they could contact and talk to other young people with diabetes, would be helpful. Of the respondents who agreed this would be helpful, 64.5% were bothered by the idea of the group being monitored by a member of the diabetes team.

**Important topics for discussion**

Young people were asked the following: ‘These are a list of things that you might want to talk about with a member of your diabetes team now or in the future. Please give each one a rating of 0-10 (10 is that you very much want to talk about them; 0 is you very much do not want to talk about them).’ Figure 8 displays mean ratings of helpfulness of these suggested topics.

*Figure 8. Bar graph showing participants’ mean rated wish to discuss diabetes related topics*

<table>
<thead>
<tr>
<th>Suggested Topics</th>
<th>Mean score on 0-10 scale (10= very much want to talk about this topic)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managing your diabetes day to day - diet,</td>
<td>7</td>
</tr>
<tr>
<td>exercise, blood monitoring, insulin</td>
<td></td>
</tr>
<tr>
<td>Managing diabetes in and around school</td>
<td>7</td>
</tr>
<tr>
<td>How to answer when people ask about it</td>
<td>6</td>
</tr>
<tr>
<td>Telling friends about diabetes</td>
<td>5</td>
</tr>
<tr>
<td>How you feel about your diabetes</td>
<td>4</td>
</tr>
</tbody>
</table>

Table 9 summarises participants’ ratings of how much they would like to talk about each of the suggested topics.

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Table 9

Rated Helpfulness of Suggested Discussion Topics

<table>
<thead>
<tr>
<th>Suggested things to talk about with the diabetes team</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Grouped rating from 0-10 interval scale</td>
</tr>
<tr>
<td></td>
<td>0-3</td>
</tr>
<tr>
<td>Managing your diabetes day to day—diet, exercise, blood monitoring, insulin</td>
<td>9 (20.5)</td>
</tr>
<tr>
<td>Managing diabetes in and around school</td>
<td>11 (25.0)</td>
</tr>
<tr>
<td>How to answer when people ask about it</td>
<td>14 (32.6)</td>
</tr>
<tr>
<td>Telling friends about diabetes</td>
<td>13 (29.5)</td>
</tr>
<tr>
<td>How you feel about your diabetes</td>
<td>18 (40.9)</td>
</tr>
</tbody>
</table>

The mean ratings in figure 8 showed that ‘Managing your diabetes day to day—diet, exercise, blood monitoring, and insulin’ was the topic that young people most wanted to talk to their diabetes team about. ‘Managing diabetes in and around school’ was also rated highly. ‘How you feel about your diabetes’ was the discussion topic rated least helpful to talk about.

As with the suggested improvement ratings, there is quite a large variation amongst participants’ ratings of helpfulness for each discussion topic. The discussion topics tended to generate a fairly equal number of low (0-3), medium (4-7) and high (8+) helpfulness ratings.

Discussion

The aim of the present service evaluation was to elicit children and young people’s opinions of their paediatric diabetes service provided by an NHS trust. It also aimed to generate recommendations from participants about how the service could be improved.
Evaluation of Existing Clinic Services

Encouragingly, findings suggest that participants felt very positively about their attendance at diabetes clinics. The majority of respondents reported feeling listened to or very well listened to (86.0%) at these appointments and to finding clinic appointments helpful or very helpful overall (87.8%). Additionally, they reported feeling able to communicate with clinic staff: 95.0% reported they had said everything they wanted to in their most recent appointment.

As regards provision of information about diabetes, the majority (93.9%) reported they’d received enough information from their diabetes team since diagnosis. This is in line with the Patient Experience of Diabetes Services (PEDS) Survey 2013-2014, which indicated that professionals were spending sufficient time giving information during appointments (NDA, 2014). Qualitative responses in the present evaluation suggested it is the practical support, rather than emotional support, that young people value the most from these clinic appointments.

Children and young people reported feeling somewhat less positive about how comfortable and well understood they felt during clinic appointments. About two thirds (64%) of respondents reported feeling comfortable or very comfortable and three quarters (74%) of respondents reported feeling well understood or very well understood. The diabetes team appear to be meeting many young people’s care needs, however for some individuals, clinic appointments may not be a comfortable experience where they feel completely understood.

In terms of helpfulness of clinics and staff providing services, the majority (87.70%) of respondents reported clinic appointments as helpful or very helpful, and over 85.0% of respondents reported that the meetings with their diabetes nurse, psychologist or dietitian were helpful or very helpful. Those that responded described their out of clinic meetings with their diabetes nurses as a more personal and trusting experience than that at clinic appointments. They valued the discussions and advice they received from their nurse in these meetings. The PEDS survey also highlighted that support and encouragement specifically from diabetic specialist nurses was particularly highly rated (NDA, 2014).

Young people also described positive experiences of meetings with their psychologist, especially in terms of coping with feelings towards diabetes. However the percentage of young people who had accessed a psychologist was far fewer than the percentage that had accessed other professions. This reflects the findings of the 2014
findings of the NPD peer review for the Trust which highlighted a lack of psychological support for patients as a serious concern.

Meetings with dietitians were identified as helpful in terms of information and advice around food, with carbohydrate counting mentioned specifically by several respondents.

There were some negative experiences and aspects reported regarding contact with the diabetes service. However, it is of note that when asked ‘What are the bad/unhelpful things about clinic appointments?’ a significant number of participants (14) responded by indicating ‘none’ and many more did not respond at all. This is consistent with the findings of the PEDS survey which found that over one third of respondents said that there was nothing that they would like to see improved about their diabetes services (NDA, 2014).

The majority of the bad/unhelpful things reported were to do with the practical difficulties of attending appointments. Problems such as the length of appointments and having to wait at clinic were identified by participants. Other bad/unhelpful things about clinic appointments reported were to do with having negative experiences. Some participants found the appointments repetitive and boring. Having to repeat the same information to clinic staff and waiting times were also negative aspects of diabetes services identified in the PEDS survey (NDA, 2014). In the present evaluation, some young people also found aspects of the appointments judgemental and patronising and a few felt they were not receiving enough support or solutions in their clinic appointments. Christie (2007) recommends that diabetes teams to focus on the strengths of young people and how strengths and abilities from a non-problem area might be transferred to generating solutions to difficulties with diabetes management. This may go some way to change the tone of appointments and help ensure young people feel less harshly judged during appointments.

Almost all of participants suggested that changes to clinic appointments were organisational changes. Young people want less frequent, shorter appointments, with shorter waits at clinic, held at more convenient times. They would also prefer for there to be fewer professionals in the room during clinic appointments. It is also of note that a significant minority (22.4%) reported that they do not attend scheduled clinic appointments. The reasons given for this were reported mainly as practical ones, for instance inconvenient appointment times. It is therefore important to consider if there is any scope for increasing the flexibility of appointment length and timings.

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Improving the Paediatric Diabetes Service

In terms of participants’ responses to suggested service improvements, it is clear that more flexibility is desired. ‘Being about to contact someone from your diabetes team for advice on weekends/evenings’ was rated as the most helpful (over half of participants rating this at 8-10 (10 being ‘extremely helpful’ on a 0-10 interval scale). This is consistent with the National Paediatric Diabetes Service Improvement Plan (2013-18), which emphasises the need for 24 hour access to advice on management of diabetes (NHS Diabetes, 2013).

Currently within the Trust there are arrangements in place for the provision of out of hours’ advice. Children, young people and their families can contact the hospital ward for out of hours’ advice. If a paediatric diabetes team consultant is not on shift, another consultant will be available. There is currently no guarantee that a member of staff with specialist knowledge of diabetes will be available.

The other highly rated improvements ‘A member of your diabetes team coming into school to talk to a group of people (chosen by you) about diabetes’ (over half rating this highly at 8-10) and ‘Being able to meet other young people with diabetes’ (38.6% rating 8-10), demonstrate that the service users value initiatives focusing on the social aspects of their lives with diabetes. This is consistent with Wolpert and Anderson’s (2001) suggestion that there is a mismatch in treatment goals between young people and their diabetes team. Biomedical outcomes are sometimes exclusively focused on, and therefore exploring how best to integrate diabetes into young people’s daily social lives may be neglected. Initiatives designed to help children and young people cope socially with having diabetes would be welcomed. Rostami, Parsa–Yekta, Ghezeljeh, and Vanaki (2014), highlighted the importance of providing continuous social support to adolescents with diabetes to help them live and maintain normal lives.

In the present evaluation the majority of participants thought a Facebook or other web group, which would put them in contact with other young people with diabetes, would be helpful. However, the idea of the group being monitored by a member of the diabetes team was a concern for the majority. Diabetes UK supports a Facebook page, as well as a blog site and a support forum. However, there may be a need for a locally focused group, aimed at young people. In addition, other technology-based support aids could be considered. Franklin, Waller, Pagliari, and Greene (2006), found that ‘Sweet Talk’, a text messaging support system, improved the self-efficacy and adherence to insulin therapy regimes in young people with diabetes.
In terms of participants’ responses to potential issues they wanted to focus on with their diabetes team, it was the practical element of diabetes management that participants identified as most important. Managing diabetes day to day and in school were rated as the most important topics to talk about, whereas feelings about having diabetes was rated as the least important topic to talk about. Despite this, research has shown that adolescents with type 1 diabetes frequently report feelings of stress and guilt (Davidson, Penney, Muller, & Grey, 2004). Jaser and White (2011) found that emotional expression was associated with a better quality of life and better metabolic control. Therefore it is important that young people are given opportunities and encouraged to talk about their feelings around having diabetes, even if this is not something they report feeling positively about. It is of concern that less that a quarter of the sample reported having seen a Trust psychologist. The minority who had seen a psychologist qualitatively reported being more able to talk about how they felt about diabetes. Therefore, increasing access to psychological services may be key for addressing young people's reluctance to explore their feelings around their diabetes.

The variation found between participants in their helpfulness ratings of both potential improvements and discussion topics emphasised that young people's needs and preferences are diverse and individualised services will be needed to address this diversity. The PEDS findings indicated the need for patients to be treated as individuals rather than with a generalised approach (NDA, 2014).

As healthcare moves towards a more patient-centred approach, shared decision making is increasingly recognised as important in the care of young people with chronic health problems (Stacey et al., 2012). Shared decision making is the process where the patient and clinician collaborate in the process of selecting treatments or making care decisions, through sharing evidence, expertise and preferences (Coulter & Collins, 2011). Evidence suggests that by engaging young people in shared decision making about their care they feel increased satisfaction with, and greater inclusion in their healthcare (Loh, Simon, Wills, & Kriston, 2007). They are also more likely to adhere to treatment (Wilson et al., 2010), and experience increased self-efficacy (Huffine, 2005). Ways to increase diabetes service users’ involvement in their healthcare decisions should therefore be considered.

**Recommendations**

In light of the findings of this evaluation the following recommendations are
made for further development of the Trust’s paediatric diabetes service.

1. Flexibility: the scope for increasing the flexibility of the service should be assessed. The possibility of making available more out of school hours appointment times and decreasing the length of appointments could be considered, as well as continuing to focus on and improve waiting times once the patient has arrived at the clinic.

2. Out of hours contact: improvements could be made to extend the out of hours contact available to children and young people.

3. Social Support: some thought needs to be given as to how best to support young people with the social impact of diabetes, perhaps through facilitating meetings of groups of children in school, or by organising fun social events.

4. Social Media Group: the creation of a Facebook or other web group should be considered. It should aim to help put young people with diabetes in contact with each other for advice and support. Careful consideration should be given as to how best the diabetes team should manage and monitor the group.

5. A shared decision making approach should be used where possible with young people. Use of decision making tools should be considered.

Dissemination

Findings were presented at the Trust’s joint adult and paediatric diabetes forum in September 2014. Results were at an early stage and not fully analysed, but it was felt that presenting here would be a useful way to start discussions about the findings and think about service developments (see Appendix I for PowerPoint presentation). The results were also informally presented at the PDT quarterly multi-disciplinary meeting, with time devoted to discussion of how we might as a team pragmatically implement some of the recommendations. Results were also discussed with psychological staff in the monthly meeting. A copy of this evaluation report was provided to the board of directorate of the Trust, with an offer to present at a meeting.

Limitations

The findings and recommendations of the study should be considered in the context of several limitations. Firstly, it is important to emphasise that the above data was collected from service evaluation, rather than from audit or clinical research. Therefore, no conclusions can be made as to how well the Trust is meeting any national or local service standards. The generalisability of the findings is also limited.
This service evaluation did not generate detailed description of young people’s experiences of their service and ideas for its development. The collection of data via questionnaire with forced choice options, and which suggested options to participants for service developments, meant they were subject to response constraints. Other suggestions were asked for, but this elicited very limited qualitative information. Therefore findings are limited to general opinions and preferences on a wide range of aspects of the service and potential future developments.

Finally, this service evaluation gathered only the opinions of young people who attended for their clinic appointments. This excluded young people who did not attend their appointments from participating. There may be reason to expect that non-attendees may be those with who have not engaged well with their clinic service or the PDT, and therefore who may have reported views of the service that were more negative in content, or included different preferences for service improvements.

**Future Research**

Future research could use semi-structured interviews or focus groups to elicit more detailed opinions and ideas from young people. This would enable follow up questions to be asked in order to gain a more thorough and accurate picture of what young people think of and want from their service. The sampling strategy for this research should include young people who may not demonstrate good attendance at clinic appointments. It would be useful to reassess opinions via these methodologies if and when recommendations from this report are implemented.

Future research could also follow up on the recommendation from the NPD peer review (2014), that diabetes transition services across the Trust should replicate those in place at one of the hospital sites. It would be useful to specifically evaluate transition services across and between sites.

**Critical Appraisal**

The undertaking of this service evaluation was important in terms of terms of my development as a senior clinical psychologist working not only clinically, but at different levels and within other roles within the Trust. There have been ongoing issues for us as a trust regarding the funding for clinical psychology posts to provide services for children with medical conditions, including diabetes. The NPD peer review report (2014) highlighted this lack of access to psychological services for children and young
people with diabetes. As head of service I am working hard to address these issues with the Trust management and with commissioners. This service evaluation has gone some way to addressing the issues important to our service users, and to highlight ways in which services should be developed, which includes development of psychological services.

There were inherent issues in undertaking a project which involves any one profession seeking to evaluate others, as could be evidenced by the questions concerning opinions of participants as regards clinic appointments (where clinical psychology is not represented as a core member due to staffing issues), and other professions within the team. I was sensitive to these issues, and was mindful of the need to consult, collaborate with and inform other team members throughout the development and undertaking of the project. And, whilst not suppressing any negative findings being critical of particular professions or clinical interactions, I was mindful to present these in sensitive ways with explanation and context.
References


The Patient-Patient-Centered Outcomes Research, 6(1), 1-10. doi: 10.1007/s40271-012-0001-0


Appendix A. Self-Report Questionnaire

Service Evaluation Project: Young People’s Views of Their Diabetes Services Questionnaire V4. 28.4.15

We want to improve our services for young people with diabetes. We know that being a young person with diabetes can be tricky at times and we want to make our services as helpful as possible. We are keen to know what you think about the diabetes services you receive and your ideas for improving them. This questionnaire should take about 10 minutes to do. The information you give us is anonymous.

1. A bit about you

- How old were you when you diagnosed with diabetes? ..........
- How old are you now? ...........
- Are you male/female? (please circle) .......
- What’s the worst thing about having diabetes?...........................

- If there are any good things about having diabetes what are they?

2. At your diabetes clinic appointments at the hospital

You have just been to a diabetes clinic appointment. Do you know how often are you supposed to come to these clinic appointments? Yes/No (please circle)

If yes, how often are you supposed to come? ........................

How comfortable did you feel talking to the people at the diabetes clinic?

1  2  3  4
Very uncomfortable Slightly uncomfortable Comfortable Very comfortable

Did you feel understood by the people at the diabetes clinic?

1  2  3  4
Not understood at all Slightly understood Well understood Very well understood

Did you feel listened to by the people at the diabetes clinic?

1  2  3  4
Not listened to at all Slightly listened to Well listened to Very well listened to
Did you say everything that you wanted to? *Yes/No (please circle)*

Did you have the opportunity to talk to the doctor/nurse on your own (without your family)? *Yes/No (please circle)*

Is this something you do/would find helpful? *Yes/No (please circle)*

Overall, how helpful do you find these diabetes appointments at the hospital?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Very unhelpful</td>
<td>Unhelpful</td>
<td>Helpful</td>
<td>Very helpful</td>
</tr>
</tbody>
</table>

Please tell us what are the helpful or good things about these hospital clinic appointments?

..........................................................................................................................................................................................
..........................................................................................................................................................................................

Please tell us what are the unhelpful or bad things about these hospital clinic appointments?

..........................................................................................................................................................................................
..........................................................................................................................................................................................

Do you miss any appointments? *Yes/No (please circle). If yes, please write the reasons why you miss them?*

..........................................................................................................................................................................................
..........................................................................................................................................................................................

If you could change things about these appointments what would they be?

..........................................................................................................................................................................................
..........................................................................................................................................................................................

3. Information about diabetes

Since you were diagnosed with diabetes, have your diabetes clinic team given you enough information about diabetes and how to manage it? *Yes/No (please circle)*

Please tell us here if there is anything you need more information about.

..........................................................................................................................................................................................
..........................................................................................................................................................................................

Where or who would you go to to get more information about diabetes if you needed it?

..........................................................................................................................................................................................
..........................................................................................................................................................................................
4. About the Diabetes Nurses

Do you see your diabetes nurse outside of the hospital? Yes/No (please circle)

If yes, how helpful do you find these meetings with the diabetes nurse?

1  2  3  4

Very unhelpful Unhelpful Helpful Very helpful

What are the helpful or good things about your meetings with your diabetes nurse?

What are the unhelpful or bad things about your meetings with your diabetes nurse?

5. About the Psychologists

Have you ever seen a psychologist about your diabetes? Yes/No (please circle)

If yes, how helpful did/do you find your appointments with the psychologist?

1  2  3  4

Very Unhelpful Helpful Very helpful

Unhelpful

What are the helpful or good things about your meetings with the psychologist?

What are the unhelpful or bad things about your meetings with the psychologist?

6. About the Dieticians

Have you ever seen a dietician about your diabetes? Yes/No (please circle)

If yes, how helpful did/do you find your appointments with the dietician?

1  2  3  4

Very unhelpful Unhelpful Helpful Very helpful

160
What are the helpful or good things about your meetings with the dietician?
...................................................................................................................................................

What are the unhelpful or bad things about your meetings with the dietician?
...................................................................................................................................................

7. Help us to improve our services

These are some things that young people with diabetes have told us might be helpful to them. Please give each one a number from 0 to 10 as to how helpful or useful they might be to you (10 is extremely helpful; 0 is not helpful at all)

- Being able to contact someone from your diabetes team for advice on weekends/evenings. ...........
- A member of your diabetes team coming into school to talk to a group of people (chosen by you) about diabetes. ........
- A member of your diabetes team talking to your year group or whole school about diabetes. ........
- Being able to meet other young people with diabetes........
- Having a diabetes mentor to talk to – an older teenager or young adult with diabetes ........
- Being a diabetes mentor yourself to another child/teenager at some point. ........

- If you would find it helpful to meet other young people with diabetes, what would be the best way to do this (underline all that you think would be good): A group in school / A group in hospital clinic / A fun event like a day trip / other (tell us what)................................................. ..........................................................................

- How often would they be held? (underline all that you think would be good) Weekly / monthly / a few times a year / in the school holidays / other (tell us when)................................................. ........................................................................................................................................

Do you use a social network site? Yes/No (please circle)

- Would having access to a Facebook group or other webgroup be helpful - one where you could contact and talk to other young people with diabetes? Yes/No (please circle)

- Would it make a difference if this was monitored by members of the diabetes clinic staff? Yes/No (please circle)

- Do you know anyone else with diabetes? Yes/No (please circle)

If yes who are they: relative/friend/other (tell us who)
........................................................................................................................................

8. Things that might be important to you

These are a list of things that you might want to talk about with a member of your diabetes team now or in the future. Please give each one a rating of 0-10. (10 is that
you very much want to talk about them; 0 is you very much do not want to talk about them)

- Managing your diabetes day to day—diet; exercise, blood monitoring, insulin……
- How you feel about your diabetes……
- Telling friends about diabetes……
- Managing diabetes in and around school……
- How to answer when people ask about it……
- Anything else (please tell us what it is)

Thank you for helping us to make our clinics better. In a few months we will send you a leaflet which tells you what we found.
Appendix B. Research and Development Permission Letter

21/05/2015

Dear [Redacted]

Teenagers’ Experiences of their Diabetes Services

R&D Ref 2015/PAEDS/05

Thank you for submitting the above referenced protocol/proposal for approval as a Grey Area Project.

I am pleased to confirm that your study has now been approved by the Trust on the understanding that you advise the R&D Department immediately of any unusual or unexpected incidents clinical or non-clinical that raise questions about the safety of the research. All staff are responsible for reporting all adverse incidents, whether or not related to research in accordance with the Trust Managing Adverse Incidents Protocol.

Researchers should complete and submit the Trust Incident Form identifying both the nature of the incident and ticking the ‘research project’ box. It should be sent to the R&D office within 24 hours of the serious adverse event.

In undertaking this work, you must ensure that your activities are conducted in line with the Local Research Governance Implementation Plan, and you are fully aware of your responsibilities as outlined in the Department of Health’s Research Governance Framework for Health and Social Care.

Please note the R&D Department will request for a progress report and information on the dissemination of the outcomes as part of compliance with the local Research Governance Implementation Plan. Failure to provide a report or update on the progress shall be deemed as non-compliance with the Trust Management of R&D Policy and the Trust shall suspend your study.

Do not hesitate to contact the R&D Office if you require further assistance.

Yours sincerely

[Redacted]

Dr [Redacted]
R&D Manager
Appendix C. Initial Letter to Families

Dear name of parent/carer

RE: Service Evaluation: Young People’s Views of Their Diabetes Services:

XXX Services within Child Development and Paediatrics are undertaking a project to try and improve diabetes services for young people. This project will ask young people about their experiences and opinions of their diabetes service provided by XXX Trust. The findings will identify the things that we are doing well and where we can get better. Their opinions will be used to help us create better services.

Having diabetes mellitus type 1 presents challenges to young people. As providers of services for young people with diabetes we know that currently diabetes services across the country do not always meet the needs of young people. We know that asking young people about the services they receive is important to help us develop better services for them.

The enclosed information sheets tell you more about the project. If you and your son/daughter decide they can take part this would involve completing a short self-report questionnaire at a routine diabetes clinic appointment at the hospital.

I very much hope you would be interested in your son/daughter taking part in this research. If you are interested and would like to find out more, or have any questions please either contact me directly on the telephone number or email above. If you do not wish for your son/daughter to take part please contact me similarly, or tell clinic staff on the day of your appointment and we will not approach you to participate on the day.

Yours sincerely

Name and job title of researcher
Appendix D. Information Sheet for Parent or Carer

Information Sheet for Parent or Carer (Version 4 - 28.4.15)

Service Evaluation: Young People’s Views of Their Diabetes Services
I would like to invite your son/daughter to take part in this project. Before you decide, I would like you to understand why the project is being done and what it will involve for your son/daughter. Please read the information provided.

What is the project about?
Diabetes mellitus type 1 is becoming more common. A lot of young people with diabetes are diagnosed with this between the ages of 10 and 14, and the number of young people with diabetes of all types will probably increase a lot over the coming years. Young people can face challenges in managing their diabetes, even if they were diagnosed a while ago. As young people get older they are expected to take more responsibility for managing their diabetes, but we know that this can be tricky sometimes. We know that currently diabetes services across the country do not always meet the needs of young people, and that asking young people about the services they receive can help us improve these services.

What are we trying to do?
This project asks young people about their experiences and opinions of their diabetes service provided by XXXX Trust. The findings will identify what we are doing well and where we can get better. The findings will be used to help us create better services. This study will also contribute to a professional doctorate (PsyD) qualification for the clinical psychologist undertaking the research.

How would my son/daughter be involved?
The project would involve your son/daughter spending 10 minutes completing a questionnaire about their diabetes services. This will take place just before or after a routine diabetes clinic appointment. Our Assistant Psychologist or Student Psychologist on Placement will be around if you or your son/daughter need more information about the project or to answer any questions you have about it. The questionnaire will ask your son/daughter questions about their NHS diabetes services. The information they give us is confidential and no one in their diabetes team will know what they have told us.

Will my taking part in this study be kept confidential?
Taking part in this project is up to you and your son/daughter. You can decide to stop taking part at any time. You and your son/daughter will be asked for consent in writing before taking part. I will keep all the information I collect very safe in locked cabinets and use passwords on computer.

What if there is a problem?
If you have a question or worry about anything to do with the project, you should speak to me and I will do my best to answer your questions. If you are still not happy and wish to complain then you can do this by contacting the Patient Experience Team: Write to: Patient Experience Team, address of team and contact details.

I hope you will think about your son/daughter taking part in this project and I will be happy to answer any questions that you may have.

XXXX, Job title of investigator, Tel number and email
Appendix E: Information Sheet for Young Person aged 15-18

Information Sheet for Young Person aged 15-18 (Version 3 - 2.5.15)

Service Evaluation: Young People’s Views of Their Diabetes Services:
Name of Researcher: XXXX, Job title of investigator

I would like to invite you to take part in this project. Before you decide, I would like you to understand why the project is being done and what it will involve for you. Please read the information provided. I am happy to answer any questions you may have.

What is the project about?
Numbers of young people with diabetes mellitus type 1 will probably increase a lot over the coming years. Young people can face challenges in managing their diabetes, even if they were diagnosed a while ago. As young people get older they are expected to take more responsibility for the management of their diabetes, but we know that this can be tricky sometimes. We know that currently diabetes services across the country do not always meet the needs of young people. We know that asking young people about the services they receive is important to help us improve those services.

What are we trying to do?
This project asks young people about their experiences and opinions of their diabetes service provided by XXX Trust. The findings will identify the things that we are doing well and where we can get better. Your opinions will be used to help us create better services.

How would I be involved?
The project would involve you spending 10 minutes completing a questionnaire about the diabetes services you have. This will take place just after your next diabetes clinic appointment. Our Assistant XXXX (job title) or Student XXXX (job title) on Placement will be around to help you if you need it. The questionnaire will ask you some questions about that appointment in particular and your views on the diabetes service overall. The information you give us is confidential and no one in your diabetes team will know what you have told us.

Will my taking part in this study be kept confidential?
Taking part in this project is up to you. You can decide at any time that you don’t want to take part. You will be asked for your consent in writing before you take part. The information from you has nothing that could identify you. The information I collect about you will be stored in safe, locked cabinets and I will use passwords on computer.

What if there is a problem?
If you have a question or worry about anything to do with the project, you should speak to me and I will do my best to answer your questions. If you are still not happy and wish to complain then you can do this by contacting the Patient Experience team: Write to: Patient Experience Team, address and contact details.

I hope you will think about taking part in this project and I will be happy to answer any questions that you may have. If you wish to take part or would like to talk about the research a bit more, please contact me or ask your family to contact me on the number/email below.

XXXX, Job title of investigator, Tel number and email
These pages give you information about a research project asking young people about their NHS diabetes services

I am XXXX. I am a (job title) and I work in the XXXX Hospital. My work involves helping children and young people with problems like worries, being sad and coping with being ill.

I am doing a research project. I am writing to ask if you would like to take part. Before you decide if you want to take part, it’s important you understand what the project is about, why it is being done and what it will mean if you take part. Please read this information sheet carefully and talk to your family or friends about it if you wish. If something doesn’t make sense or you have some questions about it, you or your family can call me to talk about it in more detail.

What is research?
Research is a good way to find out answers to questions. The question I want to answer in this research project is ‘What do young people with diabetes in XXXX(area) think about their diabetes services?’
What do I do if I want to take part?
Taking part would involve you spending 10 minutes completing a short questionnaire just after your next diabetes clinic appointment. Our Assistant XXXX (job title) or Student XXX (job title) on Placement will be around to help you if you need it. The questionnaire asks you some questions about your diabetes services.

Do I have to take part?
No you don’t have to take part. If you don’t want to, just tell your parent or someone at the clinic appointment that you don’t want to fill in the questionnaire. You can choose to take part if you want to. But if you change your mind at any time, you can always stop taking part straightaway.

Will my taking part in this study be kept confidential?
You will be asked for your consent in writing before you take part and fill in the questionnaire. I will keep all the information I collect about you very safe in locked cabinets and use passwords on computer. What you tell us is confidential and no one in your diabetes team will know what you have told us.

Did anyone check the project to make sure it is fair and safe?
Before any research projects can happen it is checked by a group of people who make sure it is fair and safe.

I hope you will consider taking part in this research project. If you would like to talk about the research a bit more or ask questions, please contact me or ask your family to contact me on the number/email below.

XXXX
Job title of investigator
Tel and email
Appendix G. Consent Form for Parent or Carer

Consent Form for Parent or Carer (Version 1 - 30.12.14)

Young People’s Views of Their Diabetes Services:

Name of Researcher: XXXX, Job title

Please initial box

15. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

16. I understand that my son’s/daughter’s participation is voluntary and that s/he is free to withdraw at any time without giving any reason, without his/her medical care or legal rights being affected.

17. I understand that relevant sections of my son’s/daughter’s medical notes and data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my son’s/daughter’s records.

18. I agree to my data being stored as outlined on the information sheet.

19. I agree for my son/daughter to take part in the above study.

_________________  ________________  ____________
Name of respondent   Date     Signature

_________________  ________________     _____________________
Name of person   Date     Signature taking consent

Name of child ____________________________
Appendix H. Consent Form for Young Person

Consent Form for Young Person (Version 1 – 30.12.14)

Young People’s Views of Their Diabetes Services:

Name of Researcher: XXXX, Job title

Please initial box

20. I have read the information sheet about this study. I understand it. I have asked any questions that I wanted to and these have been answered for me.

21. I understand that I am volunteering to take part. I can stop taking part any time they want to, and I don’t have to say why. Taking part will not affect any health treatment I have.

22. I understand that parts of my medical notes and information collected during the research might be looked at by people who look at research or people from the NHS Trust. I give permission for these people to look at my medical records.

23. I agree to information about me being stored as I read it on the information sheet.

24. I agree that I will take part in the above study.

_________________   ________________   ____________ ____________
Name of young person   Date   Signature

_________________   ________________   ________________
Name of person taking consent   Date   Signature
Appendix I. PowerPoint Overheads from Presentation to Trust Diabetes Joint Adult and Paediatric Forum

Who are psychological Services?

Diabetes: Issues in adolescence
- Adolescence can be a difficult time for YP
- Adolescence YP expected to take increasing responsibility for their day to day management of their diabetes (Wysocki et al. 1992)
- Research finds consistent evidence of decline in metabolic control in adolescence (Haeys et al. 1999)
- Decline in control is particularly around insulin admin - missing injections common (Morris et al. 1997)

Diabetes UK
- Diabetes UK recognises the importance of involving C&YP in shaping their diabetes services
- Did a project identifying examples where C&YP have been consulted by their diabetes services
- They produced a document with useful information about the “why” and “how to” of involving children and young people
- Developed the Children’s Charter for Diabetes (2010) which says: “Children and young people’s services must be prioritised to meet the needs identified by young people and their families”

The challenge
- The challenge - to provide services conducive to the collaborative management of diabetes by C&YP, their family and their healthcare team and which promote empowerment in self-care and management
- Can be particularly difficult across the adolescent period
- Patient reports, anecdotal evidence from young people, their families & results of national audits, indicate current diabetes provision does not always meet the needs of C&YP

Future directions for development of paediatric diabetes services means

’Services will need to be designed in response to local needs assessments, in partnership with children and young people, ensuring that they can meet the specific needs of the local population.’

(Making Every Young Person with Diabetes Matter, Department of Health, 2007)
Methodology

- Aims: to elicit the experiences and opinions of young people about their paediatric diabetes service provided by Trust
- Identify examples of good practice valued by young people
- Findings to be used to make recommendations to shape services
- Developed and piloted questionnaires with service users and diabetes team
- Relevant R&D permissions
- Participants: 50 young people of secondary school age 11+
- Consent clinic lists were sent to young people and their families telling them about project that they will likely be approached
- Sent participant information sheets telling more about project
- Asked to opt out if they wished
- At clinic informed written consent/assent taken
- Complete the questionnaire - 10-15 mins
- Project worker on hand to explain anything that is not clear

This evaluation

- Demographics: age; gender; age of diagnosis
- Satisfaction with clinic services
- Relationships with clinic staff
- Reasons for missing clinic appointments
- Ways of improving clinic appointments
- Ways of improving diabetes services more generally

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequencies</th>
<th>Mean</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of diagnosis</td>
<td>8.94</td>
<td>0.67-16</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td>14.65</td>
<td>11-18</td>
</tr>
<tr>
<td>Gender</td>
<td>Male: 23 (46%) Female: 27 (54%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Location</td>
<td>Site 1: 7 Site 2: 7 Site 3: 9 Site 4: 7 Site 5: 20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinic Type</td>
<td>General or pump: 36 Transition: 14</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you know how often you need to come to these appts?</td>
<td>39 (65%)</td>
<td>8 (17%)</td>
</tr>
<tr>
<td>Do you get a chance to say everything you want to?</td>
<td>38 (95%)</td>
<td>2 (5%)</td>
</tr>
<tr>
<td>Do you get a chance to talk alone?</td>
<td>30 (60.2%)</td>
<td>14 (28.9%)</td>
</tr>
<tr>
<td>Would it be helpful to talk alone?</td>
<td>23 (51.1%)</td>
<td>22 (46.9%)</td>
</tr>
<tr>
<td>Do you miss any appointments?</td>
<td>11 (22.6%)</td>
<td>38 (37.6%)</td>
</tr>
<tr>
<td>Since diagnosis have you given you enough info about diabetes and how to manage it?</td>
<td>46 (93.9%)</td>
<td>3 (6.1%)</td>
</tr>
<tr>
<td>Seen your nurse outside of hospital?</td>
<td>37 (77.1%)</td>
<td>11 (22.9%)</td>
</tr>
<tr>
<td>Seen CP?</td>
<td>12 (24.5%)</td>
<td>37 (75.5%)</td>
</tr>
<tr>
<td>Seen Dietician</td>
<td>94 (99.8%)</td>
<td>5 (10.2%)</td>
</tr>
</tbody>
</table>

Why did not attend clinic appts?

<table>
<thead>
<tr>
<th>School / exams</th>
<th>Parent working</th>
<th>Appointment clashes</th>
<th>Bad date/time</th>
<th>Forgot</th>
<th>Getting lost</th>
<th>Family problems</th>
<th>Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Where do you get your information from about diabetes?

<table>
<thead>
<tr>
<th>Diabetes Team</th>
<th>Website/ internet</th>
<th>Another person with diabetes</th>
<th>Book</th>
<th>School</th>
</tr>
</thead>
<tbody>
<tr>
<td>33</td>
<td>11</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>
Conclusions?

- We’re doing pretty well
- YP tell us they get to say what they want at their appts, and they feel listened to (but not entirely comfortable)
- 35% said there was nothing wrong with the appts (some left blank)
- And what they say they don’t like about them: 40% say they are boring, time consuming etc— not actively awful
- They find talking to team staff helpful – over 85% for all professions
- We give them enough info, and most of them get that info from the team
- They want flexibility in team contact - most highly rated potential improvement was being able contact someone from diabetes team for advice on weekends/ evenings
- There’s something important about dealing with the social aspects of diabetes – how to manage it in school, tell friends about it and answer when people ask, less relevant to talk about their feelings about having diabetes (but could be lying!)
- Of possible suggested improvements to meet other YPs + diabetes - they want something fun and they don’t want it very often
- Over half would welcome FB group, and about a third of those wouldn’t mind if it was monitored