NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Nocturnal enuresis

Date of Quality Standards Advisory Committee post-consultation meeting:
18 June 2014

2 Introduction

The draft quality standard for nocturnal enuresis was made available on the NICE website for a 4-week public consultation period between 25 April and 27 May 2014. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 10 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the Quality Standards Advisory Committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the Committee as part of the final meeting where the Committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the Committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the Committee should read this summary alongside the full set of consultation comments, which are provided in appendices 1 and 2.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

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

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

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

- The quality standard was generally well received and stakeholders felt it will help to address the challenges of supporting children and young people affected by this condition.
- Some stakeholders supported the lack of differentiation between an alarm and desmopressin treatment within the statements while others were concerned this is misleading and could result in negative consequences.
- There was some support for using the age group 5-18 years but a query about the unconventional format of including the age group in brackets within each statement.

- Some stakeholders suggested the quality standard should be more extensive and made specific suggestions for additional statements. There was particular concern that the current statements may not be sufficient to overcome the current barriers to accessing services such as waiting lists for alarms, shortages of appropriately trained staff and a lack of provision of specialist services in some areas.
- More specific definitions of the roles of different healthcare professionals are needed to ensure it is clear who is responsible for delivering on the quality improvement priorities.

Consultation comments on data collection

- There was general agreement that it should be possible to collect the data.
- Development work is ongoing to improve data collection nationally and to provide specific tools such as a new Quality of Life tool for childhood continence. This will support data collection for this quality standard.

5 Summary of consultation feedback by draft statement

5.1 Draft 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.

Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- Suggestion that statement wording should be extended to include family factors.
- Make it clearer that assessment should take into consideration other medications and associated conditions including autism.
- More emphasis needed in the statement itself that this includes those with a developmental or learning difficulty.
- Make it clearer that there can be safeguarding issues when assessing children and young people with nocturnal enuresis.

5.2 Draft 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.

Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

- Concern that it is not appropriate to promote treatment with an alarm or desmopressin for those aged 5 to 7 years.
- Suggest a timescale (e.g. 4 weeks) is needed for 'changing their daily routine'.
- Queried whether 'have a discussion about initial treatment' adequately captures the quality improvement priority for improving access to treatment. Would it be appropriate to re-phrase to a stronger statement such as 'Children and young people (aged 5-18 years) have the opportunity to be treated with either an alarm or desmopressin when bedwetting has not improved after changing their daily routine.'
- Need to ensure there is an exclusion from initial treatment for children or young people who suddenly develop bedwetting which may be a result of a physical problem that needs to be dealt with by a specialist.
- Consider including an outcome of 'reduced waiting lists for alarms.'
- Suggest audience descriptor for commissioners says 'Commissioners ensure sufficient alarms are available.'

5.3 Draft 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.

Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

- Statement wording should refer to appropriate time frames for ‘bedwetting that has not responded to treatment’ as children sometimes continue with treatment longer than they need to.
- Is a paediatric continence review appropriate for those aged over 16 years? Does this require re-wording?
- To support data collection it will be important to provide a good quality GP referral letter which provides details of management already undertaken.
- It needs to be clearer which staff will carry out the specialist paediatric continence review i.e. paediatric continence service.
- Definition for ‘Paediatric continence service’:
  - should be updated in line with recommendations in the updated Paediatric Continence Forum’s ‘Paediatric Continence Commissioning guide’ (draft until September).
  - should emphasise that staff need to be trained in paediatric continence, particularly if the service is integrated with adult continence services.
  - needs to be clear where these services are based. The current definition should be updated to include services based in a tertiary setting even though the Commissioning guide advocates a community based service.
- It would be better to recommend referral to specialist paediatric continence review (e.g. by appropriately trained school nurses) before first use of alarm or desmopressin in order to ensure these are not used inappropriately.

6 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

- Access to initial treatments within a suitable time frame (to avoid parents buying their own alarms).
- Separate statement for treatment for 5-7 year olds.
- Recording the outcome at the end of initial treatment.
- Opportunity for referral back to primary care if specialist continence review cannot add any further support.

Appendix 1: Quality standard consultation comments table

ID	Stakeholder	Statement No	Comments[1]
1	ERIC (Education and Resources for Improving Childhood Continence)	General	We welcome the draft Quality Standard as a means of improving the quality of care for children with continence problems. We like the lack of differentiation between the treatments alarm and desmopressin and the stipulation of the age group 5-18 years. We think that the guideline could be more extensive and find it disappointing that only 3 statements are available as we feel that many more could be generated from the NICE guideline. We would also like NICE to be aware that there are areas around the country where enuresis services are not being commissioned although we recognise that this is beyond the remit of this document.
2	Malem Medical Ltd	General	Changing the guidelines to offer alarms or anti-diuretic hormone 'Desmopressin' as first line therapy is misleading and does the patient and family/carers an injustice. The fundamental problem with this advice is that it implies the two therapies are largely equivalent with the choice of which one to use being more down to convenience than actual therapeutic outcomes. Alarms, as have been recognised for many years, are the curative therapy for nocturnal enuresis. The anti-diuretic hormone 'Desmopressin' is fundamentally different and is purely a symptomatic intervention. Through its actions as an anti-diuretic hormone, it temporarily prevents the patient from producing normal amounts of urine. This function ceases once the drug is no longer taken and the patient relapses into wetting again, unless they have naturally become dry in the meantime. There are 3 main problems with changing the advice to state either alarms or Desmopressin or both as first line. 1) The ultimate aim of any intervention in medicine is, or should be, to cure where possible. As it is well recognised, alarms are the superior intervention to achieve this fundamental goal and this should be clearly stated. Not to do so will serve an injustice for those patients who will be started on drugs inappropriately because it is not clearly outlined in the guidelines to their healthcare provider that the alarms are the safest, cheapest and most effective treatment for achieving long term dryness. 2) Advising patients that both alarms and the anti-diuretic hormone ‘Desmopressin’ can be used together is not sensible. Firstly, as it is in the patient's best interests to cure bedwetting as quickly as possible, using Desmopressin to prevent normal urine production will reduce the number of wet nights in some patients. In these patients the effectiveness of the alarm will suffer as its curative function depends on wetting and waking the patient. As is stated in the previous guidelines, alarms are undesirable if wetting is less than 2 wet beds per week, thus using Desmopressin at the same time will make this more likely. This change therefore at best offers no benefit to the patient and at worst is detrimental to achieving long term dryness and contradicts previous guideline advice. In addition, the anti-diuretic hormone

[1]PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

ID	Stakeholder	Statement No	Comments[1]
			'Desmopressin' has potential serious fluid retention side effects if fluid intake is not strictly monitored and restricted. There is no such requirement for alarms and as stated before, more wet nights (therefore no fluid intake restriction) is in fact related to faster results. This contradictory requirement of the two interventions could easily be a source of confusion for parents/carers and patients with potentially dangerous consequences. 3) The cost of prescribing the anti-diuretic hormone 'Desmopressin' first line to patients, who may have been cured of wetting by alarms if given first, is significant and should not be ignored. Desmopressin costs between £30-£90 a week. The majority of whom achieve no more than transient symptom relief and a return to wetting on cessation of therapy. In comparison alarms cost on average £40 per cured patient. The anti-diuretic hormone 'Desmopressin' should therefore only be given when absolutely necessary and not at an equivalent rate to alarms. These points highlight the serious problem in treating the two interventions as equivalent and equally appropriate first line interventions, which is the natural inference to make with these proposed guideline changes.
3	Malem Medical Ltd	General	In addition please provide an up to date declaration of interest in keeping with the guidance outlined in the NICE code of practice: conflict of interest policy December 2009.
4	Royal College of Paediatrics and Child Health	General	Thank you for inviting the Royal College of Paediatrics and Child Health to comment on the nocturnal enuresis consultation. We have not received any responses for this consultation.
5	British Association of Paediatric Urologists	General	This statement is aimed at initial assessment of the children with nocturnal enuresis in primary care setting. The opinion is provided on behalf of British Association of Paediatric Urologists which is organisation which primarily encompasses Paediatric Urologists involved in specialist service provision for refractory cases.
6	Department of Health	General	I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.
7	NHS Choices	General	The digital assessment service welcome the guidance and have no comments as part of the consultation
8	NHS England	General	Thank you for the opportunity to comment on the engagement exercise for the above Quality Standard. I wish to confirm that NHS England has no substantive comments to make regarding this consultation.
9	Paediatric Continence Forum	General	The Paediatric Continence Forum (PCF) welcomes the development of this quality standard for nocturnal enuresis in children and young people, which we hope we help address the significant challenges of supporting those children and young people affected by this condition. The PCF is a national group of patient representatives and healthcare professionals which campaigns for improved services for children with continence problems (bladder and bowel dysfunction). It was established in 2003, and works closely with the national charities ERIC (Education and Resources for Improving Childhood Continence) and PromoCon (Promoting Continence through Product Awareness) and with representation from the Royal College of Paediatrics and Child Health, the Royal College of Nursing and the Community Practitioners' and Health Visitors' Association. One of the key goals of the PCF is for every area in the UK to have a proper community-based integrated paediatric continence treatment service, led by an expert paediatric continence professional, with a clear system of referral and care pathways across primary and secondary NHS care, education and social services. There is evidence that clinical outcomes are higher when a service is integrated (Royal College of Physicians National Audit of Continence Care 2010). NICE states that an effective, integrated

ID	Stakeholder	Statement No	Comments[1]
			paediatric continence service could lead to up to an 80% reduction in the number of emergency admissions to secondary care (NICE Commissioning Guide 2010).
10	Royal College of Nursing	General	The Royal College of Nursing was invited to comment on the NICE quality standard for Nocturnal enuresis in children and young people. The document was circulated to RCN staff and nocturnal enuresis committee members for their views. Find below comments received from the reviewers.
11	Royal College of Nursing	General	Health visitor training should be mentioned in addition to the role of public health and school nursing etc especially as recent commentary in the press has indicated that parents are being blamed for their child's continence issues as they have been too busy to toilet train them. If this is indeed the case then a way should be found to track this information and it should be logged at health visitor visits and also within the early years in primary school etc in order that we can pull out this information. Only if we collect reasonable data do we ever have a chance of influencing change. Linked to this point, it would be helpful to include information on the area in which patients live when collecting data as this would then help at mapping against the existing data set and will determine what effect, is any, socioeconomic factors have.
12	Paediatric Continence Forum	Introduction	The PCF confirms that continence problems occur at a formative time for children, which influence their health, wellbeing, and emotional development. There is evidence that they are associated with emotional and behavioural problems, including a strong association with bullying, both as recipients and perpetrators. They can also affect children and young people at a crucial time during their emotional development and risking their exclusion from normal social interaction (e.g. school trips or sleepovers).
13	Paediatric Continence Forum	Question 1	The PCF is concerned about the lack of a specific definition as to who will deliver front line services. By using the generic terms “healthcare professionals” and “health and social care practitioners”, the roles for each potential appropriately trained health professional (GPs, health visitors, school nurses) are not defined. This may lead to one group of professionals relying on others to deliver enuresis services
14	Paediatric Continence Forum	Question 1	The PCF believes that this quality statement should be amended to emphasise that all children and young people, including with those with a developmental or learning difficulty, should have an initial assessment and review.
15	Paediatric Continence Forum	Question 1	While the PCF supports the clinical statements within the Quality Standards, we would like to highlight the current problems in putting these into practice. For example, from our experience, many areas have waiting lists for alarms; thus affecting treatment outcomes. Also, there could be more nurses who are trained to prescribe desmopressin and/or laxatives where required. We would like to see a stronger statement about the necessary availability of the above resources to enable “ children, young people and their families and carers to access the full range of treatments”
16	Paediatric Continence Forum	Question 2	The PCF would like to highlight that it is working with the Child and Maternal Health Observatory (CHIMAT), who are currently responsible for collecting data on hospital admissions for urinary tract infections and constipation in children. Our concern is that, as we currently understand, the system used to collect data is not sufficiently developed to collect data relating to A&E and outpatient appointments.
17	Paediatric Continence	Question 2	Evidence needs to be collected in a succinct way for the purpose and outcomes of the assessment, treatment plan,

ID	Stakeholder	Statement No	Comments[1]
	Forum		follow-up, discharge and any secondary or tertiary referrals. Also, data collection to support Key Outcome Indicators within PCF Commissioning Guide (section 1.4 Commissioning Guide), e.g. percentage of children and young people successfully treated within the service or post discharge.
18	British Association of Paediatric Urologists	Quality Statement 1	Support the statement. It does reflect the key area of improvement. Patients on other medications, associated illnesses including autism need to be taken into consideration. Data collection should be possible in primary care with appropriate structures in place.
19	Paediatric Continence Forum	Quality Statement 1	PCF believes that this quality statement should be amended to provide clarification on what type(s) of healthcare professionals will be providing the initial assessment and what training would need to be undertaken to ensure consistency nationally.
20	ERIC (Education and Resources for Improving Childhood Continence)	Quality Statement 1	We thought *family factors* along with physical, social, emotional or developmental issues should be included
21	ERIC (Education and Resources for Improving Childhood Continence)	Quality Statement 1	We feel it would be feasible to collect evidence of whether the issues in Statement 1 had been addressed
22	Royal College of Nursing	Quality Statement 1	The evaluation of the psychological aspects is important but I would like to know how this is measured or achieved. If it's a tick box to confirm that this has happened then this would raise concerns as people may tick the box when a psychological assessment hasn't actually taken place. It should also be noted that there can be issues around safeguarding when dealing with children and young people with nocturnal enuresis (NE) symptoms and it would be helpful if there was a flag to highlight if any children presenting with NE symptoms have been identified as triggering safeguarding issues.
23	Leeds Teaching Hospitals NHS Trust	Quality Statement 2	I am concerned that this statement promotes treatment with alarm or Desmopressin in children between the age of 5 and 7 years when it may not be appropriate. It should be qualified to indicate that such treatment will not usually be appropriate in this age range, particularly under 6.5 years. Use of alarms at a too young age prejudice future successful use of alarms later. Evidence supporting routine use of Desmopressin in this age range is lacking.
24	British Association of Paediatric Urologists	Quality Statement 2	Agree with the statement. It reflects area of improvement. Data collection possible in primary care
25	Paediatric Continence Forum	Quality Statement 2	The PCF recommends that greater clarity is provided on which healthcare professionals will discuss initial treatment with children and young people, and their parents and carers if appropriate. It is not very clear that the Initial Treatment is carried out in the community by the school nurse, health visitor, GP and that the next stage "Access to specialist continence review" is carried out by the paediatric continence service
26	ERIC (Education and Resources for Improving Childhood Continence)	Quality Statement 2	Should a time frame be attached to the intervention of altering daily routine ? e.g. 4 weeks
27	ERIC (Education and	Quality	We feel it is feasible to collect this evidence

ID	Stakeholder	Statement No	Comments[1]
	Resources for Improving Childhood Continence)	Statement 2	
28	Leeds Teaching Hospitals NHS Trust	Quality Statement 3	It would be better to recommend proper specialist paediatric continence review (e.g. by appropriately trained school nurses) before first use of alarm or Desmopressin. Otherwise these may be used inappropriately.
29	British Association of Paediatric Urologists	Quality Statement 3	Support the outcome of decreasing unnecessary referral to specialist services. Suggest including patients with associated daytime symptoms who are refractory to conservative management. Data collection and audit is possible and will need good quality GP referral letter which provides details of management already undertaken. If the review does not add any further help, consideration should be given for pathways for referral back to continence services in primary care if available.
30	Paediatric Continence Forum	Quality Statement 3	In response to evidence that paediatric continence services are not being properly commissioned, the PCF has written a Commissioning Guide for Paediatric Continence, which is currently being considered for “fast track” accreditation by NICE.
31	Paediatric Continence Forum	Quality Statement 3	The PCF believes that it should be stated that an integrated paediatric continence service, led by a nurse who is a trained paediatric continence nurse specialist, should ideally be community-based and comprised of a multi-disciplinary team (as in the recommendations within PCF’s Paediatric Continence Commissioning Guide, which is available on in draft format on the PCF’s website – available at www.paediatriccontinenceforum.org/resources). Regarding the Definitions of Terms, the document states that “it may be a dedicated paediatric continence service, or integrated with adult continence services” We suggest that in the latter situation it should be made clear that the paediatric continence element of the combined service should comprise a practitioner team that is paediatric trained.
32	Paediatric Continence Forum	Quality Statement 3	The PCF recommends that this quality statement be amended to provide a timescale for non-response to treatment before making a referral to the Paediatric Continence Service. The PCF understands that it is sometimes the case that children often continue with treatment longer than they have to in hope that their condition will improve.
33	ERIC (Education and Resources for Improving Childhood Continence)	Quality Statement 3	We feel that a time frame needs to be inserted here along the lines of “Children and young people (aged 5-18 years) whose bedwetting has not responded to treatment with an alarm or desmopressin or both *within the time frames recommended by NICE guideline 111* should be referred to a specialist paediatric continence review. (the treatment algorithms for alarm and desmopressin use are the timelines we are referring to).
34	ERIC (Education and Resources for Improving Childhood Continence)	Quality Statement 3	We do not think that the definition of a paediatric continence service should stipulate primary secondary or community as sometimes this service is found in a tertiary setting and a child should not be denied access just because of this. Many community paediatricians who run enuresis services are now based in hospitals. We also feel strongly that the service should be run by “health professionals trained in paediatric continence.” Whilst some *adult* continence advisers are also trained in paediatrics often they are not.
35	ERIC (Education and Resources for Improving Childhood Continence)	Quality Statement 3	It is feasible to measure this outcome
36	Royal College of Nursing	Quality	Children's continence services are not available across all areas. In addition more clarity on training would be

ID	Stakeholder	Statement No	Comments[1]
		Statement 3	helpful. It is assumed that hospital systems will have to capture the NE patients that attend but would query whether this includes those with day time symptoms as well when the primary issue for the family is NE.
37	Royal College of Nursing	Quality Statement 3	If there is a referral to a specialist service then it should be identified where these are i.e. within the community or at a children's hospital etc. It would be helpful to be able to track those that end up seeing paediatricians, and urologists etc - there should be easy access to these outputs and regionally identified traffic lights or flags so it is possible to see the areas a service is struggling with.
38	ERIC (Education and Resources for Improving Childhood Continence)	Additional area of improvement	We feel that the following statement should be added with regards to quality improvement: a. a. Children and young people (aged 5-18 years), and their parents and carers if appropriate, who have had a discussion about initial treatment with an alarm or desmopressin should have access to their treatment of choice within a suitable time frame thereafter. We are aware that many areas do not have access to enuresis alarms and parents are having to buy these themselves. This is easily measured.
39	ERIC (Education and Resources for Improving Childhood Continence)	Additional area of improvement	We feel that the following statement should be added with regards to quality improvement: b. Children and young people who have used an initial treatment should have the outcome/results recorded at the end of treatment. This is easily measured.

Stakeholders who submitted comments at consultation

- British Association of Paediatric Urologists
- Department of Health
- ERIC (Education and Resources for Improving Childhood Continence)
- Leeds Teaching Hospitals NHS Trust
- Malem Medical Ltd
- NHS Choices
- NHS England
- Paediatric Continence Forum
- Royal College of Nursing
- Royal College of Paediatrics and Child Health