NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Nocturnal enuresis in children and young people.

Output: Prioritised quality improvement areas for development.

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Contents

1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for nocturnal enuresis in children and young people. It provides the Committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

1.1 Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the Committee in considering potential statements and measures.

1.2 Development source

The key development source(s) referenced in this briefing paper is:

Nocturnal enuresis. NICE clinical guideline 111 (2010).

2 Overview

2.1 Focus of quality standard

This quality standard will cover the management of nocturnal enuresis (bedwetting) in children and young people up to 19 years.

2.2 Definition

‘Nocturnal enuresis’ is the medical term for ‘bedwetting’. Experts and expert bodies differ in their definitions of nocturnal enuresis and bedwetting and in the context of NICE CG111 the term 'bedwetting' is used to describe the symptom of involuntary wetting during sleep without any inherent suggestion of frequency of bedwetting or pathophysiology.

2.3 Incidence and prevalence

Bedwetting is a widespread and distressing condition that can have a deep impact on a child or young person's behaviour, emotional wellbeing and social life. It can also be very stressful for the parents or carers. The prevalence of bedwetting decreases with age. Bedwetting less than 2 nights a week has a prevalence of 21% at about 4 and a half years and 8% at 9 and a half years. Bedwetting more than 2 nights a week is less common and has a prevalence of 8% at 4 and a half years and

1.5% at 9 and a half years[1]. Stakeholders have highlighted that bedwetting affects vulnerable groups disproportionately, especially those children and young people with physical disabilities, mental health issues, learning disabilities and looked after children.

2.4 Management

The causes of bedwetting are not fully understood. Children, young people and their parents or carers should be advised that bedwetting is not the fault of the child's and that punitive measures should not be used. Bedwetting can be considered to be a symptom that may result from a combination of different predisposing factors. There are a number of different disturbances of physiology that may be associated with bedwetting. These disturbances may be categorised as sleep arousal difficulties, polyuria and bladder dysfunction. Bedwetting also often runs in families.

Children are generally expected to be dry by a developmental age of 5 years, and historically it has been common practice to consider children for treatment only when they reach 7 years. The clinical guideline applies to children and young people up to 19 years with the symptom of bedwetting. The guideline also includes recommendations which make specific advice for children under 5 years, and indicated treatment options for children between 5 and 7 years.

Children and young people with bedwetting may also have symptoms related to the urinary tract during the day. A history of daytime urinary symptoms may be important in determining the approach to management of bedwetting.

Children presenting with bedwetting require a thorough assessment to identify any medical, emotional or physical triggers and to consider whether assessment and treatment of the identified triggers are needed. Asking about the pattern of bedwetting, daytime symptoms, daytime fluid intake and toileting patterns can help to further understand possible triggers. Treatment of or referral for management of identified medical causes (for example diabetes, constipation, urinary tract infection), emotional causes (for example bereavement, family problems) or physical problems (for example sleeping arrangements, proximity of parents during the night) may be necessary.

Prior to commencing formal treatment families should be advised on the use of reward systems to encourage the child to have appropriate fluid intake, diet and toileting patterns. Where active intervention is required CG111 recommends that first-line treatment can be the use of an alarm system (where this is clinically appropriate and acceptable to the child or young person and their family) or a medication called desmopressin. A bedwetting alarm consists of a small sensor and

[1] Butler RJ, Heron J (2008) The prevalence of infrequent bedwetting and nocturnal enuresis in childhood: A large British cohort. Scandinavian Journal of Urology and Nephrology 42: 257–64

an alarm. The sensor is attached to the child's underwear and the alarm is worn on the pyjamas. If the sensor starts to get wet, it sets off the alarm. Vibrating alarms are also available for children who are hearing impaired. Over time, the alarm should help the child to recognise when they need to wake up to go to the toilet. CG111 recommends that the alarm system is combined with a reward system to promote good behaviour such as fluid and diet intake and going to the toilet when the alarm sounds.

If the bedwetting does not respond to the initial alarm treatment, or is not appropriate or desirable to the child, young person and their family, then children and young people may be offered drug treatment with desmopressin in combination with continued alarm treatment, or desmopression alone. Desmopression is a synthetic (man-made) version of the hormone that regulates the production of urine, called vasopressin. It helps to reduce the amount of urine produced by the kidneys.

Where bedwetting in children and young people does not respond to courses of treatment with an alarm and/ or desmopression, children and young people should be referred to a healthcare professional with expertise in prescribing anticholinergics in combination with desmopression. Anticholinergic drugs work by relaxing the muscles of the bladder, which can help improve its capacity and reduce the urge to pass urine during the night. Where all other treatment options are unsuitable or have not produced satisfactory outcomes, tricyclics (imipramine) may be used. Imipramine also relaxes the muscles of the bladder, increasing its capacity and reducing the urge to urinate.

Also see NICE pathway for bedwetting.

2.5 National Outcome Frameworks

Table 1shows the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 NHS Outcomes Framework 2014/15

Domain	Overarching indicators and improvement areas
4 Ensuring that people have a positive experience of care	***Improvement areas*** Improving children and young people's experience of healthcare 4.8 Children and young people's experience of outpatient services (in development)

3 Summary of suggestions

3.1 Responses

In total 8 stakeholders (including 2 specialist committee members) responded to the 2-week engagement exercise 16/12/13-10/01/14. A further 2 stakeholders (NHS England and the Royal College of Nursing) also confirmed that they had no comments to make at the topic engagement stage.

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been merged and summarised in table 2 for further consideration by the Committee.

Full details on the suggestions provided are given in appendix 4 for information.

Table 2 Summary of suggested quality improvement areas

Suggested area for improvement	Stakeholders
Assessment and investigation • Assessment to establish if there is an underlying cause. • Common causes highlighted include constipation, daytime symptoms which may suggest overactive bladder and sleep disorders/ apnoea.	PromoCon, LTH NHS Tr, BAPU, RCPCH
Avoiding punitive treatment • Punitive measures should not be used in the management of bedwetting.	RCPCH, BAPU, PCF, SCM (lay person)
Treatment for children aged 5-7 years • Stakeholders highlight that, contrary to CG111, children aged 5-7 years are not always being offered treatments for bedwetting.	PromoCon, BAPU, PCF, Ferr Pharma.
Appropriate first-line treatment • Stakeholders highlighted that CG111 is sometimes being misinterpreted leading to some clinicians insisting on a trial with an alarm system when it is inappropriate. • Stakeholders highlighted that provision of alarm systems is variable across the country, and inappropriate use is exacerbating waiting times.	PromoCon, LTH NHS Tr, PCF, Ferr Pharma,
Integrated services • Lack of joined up services and local care pathways. • Services are often not integrated, and some treat only the bedwetting and not underlying or related issues such as constipation, toilet training and daytime wetting. • Children's continence services often amalgamated with adult services.	PromoCon, RCPCH, PCF
Appropriate onward referral • Bedwetting is not always taken seriously by clinicians and some families live with bedwetting for many years and are not offered onward referral to a specialist. • Advice regarding fluid intake, toileting and initial treatment can be delivered in a primary care setting. However in some areas primary care rely on specialist services for the initial assessment and treatments.	SCM BAPU
Parent information sessions • Improving parental knowledge through group education sessions. This service model is also anticipated to reduce waiting times.	SCM

Ferr Pharma, Ferring Pharmaceuticals
PCF.Paediatric Continence Forum
BAPU, British Association of Paediatric Urologists
LTH NHS Tr, Leeds Teaching Hospitals NHS Trust
PromoCon, Promoting Continence and Product Awareness
RCPCH, Royal College of Paediatrics and Child Health
SCM, Specialist Committee Member

4 Suggested improvement areas

4.1 Assessment and investigation

4.1.1 Summary of suggestions

Assessment and investigation

Stakeholders highlighted the importance of the child undergoing a thorough assessment on presentation. Stakeholders reported that sometimes the underlying cause of the nocturnal enuresis is not identified thereby leading to inappropriate treatments being offered, treatment failure and further distress. Although this theme relates to the importance of assessment broadly, stakeholders highlighted that constipation (3 stakeholders), daytime symptoms which are suggestive of an over active bladder (2 stakeholders) and sleep apnoea (1 stakeholder) are specific underlying causes which sometimes remain undiagnosed.

4.1.2 Selected recommendations from development source

Table 3 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 3 to help inform the Committee's discussion.

Table 3 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Assessment and investigation	Assessment and investigation CG111 Recommendations in section 1.3.9

Assessment and investigation

NICE CG111 – Recommendations 1.3.1-1.3.10

1.3.1 Ask whether the bedwetting started in the last few days or weeks. If so, consider whether this is a presentation of a systemic illness.

1.3.2 Ask if the child or young person had previously been dry at night without assistance for 6 months. If so, enquire about any possible medical, emotional or physical triggers, and consider whether assessment and treatment is needed for any identified triggers.

1.3.3 Ask about the pattern of bedwetting, including questions such as:

- How many nights a week does bedwetting occur?
- How many times a night does bedwetting occur?
- Does there seem to be a large amount of urine?
- At what times of night does the bedwetting occur?
- Does the child or young person wake up after bedwetting?

1.3.4 Ask about the presence of daytime symptoms in a child or young person with bedwetting, including:

- daytime frequency (that is, passing urine more than seven times a day)
- daytime urgency
- daytime wetting
- passing urine infrequently (fewer than four times a day)
- abdominal straining or poor urinary stream
- pain passing urine.

1.3.5 Ask about daytime toileting patterns in a child or young person with bedwetting, including:

- whether daytime symptoms occur only in some situations
- avoidance of toilets at school or other settings
- whether the child or young person goes to the toilet more or less frequently than his or her peers.

1.3.6 Ask about the child or young person's fluid intake throughout the day. In particular, ask whether the child or young person, or the parents or carers are restricting fluids.

1.3.7 Consider whether a record of the child or young person's fluid intake, daytime symptoms, bedwetting and toileting patterns would be useful in the assessment and management of bedwetting. If so, consider asking the child or young person and parents or carers to record this information.

1.3.8 Do not perform urinalysis routinely in children and young people with bedwetting, unless any of the following apply:

- bedwetting started in the last few days or weeks

- there are daytime symptoms
- there are any signs of ill health
- there is a history, symptoms or signs suggestive of urinary tract infection
- there is a history, symptoms or signs suggestive of diabetes mellitus.

1.3.9 Assess whether the child or young person has any comorbidities or there are other factors to consider, in particular:

- constipation and/or soiling
- developmental, attention or learning difficulties
- diabetes mellitus
- behavioural or emotional problems
- family problems or a vulnerable child or young person or family.

1.3.10 Consider assessment, investigation and/or referral when bedwetting is associated with:

- severe daytime symptoms
- a history of recurrent urinary infections
- known or suspected physical or neurological problems
- comorbidities or other factors (for example, those listed in recommendation 1.3.9).

4.1.3 Current UK practice

None identified.

4.2 Avoiding punitive treatment

4.2.1 Summary of suggestions

Stakeholders highlighted the importance of educating children, young people and parents that bedwetting is not the child's fault and that punitive measures should not be used against the child or young person. Stakeholders highlighted that it is important that parents and carers are offered support and assistance particularly if they are having difficulty coping (emotionally, economically, logistically) with the burden of bedwetting, or if they are expressing anger and negativity towards the child as a consequence of bedwetting.

4.2.2 Selected recommendations from development source

Table 4 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 4 to help inform the Committee's discussion.

Table 4 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Avoiding punitive treatment	**Principles of care** NICE CG111 recommendation 1.1.1 (KPI) **Assessment and investigation** NICE CG111 recommendation 1.3.17 (KPI).

Principles of care

NICE CG111 recommendation 1.1.1 (KPI)

Inform children and young people with bedwetting and their parents or carers that bedwetting is not the child or young person's fault and that punitive measures should not be used in the management of bedwetting.

Assessment and investigation

NICE CG111 recommendations 1.3.17 (KPI)

Discuss with the parents or carers whether they need support, particularly if they are having difficulty coping with the burden of bedwetting, or if they are expressing anger, negativity or blame towards the child or young person.

4.2.3 Current UK practice

None identified.

4.3 Treatment for children aged 5-7 years

4.3.1 Summary of suggestions

Stakeholders reported that some children aged 5-7 years are not being considered for treatment despite a specific key priority for implementation recommendation that children under 7 years of age should not be excluded from the management of bedwetting on the basis of age alone. Although this area relates broadly to the full range of treatments, stakeholders also specifically mentioned that the drug treatment desmopressin is not usually considered for children aged 5-7 years.

4.3.2 Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 5 to help inform the Committee's discussion.

Table 5 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Treatment for children aged 5-7 years	**Principles of care** NICE CG111 Recommendation 1.1.3 (KPI) **Initial treatment - alarms** NICE CG111 Recommendation 1.8.8 **Initial treatment - desmopressin** NICE CG111 Recommendation 1.10.2

Principles of care

NICE CG111 Recommendation 1.1.3 (KPI)

Do not exclude younger children (for example, those under 7 years) from the management of bedwetting on the basis of age alone.

Initial treatment – alarms

NICE CG111 Recommendation 1.8.8

Consider an alarm for the treatment of bedwetting in children under 7 years, depending on their ability, maturity, motivation and understanding of the alarm.

Initial treatment – desmopressin

NICE CG111 Recommendation 1.10.2

Consider desmopressin for children aged 5–7 years if treatment is required and:

- rapid-onset and/or short-term improvement in bedwetting is the priority of treatment **or**
- an alarm is inappropriate or undesirable (see recommendation 1.8.1).

4.3.3 Current UK practice

None identified.

4.4 Appropriate first-line treatment

4.4.1 Summary of suggestions

Stakeholders highlighted that the recommendations in CG111 are sometimes being misinterpreted leading to some clinicians insisting on a trial with an alarm system for children in which this system is inappropriate. Stakeholders emphasised that treatment with an alarm system can be successful where this is clinically appropriate, but in some children alarms systems are unsuitable. Stakeholders emphasised that recommendations in CG111 state that children can be offered drug treatment with desmopressin if an alarm system is unsuitable for them.

Stakeholders highlighted that provision of alarm systems is variable across the country, and inappropriate use of alarm systems is exacerbating waiting times.

4.4.2 Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 6 to help inform the Committee's discussion.

Table 6 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Appropriate first-line treatment	**Initial treatment - alarms** NICE CG111 recommendations 1.8.1 (KPI) **Initial treatment – desmopressin** NICE CG111 recommendations 1.10.1 (KPI)

Initial treatment – alarms

NICE CG111 recommendations 1.8.1 (KPI)

Offer an alarm as the first-line treatment to children and young people whose bedwetting has not responded to advice on fluids, toileting or an appropriate reward system, unless:

- an alarm is considered undesirable to the child or young person or their parents or carers **or**
- an alarm is considered inappropriate, particularly if:

- bedwetting is very infrequent (that is, less than 1–2 wet beds per week)
- the parents or carers are having emotional difficulty coping with the burden of bedwetting
- the parents or carers are expressing anger, negativity or blame towards the child or young person.

Initial treatment – desmopressin

NICE CG111 recommendations 1.10.1 (KPI)

Offer desmopressin to children and young people over 7 years, if:

- rapid-onset and/or short-term improvement in bedwetting is the priority of treatment **or**
- an alarm is inappropriate or undesirable (see recommendation 1.8.1).

4.4.3 Current UK practice

None identified.

4.5 Integrated services

4.5.1 Summary of suggestions

Stakeholders highlighted a lack of joined up services and local care pathways. Stakeholders highlighted that services are often not integrated, and some treat only the bedwetting and not underlying or related issues such as constipation, urinary tract infections, toilet training and daytime wetting. This leads to children being referred on to other services and therefore delays in treatment. Delays in treatment can result in exacerbation of conditions such as UTIs and constipation, thereby resulting in more outpatient appointments and hospital admissions.

Children's bedwetting services are often amalgamated with adult continence services.

4.5.2 Selected recommendations from development source

Table 7 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 7 to help inform the Committee's discussion.

Table 7 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Integrated services	NICE CG111 recommendations 1.3.11 to 1.3.15.

NICE CG111 recommendations 1.3.11 to 1.3.15

1.3.11 Investigate and treat children and young people with suspected urinary tract infection in line with 'Urinary tract infection' (NICE clinical guideline 54).

1.3.12 Investigate and treat children and young people with soiling or constipation in line with 'Constipation in children and young people' (NICE clinical guideline 99).

1.3.13 Children and young people with suspected type 1 diabetes should be offered immediate (same day) referral to a multidisciplinary paediatric diabetes care team that has the competencies needed to confirm diagnosis and to provide immediate care.

[This recommendation is from 'Type 1 diabetes' (NICE clinical guideline 15).]

1.3.14 Consider investigating and treating daytime symptoms before bedwetting if daytime symptoms predominate.

1.3.15 Consider involving a professional with psychological expertise for children and young people with bedwetting and emotional or behavioural problems.

4.5.3 Current UK practice

National Audit of Continence Care

The National Audit of Continence Care 2010[2] excluded children's trust and did not ask specific questions in relation to children and young people's services, therefore the detailed findings are not appropriate for this briefing paper. However the headline finding from the report is that 'The great majority of continence services are poorly integrated across acute, medical, surgical, primary, care home and community settings, resulting in disjointed care for patients and carers'.

Continence Care Services in England 2013

In follow-up to the National Audit of Continence Care an All Party Parliamentary Group for Continence Care commissioned a further survey[3] which was undertaken in 2012. This survey received 89 responses and included questions specific to children's continence services. Of the respondents 17% were employed by a PCT, 48% a foundation trust, 9% a social enterprise and 26% other organisations. This survey included adult and children's continence services and of the respondents 44% worked in a service which covered the care of both children and adults, 53% a service for adults only and 2% a service for children only. This is a small-scale survey and the findings below need to be interpreted in the context of the respondent population. The key findings of relevance to the quality standard topic from this small scale survey include:

- The majority of respondents reported that the population served by the service has increased in the past 2 years (70% increased, 1% decreased and 29% no change).
- In many services staffing level have remained static or decreased over the past 2 years (44% no change, 38% decreased and 26% increased).
- In the report the authors conclude that there has been a dilution of senior staff in continence services, however the data to underpin this is not presented.
- 72% of services reported operating a waiting list for patients referred for clinical assessment. The most common waiting time is 4-8 weeks (7 services less

[2] See the Full organisational and clinical report - National Audit of Continence Care 2010
[3] See the Continence Care Services in England 2013 – Survey Report

than 3 weeks, 16 services 4-8 weeks, 10 services 9-12 weeks, 4 services 13-18 weeks and 1 service more than 18 weeks).

- The majority of services provide education for colleagues working locally and primary care clinicians are the main audience. Although those working within continence services feel this is an important element of their service, free text comments from respondents suggest that limited resources to deliver local education programmes and limited take up of education are barriers to improving the knowledge and skills of the local workforce.

Freedom of Information request by Paediatric Continence Forum

The Paediatric Continence Forum (PCF) issued a Freedom of Information (FOI)[4] request to all PCTs in the UK in February 2011. Seventy-two of the 152 PCTs responded to the questions posed concerning their paediatric continence services. The authors highlight that PCTs which commission poorly delivered services could be disproportionately represented among those that chose not to respond. Five questions were asked and questions 1, 2 and 4 are relevant to this quality improvement area. The survey focused on assessing provision of four services; bedwetting, daytime wetting, toilet training and constipation/soiling. In relation to these services the following question was asked:

Question 1: 'Of the four main paediatric continence services (bedwetting, daytime wetting, toilet training and constipation/soiling), which are being commissioned by your PCT?'

Results:

89% (63 out of 72) PCTs commissioned all four services

7% (5 out of 72) PCTs commissioned three services

4% (4 out of 72) PCTs commissioned one service

There was notable variation in the quality and type of provision.

[4] Unpublished full report obtained directly from Paediatric Continence Forum (at Frances.Powrie@whitehouseconsulting.co.uk), which includes details of results collated to a national level. Local results are available via Public Health England: Child Maternal Health Intelligence Network Website: Continence Needs Assessment module

Question 2: ‘Are these services joined-up, i.e. is there one service for all four continence problems? If so, what is the designation of the person who leads this service?’

Results:

49% (35 out of 72) PCTs described their services as not-joined up and 51% (37 out of 72) described their services as joined up.

Those that described their services as joined-up often did not have a designated lead or team delivering all services.

Of the 35 PCTs who described their services as not joined-up, 5 reported being in the process of introducing an integrated service.

Question 4: ‘In light of the current NICE guidelines for childhood constipation and nocturnal enuresis and the recently published NICE Paediatric Continence Services Commissioning Guide, is your PCT planning to commission new paediatric continence services?’

25% (18 out of 72) PCTs said they either planned to commission new services or were reviewing their existing services in light of the NICE guidance.

75% (55 out of 72) had no plans to change their services or commission new ones. Of these a number (not specified in report) said that they already complied with the NICE guidelines and a number (not specified in report) of PCTs did not elaborate on why they had no plans for new services and some did not respond to the question.

4.6 Appropriate onward referral

4.6.1 Summary of suggestions

Bedwetting is not always taken seriously by clinicians and some families live with bedwetting for many years. Appropriate onward referral to specialist services is not always offered to children, young people and their families.

Advice regarding fluid intake, toileting and initial treatment can be delivered in a primary care setting. However in some areas primary care rely on specialist services for the initial assessment and treatments.

4.6.2 Selected recommendations from development source

Table 8 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 8 to help inform the Committee's discussion.

Table 8 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Appropriate onward referral	**Lack of response to initial treatment options** NICE CG111 recommendation1.12.1 (KPI)

Lack of response to initial treatment options

NICE CG111 recommendation 1.12.

Refer children and young people with bedwetting that has not responded to courses of treatment with an alarm and/or desmopressin for further review and assessment of factors that may be associated with a poor response, such as an overactive bladder, an underlying disease or social and emotional factors.

4.6.3 Current UK practice

None identified.

4.7 Parent information sessions

4.7.1 Summary of suggestions

One stakeholder highlighted a local pilot to deliver education to parents and carers of children and young people experiencing bedwetting through group education sessions. As well as improving knowledge and understanding of bedwetting, this service model is also anticipated to reduce waiting times.

4.7.2 Selected recommendations from development source

Table 9 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 9 to help inform the Committee's discussion.

Table 9 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Parent information sessions	**Information for the child or young person and family** NICE CG111 recommendations 1.2.1, 1.2.2 and 1.2.3.

Information for the child or young person and family

NICE CG111 recommendation 1.2.1

Offer information tailored to the needs of children and young people being treated for bedwetting and their parents and carers.

NICE CG111 recommendation 1.2.2

Offer information and details of support groups to children and young people being treated for bedwetting and their parents or carers.

NICE CG111 recommendation 1.2.3

Offer information about practical ways to reduce the impact of bedwetting before and during treatment (for example, using bed protection and washable and disposable products).

4.7.3 Current UK practice

None identified.

Appendix 1: Additional information

See NICE pathway for bedwetting.

Appendix 2: Key priorities for implementation (CG111)

Recommendations that are key priorities for implementation in the source guideline and that have been referred to in the main body of this report are highlighted in grey.

- Inform children and young people with bedwetting and their parents or carers that bedwetting is not the child or young person's fault and that punitive measures should not be used in the management of bedwetting.

- Offer support, assessment and treatment tailored to the circumstances and needs of the child or young person and parents or carers.

- Do not exclude younger children (for example, those under 7 years) from the management of bedwetting on the basis of age alone.

- Discuss with the parents or carers whether they need support, particularly if they are having difficulty coping with the burden of bedwetting, or if they are expressing anger, negativity or blame towards the child or young person.

- Consider whether or not it is appropriate to offer alarm or drug treatment, depending on the age of the child or young person, the frequency of bedwetting and the motivation and needs of the child or young person and their family.

- Address excessive or insufficient fluid intake or abnormal toileting patterns before starting other treatment for bedwetting in children and young people.

- Explain that reward systems with positive rewards for agreed behaviour rather than dry nights should be used either alone or in conjunction with other treatments for bedwetting. For example, rewards may be given for:
    - drinking recommended levels of fluid during the day
    - using the toilet to pass urine before sleep
    - engaging in management (for example, taking medication or helping to change sheets).

- Offer an alarm as the first-line treatment to children and young people whose bedwetting has not responded to advice on fluids, toileting or an appropriate reward system, unless:
    - an alarm is considered undesirable to the child or young person or their parents and carers **or**
    - an alarm is considered inappropriate, particularly if:
        - bedwetting is very infrequent (that is, less than 1–2 wet beds per week)
        - the parents or carers are having emotional difficulty coping with the burden of bedwetting
        - the parents or carers are expressing anger, negativity or blame towards the child or young person.

- Offer desmopressin to children and young people over 7 years, if:
    - rapid-onset and/or short-term improvement in bedwetting is the priority of treatment **or**
    - an alarm is inappropriate or undesirable (see recommendation 1.8.1).

- Refer children and young people with bedwetting that has not responded to courses of treatment with an alarm and/or desmopressin for further review and assessment of factors that may be associated with a poor response, such as an overactive bladder, an underlying disease or social and emotional factors.

Appendix 3: Glossary

Nocturnal enuresis Enuresis is intermittent incontinence in discrete episodes when asleep; the term nocturnal is often used for clarity (Full guideline for CG111).

Bedwetting Involuntary wetting during sleep without any inherent suggestion of frequency of bedwetting or pathophysiology (section 1, CG111).

Daytime symptoms daytime urinary symptoms such as wetting, urinary frequency or urgency.

Appendix 4: Suggestions from stakeholder engagement exercise

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
01	PromoCon	Key area for quality improvement 1 Treatment recommendations for nocturnal enuresis for children under the age of 7 years	It is recognised that untreated bedwetting can lead to an impact on the child's behaviour, emotional well being and social life yet many children aged 5 years are still not having access to appropriate management/treatment	The treatment recommendations in the current NICE guideline are ambiguous and open to misinterpretation. Although one of the KPIs recommend not restricting management to those under 7 years the management advice within the document clearly does! There are no clear recommendation for treating children under the age of 7 years – one has to read through the document to tease out the actual recommendations	KPI on page 7 clearly states 'do not exclude younger children (for example, those **under 7 years**) from the management of bedwetting on the basis of age alone. However on page 22 1.10 re initial treatment with desmopressin the first statement states: Offer desmopressin to children...**over the age of 7 years.** This recommendation has proved confusing for some clinicians who skim through the guideline and only take note of the first line in the recommendation. We have been contacted by families who have been told that desmopressin will not be prescribed until the child is 6-7 years even though it is licensed from age 5 years
01	PromoCon	Key area for quality improvement 2	Children are being put on waiting lists for alarm treatment or being provided	We know alarm treatment is successful for those children for whom it has been deemed appropriate. However again the	We have been contacted by both families and clinicians who tell us that the children with bedwetting now have to try the

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		Clear treatment recommendations regarding first line treatment	with alarms treatment inappropriately.	current NICE guidance appears to give the wrong message unless the initial treatment recommendations are read within the context of the complete guideline. Alarm treatment is recommended as first line treatment for children with bedwetting only if deemed appropriate and desirable. However many clinicians have misinterpreted those recommendations to mean that ALL children have to be tried on an alarm first and only if that fails should they commence desmopressin. This means that not only are often limited resources (ie alarms) being used inappropriately leading to treatment failures but also those children for whom the alarm is suitable are having to go on, often long, waiting lists until an alarm becomes available for them to use.	alarm first before they can go on desmopressin
01	PromoCon	Key area for quality improvement 3 'Enuresis' clinics should actually provide both a bladder and bowel service to ensure children	NICE identified that constipation is a common comorbidity that can cause bedwetting and requires treatment	Many areas just provide an 'enuresis' service and only see children for 'bedwetting' which means the children have to be referred on elsewhere to address any underlying constipation. As many services are not joined up there is often a delay in the constipation being addressed appropriately if at all.	Despite NICE guidance re bedwetting and constipation a report carried out by the APPG for continence care identified that services for children with bladder and bowel problems remain poor http://www.appgcontinence.org.uk/pdfs/Continence%20Care%20Services%20England%20Repo

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		and young people have an assessment that asks about daytime symptoms and assess for any underlying constipation			rt%202013.pdf
02	Leeds Teaching Hospitals NHS Trust	Accessibility and provision of enuresis alarms	Alarms are first-line treatment within the NICE guidance, and so it is important that they are easily available and provided with appropriate support and supervision.	Anecdotally it seems that alarm provision is variable across the country, and not well supported by commissioners. This will impact on treatment and quality of life.	
02	Leeds Teaching Hospitals NHS Trust	Detailed assessment of possible constipation	There is increasing evidence that this is an underlying factor that is often missed. More detailed direct questioning is often required.	Constipation needs to be treated first, before enuresis treatments can be effective.	Hodges, Steve J. Anthony, Evelyn Y. Occult megarectum--a commonly unrecognized cause of enuresis. Urology. 79(2):421-4, 2012.
03	Royal College of Paediatrics and Child Health	Key area for quality improvement 1	There is significant evidence that patients with resistant Nocturnal enuresis have	Less patients would have prolonged wetting and labelling with a ‘resistant’ tag. This would shorten treatment leading to both physical dryness and less mental stress.	Desmopressin and oxybutynin in monosymptomatic nocturnal enuresis: a randomized, double-blind, placebo-controlled trial and an assessment of predictive

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			undiagnosed daytime dysfunction. By reiterating the need for a formal daytime voiding review the numbers of 'resistant' patients would decrease and short treatment programs would occur. Although the data overall is weak the tendency is to progress through medication without going back to reassess the daytime.		factors. Montaldo P, et al BJU Int. 2012 Oct;110(8 Pt B):E381-6. Evaluation and treatment of nonmonosymptomatic nocturnal enuresis: a standardization document from the International Children's Continence Society. Franco I, von Gontard A, De Gennaro M; International Childrens's Continence Society. J Pediatr Urol. 2013 Apr;9(2):234-43.
03	Royal College of Paediatrics and Child Health	Key area for quality improvement 1 The impact of nocturnal enuresis is a high, with a high prevalence	The National Institute for Health and Clinical Excellence (NICE) estimates that bladder and bowel dysfunction affects about 900,000 children and young people out of a population of	Affects a large number of children at high cost financially and emotionally, for the child and family.	Data on Public Health England: Child Maternal Health Intelligence Network Website: Continence Needs Assessment module. http://atlas.chimat.org.uk/IAS/profiles/needsassessments NICE Clinical Guideline (2010) Nocturnal enuresis - the management of bedwetting in children and young people

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			8,500,000 in the UK		(CG111) http://www.nice.org.uk/CG111
03	Royal College of Paediatrics and Child Health	Key area for quality improvement 2	Sleep apnoea is a recognised cause of sleep disturbance and potential enuresis.	Assessment of sleep disorders is necessary in children with truly resistant enuresis.	Childhood obstructive sleep apnea syndrome: a review of the 2012 American Academy of Pediatrics guidelines. Trosman I. Pediatr Ann. 2013 Oct;42(10):195-9.
03	Royal College of Paediatrics and Child Health	Key area for quality improvement 2 Services for children need to be commissioned as a paediatric joined up service	The Royal College of Physicians national audit of continence care concluded that clinical outcomes are higher when a service is integrated	There is evidence that services for children with continence problems are very variable across the UK, with many neither comprehensive nor properly integrated.	Royal College of Physicians: National Audit of Continence Care (2010) http://www.rcplondon.ac.uk/resources/national-audit-continence-care Paediatric Continence Forum Freedom of Information report 2011. (Available from PCF if required). In 2011 the Paediatric Continence Forum issued Freedom of Information (FOI) requests to 152 PCTs in the UK to assess how their paediatric continence services were being run. Of the seventy two PCTs that responded, 88% commissioned services in the 4 areas (toilet training, bedwetting, daytime wetting, constipation/soiling), but only 51% could say that these were

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					in any way “joined-up”, enabling either treatment “under one roof”, or with a proper care pathway to the other services. Only 25% of the sample provided a dedicated paediatric service i.e. most were amalgamated with the adult continence service. Local data from this research is available on the Child and Maternal Health Intelligence Network website, see above.
03	Royal College of Paediatrics and Child Health	Key area for quality improvement 3 Outcomes for children with continence problems are not well evidenced, and could lead to significant cost savings if they were achieved.	Level 2 services for Nocturnal enuresis (and daytime continence problems) are poorly commissioned and provided. They affect the vulnerable disproportionately, ie those with physical and mental health/ learning disabilities. Long term incontinence is costly to society	Provision and training is patchy, yet it impacts significantly on family functioning and can trigger maltreatment and safeguarding concerns of all types. It is also dangerous to leave continence problems poorly assessed, investigated and managed. This would lead to fewer hospital emergency visits/ admissions in the long term.	Improving Children and Young People’s Health Outcomes: A system wide response Department of Health (2013) https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/141430/9328-TSO-2900598-DH-SystemWideResponse.pdf.pdf NICE Clinical Guidelines CG 99 http://www.nice.org.uk/CG99 and CG111 2010 http://www.nice.org.uk/CG111 National Service Framework for Children, Young People and

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			and families.		Maternity Services—Continence issues for a child with learning difficulties Department of Health (2010) http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_119313.pdf
04	BAPU	Key area for quality improvement 1 Support and assessment should be available from earlier age	The treatment of bedwetting has a positive effect on the self-esteem of children. According to NICE guidance, there should be no minimum age limit to allow consideration of the benefit of interventions in younger children (under 7 years) previously excluded from treatment.	Traditionally children below the age of 7yrs have been excluded from management. However, parents or carers need support (emotional, economic and logistical), particularly if they are having difficulty coping with the burden of bedwetting, or if they are expressing anger, negativity or blame towards the child or young person. Children and young people with bedwetting and their parents or carers need to be educated that that bedwetting is not the child or young person's fault and that punitive measures should not be used in the management of bedwetting.	NICE guidelines: Please see section 4.2.1; 4.2.2; 4.2.3 for data on impact on self-esteem and parents and children's view on it.
04	BAPU	Key area for quality improvement 2 All children with bed wetting	Most children and parents are concerned about bed wetting and may not pay much attention to day	Overactive bladder will not respond very well to alarms or desmopressin. So an adequate assessment to identify children with symptoms of bladder overactivity earlier will reduce failure rates and ensure early	NICE guidelines (**6.2.3)** state that Consider investigating and treating daytime symptoms before bedwetting if daytime symptoms predominate and also consider referral.

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		should be assessed for signs and symptoms of overactive bladder.	time symptoms of overactive bladder especially if they are dry in day time. A study by Swinthinbank et al found bedwetting rates of 40–80% in children with frequent daytime wetting.	optimum management for this pathology.	
04	BAPU	Key area for quality improvement 3 All children with NE should have access to community enuretic services before referral to secondary or tertiary care.	Advice regarding good fluid intake and toileting will help a significant proportion of children. Also alarm and desmopressin has good success rates and can be delivered safely in primary care according to established guidelines. Also they are best placed to support families with advice regarding continence aids.	While some areas have established community enuretic services, others rely on hospital services for initial assessment and treatment. Based on personal experience, some children are referred to tertiary care centres without undergoing basic assessment and management.	Professional experience. NICE guidelines: Address excessive or insufficient fluid intake or abnormal toileting patterns before starting other treatment for bedwetting in children and young people. An assessment of polyuria and bladder dysfunction based on history should be done in primary care before commencement of treatment

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04	BAPU	Key area for quality improvement 4 All children with bed wetting should be evaluated for constipation and treated appropriately.	Constipation is a risk factor for enuresis and treatment resistance; it should be treated prior to devising a management plan for enuresis	Many parents are not aware of their childs bowel habits and constipation might go undetected and untreated if specifically assessed by bladder diary and use of Bristol stool chart.	Practical consensus guidelines for the management of enuresis. Eur J Pediatr. 2012 Jun;171(6):971-83. NICE guidelines
04	BAPU	Key area for quality improvement 5 The care pathway for management of NE should try to differentiate between causes of monosymptomatic NE: nocturnal polyuria, bladder overcativity or sleep arousal	The effectiveness of treatment depends on the cause. Knowledge of underlying aetiology will reduce failure rates.	Inappropriate treatment and thus high failure rates results in negative experience for the child and family.	NICE guidelines Diagnosis and management of nocturnal enuresis. **Curr Opin Pediatr.** 2009 Apr;21(2):199-202.
05	Paediatric Continence	Key area for	The Paediatric	Treating NE within an integrated	The PCF has led on producing a

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	Forum	quality improvement 1 Services for treating nocturnal enuresis should be commissioned as part of an integrated service.	Continence Forum (PCF) recommends that children and young people (0-19 years) with nocturnal enuresis should be treated by appropriately paediatric trained professionals within the context of community-based paediatric services that also treat conditions such as daytime incontinence, constipation/soiling , plus advice on toilet training. This service should include children with learning difficulties and physical disabilities. PCF would add that as part of this it is essential to work with	service means that children and young people would receive the support of specialist practitioners in a clinically effective and cost-effective setting. In 2011 PCF carried out a project, based on freedom of information requests, identifying how paediatric continence services were being run in primary care trusts. Of the 72 PCTs that responded, 49% were not running “joined up” services, i.e. those that treat all continence problems. NICE’s paediatric continence service commissioning guide states that an effective, integrated paediatric continence service could “lead to up to an 80% reduction in the number of emergency admissions to secondary care, by providing assessment and management of continence problems (constipation urinary tract infections which often present as acute abdominal pain) in primary and community settings”. This is currently being used as a quality measure by CHIMAT. Effective integrated paediatric	commissioning guide for paediatric continence services and is currently submitting the guide to NICE for accreditation. CHIMAT Needs Assessment Report: *Continence in children for local authorities* http://atlas.chimat.org.uk/IAS/profiles/profile?profileId=45&geoTypeId=4 Royal College of Physicians *National Audit of Continence Care* (2010). http://www.rcplondon.ac.uk/resources/national-audit-continence-care NICE paediatric continence service commissioning guide (2010) http://www.nice.org.uk/usingguidance/commissioningguides/paediatriccontinenceservice/home.jsp

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			commissioners to educate them on the value and greater cost-effectiveness of integrated services.	services lead to fewer outpatient appointments (for UTIs and constipation). While we understand the present difficulty in using this as a quality measure, PCF believes that this should be worked towards.	
05	Paediatric Continence Forum	Key area for quality improvement 2 Recognition of the impact of continence problems on children.	NICE estimates that 900,000 children and young people in the UK are affected by bladder or bowel dysfunction (around 11%). Half of all children with a physical disability may have a continence problem.	Continence problems occur at a formative time for children, influencing their health, wellbeing and emotional development. NICE clinical guidelines recognise the association with emotional and behavioural problems – including particularly with bullying. Nocturnal enuresis is not the child's "fault", and children and parents should be educated to understand this. It is essential that children are not punished for wetting accidents, which can result in a "vicious cycle" of increased stress, more accidents, potentially leading to harsher chastisement and a risk of child abuse. Issues of safeguarding need to be addressed.	NICE clinical guidelines 99 and 111. Goodinge S (1998) *Removing Barriers for Disabled Children: Inspection of Services to Disabled Children and their Families*. Social Service Inspectorate.
05	Paediatric Continence	Key area for	There should be	PCF agrees that a key priority for	NICE clinical guideline 111, p7-8

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	Forum	quality improvement 3 A focus on the importance of appropriate treatment for children under the age of seven.	clear recommendations for treating children under the age of seven reflecting the added importance of addressing nocturnal enuresis and its effect on behaviour, wellbeing and social life at a young age.	implementation is not excluding younger children from the management of bedwetting on the basis of age alone. While the existing clinical guideline contains treatment recommendations PCF feels these are ambiguous, particularly in relation to the use of desmopressin which is licensed from age five. The key priorities for implementation (p8 says “offer desmopressin to children and young people over 7 years”, but does not discuss those who are younger. However, the guidance goes on to suggest consideration of desmopressin for those aged 5-7 on p 22.	and p22.
05	Paediatric Continence Forum	Key area for quality improvement 4 Clarity around first line treatment.	Children and young people should only receive alarm treatment under appropriate circumstances, as reflected in guidance.	NICE’s guidance is clear that alarm treatment should be the first line treatment under certain circumstances(p18-19). While alarm treatment is often successful, the guidance should not be interpreted to mean that alarm treatment should have been tried and failed with all children and young people before commencing treatment with desmopressin. This is particularly important given the limited availability of alarms and the lengthy	Through its membership the PCF has been made aware of anecdotal evidence from clinicians, that children and young people have to try the alarm first before they can treat with desmopressin.

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				waiting list for children and young people.	
06	Ferring Pharmaceuticals	Key area for quality improvement 1 Clear & defined treatment recommendations	Children are being inappropriately put onto alarms when medication would be more appropriate based on the child's/families circumstances..	The current NICE guidance is very ambiguous and open to misinterpretation unless the entirety/ the complete guidance is read. The majority of Healthcare professionals who do not specialise in Enuresis interpret the treatment recommendations as "ALL children should be first tried on an alarm first and only if that fails should they initiate medication in the form of Desmopressin . This misinterpretation is leading to children & families who are clearly unsuitable for alarms being used 1st line even when compliance & adherence will be a significant issue. This will delay the success for the child, increase failure rates & subsequent requirement for further management consultations and in many cases a huge waste of expense for the alarm for families.	NICE guideline 111 within the full guidance states 'Healthcare professionals should persist in offering different treatments and treatment combinations if the first-choice treatment is not successful' followed by Consider whether or not it is appropriate to offer alarm or drug treatment, depending on the age of the child or young person, the frequency of bedwetting and the motivation and needs of the child or young person and their family The NICE pathway clearly shows that either Alarms or Desmopressin could be initiated as 1st line treatment. However as a top line heading within the summary which many GP's will only reads it states the following: '*Offer an alarm as the **first-line treatment to children** and young people whose bedwetting has not responded to advice on fluids, toileting or an appropriate reward system'*

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06	Ferring Pharmaceuticals	Key area for quality improvement 2 Recommendations for the age of treatment with Desmopressin and those under the age of 7.	From a developmental perspective children are expected to be dry at night at 5 years of age. However a significant proportion of children under the age of 7 are not receiving the appropriate management & subsequent treatment management/treatment	The current treatment recommendations in relation to age of initiation with medication are conflicting and are open to misinterpretation. Without reading the complete guidance it states that Desmopressin should only be offered to those over 7 years of age? The misinterpretation leads to safety concerns of medications as well as a child's own vasopressin development from those healthcare professionals who do not specialise in enuresis.	NICE clinical guideline 111 on nocturnal enuresis states, 'It is not been common practice to consider children for treatment only when they reach 7 years' However later within the text it states 'do not exclude younger children (for example, those under 7 years) from the management of bedwetting on the basis of age alone. Regarding the management of enuresis on page 22 its states: **Offer desmopressin to children...over the age of 7 years.** Desmopressin licence indication found within the SPC is 'Treatment of primary nocturnal enuresis (5 to 65 years of age)'. Our medical information & sales team are routinely questioned as to the correct age of usage of Desmopressin and even from experienced continence advisors who quote NICE guidelines.
07	SCM	Key area for quality improvement 1 **Promotion of the**	When the steps outlined in the guidelines are followed, there is	As a parent/carer representative, I have regularly quoted the guidelines to other parents/carers I meet through support groups, charities,	The research evidence that was used in the compilation of the original guideline.

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		Guideline to parents	evidence that children's nocturnal enuresis can be "cured" within months	training that I am involved with. Many of them are still unaware of this NICE Guideline, or indeed any other or the purpose of NICE other than those areas that hit the headlines like cancer treatment.	
07	SCM	Key area for quality improvement 2 **Promotion of the Guideline to frontline staff – eg. health visitors, special needs health visitors, Looked After Children's Nurses, school nurses, teachers, social workers**	If nocturnal enuresis is not addressed as early as possible, it can damage relationships within families and lead to more serious issues including inappropriate "punishment" for bed-wetting, behavioural issues, etc.	As a parent/carer representative, I am aware that families which I come into contact with are not being told about the Guideline or their entitlement to support from GP/specialist healthcare professionals; or about support with materials eg. bedding, washing machine, nappies, Family Fund, etc.	As above and several pieces of anecdotal evidence about families who have "accepted" NE for years because their GPs did not refer on appropriately
07	SCM	Key area for quality improvement 3 **Promotion of the Guideline specifically to individuals and groups working with children who have been**	18% of the LAC population as opposed to 5% of the mainstream population have issues with nocturnal enuresis.	Foster carers, adopters and the people who work with them need access to appropriate, timely advice about nocturnal enuresis in order to address problems before they become entrenched.	As above

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		looked after			
08	SCM	One area of quality improvement that I am aware of locally is the role out of a Parent Information session on a group basis.	This group session involves the presentation of basic information to the parents/carers of children who present with nocturnal enuresis.	The hope is that this will improve parental knowledge and understanding, as well as parental engagement in any ongoing individual intervention. It is anticipated that this group initiative will help in the triage of referred cases and reduce waiting times. I am not aware of any evidence base to underpin this initiative, but I know there are plans to evaluate the group and write it up. Given the lack of an evidence base I suspect it is a little premature to consider this initiative just yet. Please feel free to use this example or disregard it as you see fit.	
09	Royal college of nursing	No comments to make			
10	NHS England	No comments to make			