

# Nocturnal enuresis in children and young people

## NICE quality standard

### Draft for consultation

April 2014

## Introduction

This quality standard covers the assessment and management of nocturnal enuresis in children and young people aged 18 years or younger. For more information see the [topic overview](#).

### ***Why this quality standard is needed***

Nocturnal enuresis is the medical term for 'bedwetting'. It 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.

Experts and expert bodies differ in their definitions of nocturnal enuresis and bedwetting. In the NICE clinical guideline on nocturnal enuresis the term bedwetting is used to describe the symptom of involuntary wetting during sleep without any inherent suggestion of frequency of bedwetting or pathophysiology. The same definition is used in this quality standard.

The causes of bedwetting are not fully understood. 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.

The quality standard is expected to contribute to improvements in the following outcomes:

- quality of life for children, young people and their families and carers
- psychological wellbeing of children, young people and their families and carers.

## ***How this quality standard supports delivery of outcome frameworks***

NICE quality standards are a concise set of prioritised statements designed to drive measurable quality improvements within a particular area of health or care. They are derived from high-quality guidance, such as that from NICE or other sources accredited by NICE. This quality standard, in conjunction with the guidance on which it is based, should contribute to the improvements outlined in the following outcome framework published by the Department of Health:

- [NHS Outcomes Framework 2014–15.](#)

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

**Table 1** [NHS Outcomes Framework 2014–15](#)

<b>Domain</b>	<b>Overarching indicators and improvement areas</b>
4 Ensuring that people have a positive experience of care	<p><b><i>Overarching indicator</i></b></p> <p>4a Patient experience of primary care</p> <p>i GP services</p> <p><b><i>Improvement areas</i></b></p> <p>4.8 Children and young people’s experience of outpatient services (in development)</p>

### ***Coordinated services***

The quality standard for nocturnal enuresis specifies that services should be commissioned from and coordinated across all relevant agencies encompassing the whole continence care pathway. A person-centred, integrated approach to providing services is fundamental to delivering high-quality care to children and young people with nocturnal enuresis and their parents or carers.

The Health and Social Care Act 2012 sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services, as part of a general duty to secure continuous improvement in quality.

Commissioners and providers of health and social care should refer to the library of NICE quality standards when designing high-quality services. Other quality

standards that should also be considered when choosing, commissioning or providing a high-quality continence service are listed in 'Related quality standards'.

### **Training and competencies**

The quality standard should be read in the context of national and local guidelines on training and competencies. All health and social care practitioners involved in assessing, supporting and treating children and young people with nocturnal enuresis should have sufficient and appropriate training and competencies to deliver the actions and interventions described in the quality standard.

### **Role of families and carers**

Quality standards recognise the important role that families and carers have in supporting children and young people with nocturnal enuresis. If appropriate, health and social care practitioners should ensure that family members and carers are involved in the decision-making process about investigations, treatment and care.

### **List of quality statements**

Statement 1. Children and young people (aged 5-18 years) who are bedwetting have an initial assessment that includes their bedwetting pattern, daytime symptoms, fluid intake, toileting pattern and any physical, social, emotional or developmental issues.

Statement 2. Children and young people (aged 5-18 years), and their parents and carers if appropriate, have a discussion about initial treatment with an alarm or desmopressin when bedwetting has not improved after changing their daily routine.

Statement 3. Children and young people (aged 5-18 years) whose bedwetting has not responded to treatment with an alarm or desmopressin or both are referred for a specialist paediatric continence review.

## Questions for consultation

### *Questions about the quality standard*

**Question 1** Does this draft quality standard accurately reflect the key areas for quality improvement?

**Question 2** If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures?

## Quality statement 1: Assessment

### ***Quality statement***

Children and young people (aged 5-18 years) who are bedwetting have an initial assessment that includes their bedwetting pattern, daytime symptoms, fluid intake, toileting pattern and any physical, social, emotional or developmental issues.

### ***Rationale***

There can be a number of factors that cause or contribute to bedwetting in children and young people. Physical, social, emotional and developmental issues should be explored to ensure that any resultant management plan is effective.

### ***Quality measures***

#### **Structure**

Evidence of local arrangements to ensure that initial assessments of bedwetting in children and young people (aged 5-18 years) include bedwetting pattern, daytime symptoms, fluid intake, toileting pattern and any physical, social, emotional or developmental issues.

***Data source:*** Local data collection.

#### **Process**

Proportion of children and young people (aged 5-18 years) who are bedwetting who have an initial assessment that includes their bedwetting pattern, daytime symptoms, fluid intake, toileting pattern and any physical, social, emotional or developmental issues.

Numerator – the number in the denominator who have an initial assessment that includes their bedwetting pattern, daytime symptoms, fluid intake, toileting pattern and any physical, social, emotional or developmental issues.

Denominator – the number of children and young people (aged 5-18 years) presenting for the first time with bedwetting.

**Data source:** Local data collection. Data on the recording of the assessment can be collected using the [NICE nocturnal enuresis audit support](#) (criterion 1 and 2).

### ***What the quality statement means for service providers, healthcare professionals and commissioners***

**Service providers** ensure that healthcare professionals undertaking initial assessments of bedwetting in children and young people (aged 5-18 years) explore bedwetting pattern, daytime symptoms, fluid intake, toileting pattern and physical, social, emotional or developmental issues.

**Healthcare professionals** undertake an initial assessment of children and young people (aged 5-18 years) who are bedwetting that includes their bedwetting pattern, daytime symptoms, fluid intake, toileting pattern and any physical, social, emotional or developmental issues.

**Commissioners** ensure that the services they commission provide guidance to healthcare professionals who are assessing bedwetting in children and young people (aged 5-18 years) on bedwetting pattern, daytime symptoms, fluid intake, toileting pattern and any physical, social, emotional or developmental issues.

### ***What the quality statement means for children, young people, parents and carers***

**Children and young people** who are bedwetting (and their parents or carers if appropriate) are asked questions to help work out what is happening and what might be causing it. This should include being asked about their bedwetting, intake of drinks, toilet use, urinary problems during the day and any other relevant problems they might have.

### ***Source guidance***

- Nocturnal enuresis (NICE clinical guideline 111), recommendations [1.3.1 to 1.3.6 and 1.3.9](#).

***Equality and diversity considerations***

Healthcare professionals should take into consideration the communication needs of children and young people and their parents and carers when carrying out assessments of children and young people with bedwetting.

Healthcare professionals should fully assess bedwetting in children and young people with developmental or learning difficulties as symptoms can be improved with the correct support and treatment.

The quality statement does not cover children under 5 years. Necessity of formally managing bedwetting in children under 5 years would be a clinical judgement, it would not be appropriate in all cases.

## Quality statement 2: Initial treatment

### ***Quality statement***

Children and young people (aged 5-18 years), and their parents and carers if appropriate, have a discussion about initial treatment with an alarm or desmopressin when bedwetting has not improved after changing their daily routine.

### ***Rationale***

Choice of initial treatment should take into account the preference of the child or young person, and their parents or carers if appropriate. Factors such as age, associated functional difficulties and disabilities, financial burdens and living situations may affect their preferences. This will ensure children, young people and their families and carers are able to access the full range of treatments and that the treatment chosen meets their individual needs.

### ***Quality measures***

#### **Structure**

Evidence of local arrangements to ensure that children and young people (aged 5-18 years), and their parents and carers if appropriate, have a discussion about initial treatment with an alarm or desmopressin when bedwetting has not improved after changing their daily routine.

***Data source:*** Local data collection

#### **Process**

Proportion of children and young people (aged 5-18 years) whose bedwetting has not improved after changing their daily routine who have a recorded discussion (including their parents and carers if appropriate) about initial treatment with an alarm or desmopressin.

Numerator – the number in the denominator who have a recorded discussion (including their parents and carers if appropriate) about initial treatment with an alarm or desmopressin.

Denominator – the number of children and young people (aged 5-18 years) whose bedwetting has not improved after changing their daily routine.

**Data source:** Local data collection.

### **Outcome**

Children, young people and their parents and carers are actively involved in decisions about their care.

**Data source:** Local data collection. [The NHS England GP Patient Survey](#) asks how good the GP was in involving people in decisions about their care (this is not specific to bedwetting in children and young people).

### ***What the quality statement means for service providers, healthcare professionals and commissioners***

**Service providers** ensure that systems are in place for healthcare professionals to discuss initial treatment with children and young people (aged 5-18 years), and their parents and carers if appropriate, when bedwetting has not responded to changes in their daily routine.

**Healthcare professionals** discuss initial treatment with children and young people (aged 5-18 years), and their parents and carers if appropriate, when bedwetting has not responded to changes in their daily routine.

**Commissioners** ensure that the services they commission have policies to discuss initial treatment with children and young people (aged 5-18 years), and their parents and carers if appropriate, when bedwetting has not responded to changes in their daily routine.

### ***What the quality statement means for children, young people, parents and carers***

**Children and young people** (aged 5-18 years) who have bedwetting that hasn't improved after changing their daily routine discuss with their healthcare professional (including their parents and carers if appropriate) about treatment with an alarm or medication.

## **Source guidance**

- Nocturnal enuresis (NICE clinical guideline 111), recommendations [1.4.5](#), [1.8.1](#) and [1.10.1](#).

## **Definitions**

### **General advice on daily routine**

Information and advice on fluid intake, toileting, lifting and waking and the use of reward systems. [Adapted from [NICE clinical guideline 111](#) recommendations 1.5 to 1.7]

### **Equality and diversity considerations**

When discussing initial treatment of bedwetting in children and young people with developmental or learning difficulties, it should be noted that symptoms can be improved with the correct support and treatment.

Both an alarm and desmopressin may be considered as first-line treatment for children and young people with learning difficulties and physical disabilities, tailored to their individual needs and abilities.

The quality statement does not cover children under 5 years. Necessity of formally managing bedwetting in children under 5 years would be a clinical judgement, it would not be appropriate in all cases.

## **Quality statement 3: Access to specialist paediatric continence review**

### ***Quality statement***

Children and young people (aged 5-18 years) whose bedwetting has not responded to treatment with an alarm or desmopressin or both are referred for a specialist paediatric continence review.

### ***Rationale***

When bedwetting in children and young people does not respond to treatment with an alarm or desmopressin or both, referral should be made for specialist paediatric continence review for assessment of factors that may be associated with a poor response, such as an overactive bladder, an underlying disease or social and emotional factors. These specialist services may help to reduce the number of inappropriate hospital referrals, which will benefit the child or young person and may reduce costs.

### ***Quality measures***

#### **Structure**

Evidence of local arrangements to ensure that children and young people with bedwetting that has not responded to treatment with an alarm or desmopressin or both can access services providing specialist paediatric continence review.

**Data source:** Local data collection.

#### **Process**

Proportion of children and young people (aged 5-18 years) whose bedwetting has not responded to treatment with an alarm or desmopressin or both who are referred for a specialist paediatric continence review.

Numerator – the number in the denominator referred for a specialist paediatric continence review.

Denominator – the number of children and young people (aged 5-18 years) whose bedwetting has not responded to treatment with an alarm or desmopressin or both.

**Data source:** Local data collection.

### **Outcome**

Reduction in inappropriate hospital referrals

**Data source:** Local data collection.

### ***What the quality statement means for service providers, health and social care practitioners and commissioners***

**Service providers** ensure that health and social care practitioners are aware of agreed referral pathways to access specialist paediatric continence review.

**Health and social care practitioners** refer children and young people who are bedwetting for specialist paediatric continence review if they do not respond to treatment with an alarm or desmopressin or both.

**Commissioners** ensure that they commission services to provide specialist paediatric continence reviews with agreed referral pathways from primary care.

### ***What the quality statement means for children, young people, parents and carers***

**Children and young people** who have bedwetting that doesn't improve with treatment using an alarm or medication or both are referred to a specialist in supporting children and young people who are bedwetting.

### **Source guidance**

- Nocturnal enuresis (NICE clinical guideline 111), recommendation [1.12.1](#).
- [Commissioning a paediatric continence service](#). NICE commissioning guide (2010).

## ***Definitions of terms used in this quality statement***

### **Paediatric continence service**

A paediatric continence service is delivered by professionals trained in the management of continence problems in children and young people. It may be based in primary, community or secondary care. It may be a dedicated paediatric service or integrated with adult continence services. [Adapted from [Commissioning a paediatric continence service](#), NICE Commissioning Guide (2010)]

### **Bedwetting that has not responded to treatment with an alarm or desmopressin or both**

It can be agreed that bedwetting is not responding to initial treatment as follows:

- The response to an alarm or desmopressin or both should be assessed at 4 weeks. If there are no early signs of response (smaller wet patches, fewer wetting episodes per night or fewer wet nights), treatment should be reviewed.
- Children and young people should continue treatment for 3 months if there are early signs of a response at 4 weeks. If complete dryness is not achieved after 3 months, treatment should be reviewed.
- Treatment with an alarm should only continue after 3 months if the bedwetting is still improving and the child or young person and parents or carers are motivated to continue. Bedwetting may continue to improve for up to 6 months with desmopressin.

[Adapted from [NICE Clinical Guideline 111](#), recommendations 1.8.2, 1.8.4, 1.10.6 and 1.10.11]

### ***Equality and diversity considerations***

When referring children and young people for a specialist paediatric continence review any potential difficulties in accessing services, which may include distance, disability and financial barriers, should be taken into account.

When discussing treatment for bedwetting in children and young people with developmental or learning difficulties, it should be noted that symptoms can be improved with the correct support and treatment.

The quality statement does not cover children under 5 years. Necessity of formally managing bedwetting in children under 5 years would be a clinical judgement, it would not be appropriate in all cases.

## Status of this quality standard

This is the draft quality standard released for consultation from 25 April to 27 May 2014. It is not NICE's final quality standard on nocturnal enuresis. The statements and measures presented in this document are provisional and may change after consultation with stakeholders.

Comments on the content of the draft standard must be submitted by 5pm on 27 May 2014. All eligible comments received during consultation will be reviewed by the Quality Standards Advisory Committee and the quality statements and measures will be refined in line with the Quality Standards Advisory Committee's considerations. The final quality standard will be available on the [NICE website](#) from September 2014.

## Using the quality standard

### *Quality measures*

The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of care in areas identified as needing quality improvement. They are not a new set of targets or mandatory indicators for performance management.

We have indicated if current national indicators exist that could be used to measure the quality statements. These include indicators developed by the Health and Social Care Information Centre through its [Indicators for Quality Improvement Programme](#). If there is no national indicator that could be used to measure a quality statement, the quality measure should form the basis for audit criteria developed and used locally.

See NICE's [What makes up a NICE quality standard?](#) for further information, including advice on using quality measures.

### *Levels of achievement*

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of

100% should be aspired to (or 0% if the quality statement states that something should not be done). However, NICE recognises that this may not always be appropriate in practice, taking account of safety, choice and professional judgement, and therefore desired levels of achievement should be defined locally.

### ***Using other national guidance and policy documents***

Other national guidance and current policy documents have been referenced during the development of this quality standard. It is important that the quality standard is considered alongside the documents listed in 'Development sources'

## **Diversity, equality and language**

During the development of this quality standard, equality issues have been considered and [equality assessments](#) are available.

Good communication between health and social care practitioners and children and young people who are bedwetting, and their parents or carers (if appropriate), is essential. Treatment, care and support, and the information given about it, should be both age-appropriate and culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. Children and young people who are bedwetting and their parents or carers (if appropriate) should have access to an interpreter or advocate if needed.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

## **Development sources**

Further explanation of the methodology used can be found in the quality standards [Process guide](#) on the NICE website.

## ***Evidence sources***

The documents below contain recommendations from NICE guidance or other NICE-accredited recommendations that were used by the Quality Standards Advisory Committee to develop the quality standard statements and measures.

- [Nocturnal enuresis](#). NICE clinical guideline 111 (2010)
- [Commissioning a paediatric continence service](#). NICE commissioning guide (2010).

## ***Policy context***

It is important that the quality standard is considered alongside current policy documents, including:

- Department of Health (2010) [National service framework for children, young people and maternity services – continence issues for a child with learning difficulties](#).
- Department of Health (2007) [National service framework for children, young people and maternity services – continence](#)
- Department of Health (2004) [National service framework for children, young people and maternity services: core document](#).

## **Related NICE quality standards**

### ***Published***

- [Urinary tract infection in infants, children and young people under 16](#). NICE quality standard 36 (2013).
- [Patient experience in adult NHS services](#). NICE quality standard 15 (2012).

### ***Future quality standards***

This quality standard has been developed in the context of all quality standards referred to NICE, including the following topics scheduled for future development:

- Child abuse and neglect.
- Constipation in children and young people.

## **Quality Standards Advisory Committee and NICE project team**

### ***Quality Standards Advisory Committee***

This quality standard has been developed by Quality Standards Advisory Committee 3. Membership of this committee is as follows:

#### **Dr Alastair Bradley**

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#### **Ms Jan Dawson**

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## **About this quality standard**

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

The methods and processes for developing NICE quality standards are described in the [quality standards process guide](#).

This quality standard will be incorporated into the NICE pathway for [nocturnal enuresis](#).

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ISBN: