National Institute for Health and Clinical Excellence
Nocturnal Enuresis
Draft Guideline Consultation Table
11 March 2010 – 6 May 2010

Type	*Stakeholder*	*Order No*	*Document*	*Page no.*	*Line no.*	*Comment*	*Response*
SH	Association for Family Therapy and Systemic Practice (AFT)	1	Full	General		AFT members work in physical and mental health services and social care, and in the voluntary sector. Some members are employed as UKCP Registered Family Therapists, whilst others will use family therapy within their roles as psychologists, psychiatrists, social workers, nurses, etc. Those working with children and young people with enuresis will be those who have complex problems that benefit from family therapy. Details on such work can be found in *Current practice, future possibilities* (2009), www.aft.org.uk .	Thank you for your comment and for this information.
SH	Association for Family Therapy and Systemic Practice (AFT)	2	Full	56	2.10.5	Research on the effectiveness of family therapy and enuresis should be considered. There is evidence that family therapy is effective for treatment for many emotional and relationship problems that are associated with enuresis. There is evidence of cost effectiveness. Information can be found on the website: www.aft.org.uk - Peter Stratton (2005): *Report on the*	Many thanks for your comment. We have reviewed the suggested studies, and these do not match our inclusion criteria. The first study is a literature review, and the second study does not have a population with nocturnal enuresis.

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						evidence base of systemic family therapy. Carr, A (2009a) The effectiveness of family therapy and systemic interventions for child-focused problems. *Journal of Family Therapy.* 31. 3-45. Crane D.R. & Christenson, J.D. (2008) The Medical Offset Effect: Patterns in Outpatient Services Reduction for High Utilizers of Health Care. Contemporary Family Therapy. 30: 217-138	
SH	Association for Family Therapy and Systemic Practice (AFT)	3	NICE			Suggest research on the effectiveness of psychological therapies is included.	Thank you for your comment. There is a research recommendation on the effectiveness of psychological therapies. This is in the Full guideline. NICE limits the number of research recommendations included in the NICE version of the guideline.
SH	Association of Child Psychotherapists	1	NICE	3		Second paragraph: Emphasis here is on possible disturbance in physiology. There is no reference to the possibility of psychological /	Thank you for your comment. The introduction is not providing a comprehensive review of predisposing factors and associated factors or conditions. These are

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						emotional factors that may account for the disturbance.	discussed in the Full guideline.
SH	Association of Child Psychotherapists	2	NICE	General		It would be helpful if the authors made more apparent the distinction between delay (i.e., within the extremes of typical functioning) and disorder (i.e., outside the extremes of typical functioning).	Thank you for your comment. The distinction between delay and disorder does not influence which treatments should be tried. A discussion of epidemiology is included in Full guideline.
SH	Association of Child Psychotherapists	3	NICE	5		First paragraph: Include ‘treatment and care’ rather than just ‘care’.	Thank you for your comment. This is a standard section written by NICE. We will inform them of your comment.
SH	Association of Child Psychotherapists	4	NICE	9	1.1.1	We agree wholeheartedly that the condition should not be viewed as the child’s fault and punitive methods should not be used by the parents/carers. It might be helpful if the paediatrician could empathise with the frustration felt by parents / carers and how this may lead them to behave unreasonably, but managing this is an important aspect of whatever intervention is	Thank you for your comment. The GDG agreed that attention to the frustration and potential emotional difficulties is important and have included a number of recommendation which emphasise support and attention to the difficulties of parents and carers e.g. recommendation 1.1.2 recommends support, assessment and treatment

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						recommended. Should the children / carers also be informed that there are a number of possible factors that may contribute to the difficulty? Parents / carers are likely to require a period of ongoing support if they have adopted punitive methods in the past, especially if the bedwetting has been long term. This is best provided by a professional who can help the parents / carers think about the impact on them and the child (e.g., Child Psychotherapist or Child Psychologist).	to children and families. Recommendation 1.4.1 recommends explaining the condition to the child and family. The GDG considered that they did not want to be prescriptive about this as it will need to be individualised for each patient. Recommendation 1.2.2 recommends information about support groups where further information is available. The GDG were not convinced that ongoing support would have to be provided by a child psychologist or psychotherapist. They considered that many children and young people with bedwetting are managed by school nurses and other specialist nursing staff in community settings. The GDG considered that these staff can provide support for most children. A recommendation is included (1.3.15) to consider referral to a professional with psychological expertise for children with

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							bedwetting and emotional/behavioural problems.
SH	Association of Child Psychotherapists	5	NICE	9	1.2	Would it not be important to ascertain whether or not there is a history of this kind of difficulty in any of the other family members?	Thank you for your comment. There is no evidence that family history predicts response to treatment or choice of treatment.
SH	Association of Child Psychotherapists	6	NICE	11	1.2.1 4	With younger children might it not be important to involve a Child Psychotherapist or Child Psychologist who would be practiced in communicating with them? It also seems important to acknowledge that in some cases the investigation of the child's view may require more than one consultation.	Thank you for your comment. The GDG did not consider that a child psychotherapist or psychologist would be required to communicate with the majority of children.
SH	Association of Child Psychotherapists	7	NICE	Gene ral		Reference is made to the possible involvement of emotional triggers (e.g., 1.2.2 and 1.2.9), which suggests that bedwetting may be understood as a symptom of an underlying familial / emotional /	Thank you for your comment. There is a recommendation to consider referral to a professional with psychological expertise (recommendation 1.3.15 of final draft).

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						psychological problem, but there are no recommendations for psychological intervention / treatment.	
SH	Association of Child Psychotherapists	8	NICE	15	1.3.9	This statement seems to take for granted that there is a physiological disturbance underling the condition. If a physiological disturbance is determined then it seems appropriate to consider alarm or pharmacological therapy. If the underlying cause is uncertain it would suggest the need for a broader assessment that includes the child's state of mind by a professional qualified to do this.	Thank you for your comment. The evidence indicates that precise identification of cause is not necessarily required; children with secondary enuresis for example respond to standard treatments. There is a separate recommendation to consider referral to a health professional with professional expertise for children with emotional or behavioural problems.
SH	Association of Child Psychotherapists	9	NICE	15	1.3.1 0	To consider the likelihood child maltreatment is important. The three criteria listed are clear. Might it not be important to mention that there may be less obvious signs that could point to the possibility of	Thank you for your comment. This recommendation is from the NICE guideline on 'When to consider maltreatment' . That guideline also includes recommendation concerning aspects of parent/carer-child communication.

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						maltreatment, as for instance poor communication between child and carer? Might it not be important to support the paediatrician in coming to a decision to allow them to draw on their own sense that something does not seem right when they consult to the family and thus request a state of mind assessment from a Child Psychotherapist / Child Psychologist / Child Psychiatrist?	
SH	Association of Child Psychotherapists	10	NICE	17	1.6.5	This statement requires further explanation. It seems reasonable not to use psychotherapy as a specific treatment for bedwetting IF physiological factors have been identified or are implicated. However if investigations indicate no physiological / medical basis to the condition it seems entirely appropriate that the child and family are offered psychotherapy to consider not only the impact of the	Thank you for your comment. We have removed this recommendation. There was no evidence that psychotherapy is beneficial in management of bedwetting. However following stakeholder comments the GDG considered the recommendation too negative.

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						condition but also the possible psychological / emotional factors that may be involved.	
SH	Association of Child Psychotherapists	11	NICE	19	1.7.10	Before advising parents / carers to use ‘positive rewards for desirable behaviour’ it should be acknowledged how frustrating and exhausting bedwetting is for the child and themselves and that they should be encouraged to adopt a more tolerant attitude to support the child feel less ashamed or incompetent or whatever negative evaluation they may be making about themselves. ‘Positive rewards for desirable behaviour’ may manifest as material rewards, but more importantly will include parent / carer praise. Some parents / carers require guidance from mental health professionals as to how to use reward systems in a consistent and fruitful way.	Thank you for your comment. There are a number of recommendations which advise health care professionals to assess the support needs of the family and consider how they are coping with the burden of bedwetting.

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SH	Association of Child Psychotherapists	12	NICE	General		There is no reference about how to deal with the wet bed wear, sheets and bed following a bed wetting incident. The sorting out of clean bed wear, sheets so that sleep can be resumed; the cleaning of soiled bed wear and sheets in the morning. The point being that the attitude of tolerance by the parents / carers must be maintained throughout the intervention, whether it be alarm or pharmacological.	Thank you for your comment. The GDG did not consider it appropriate to provide specific recommendations on dealing with wet bed etc as this is likely to vary from family to family. Guidance is contained in recommendations 1.2.2 and 1.2.3.on information and support groups and practical ways to manage bedwetting.
SH	Association of Child Psychotherapists	13	APPENDIX C			There is no reference in the algorithms to psychological involvement either in terms of further assessment or intervention (whether supportive or primary).	Thank you for your comment. The algorithms are not intended to include all aspects of assessment and interventions. Several aspects of management are not included. Following consultation process we have retained the algorithim on use of drugs and/or pharmacological intervention only. All aspects of care will be included in the Quick Reference Guide which is developed from all the recommendations..

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SH	Citizens Commission on Human Rights	1	NICE	General		CCHR is grateful for the opportunity to respond and would comment generally as follows. It is acknowledged that enuresis can be disruptive and cause negative emotional reactions, it is most often a situation which needs handling over a period of time. However, it is a condition that, in the majority, improves over time without any intervention, i.e. in particular children generally grow out of it. Therefore, we would wish to encourage an approach which favours re-training, encouragement and support, rather than medication. Full disclosure of the contraindications of any medication proposed, specifically to be included in the guideline.	Thank you for your comment.
SH	Citizens Commission on Human Rights	2	NICE	14	1.3.2	We respectfully request that additional wording be added: 'Explain the aims of the treatment to the child and parents or carers and openly discuss the pros and cons of proposed treatment, including full disclosure of the potential side effects and withdrawal symptoms of	Thank you for your comment. The GDG have included specific points about the drugs recommended including overdose for tricyclic medication. They did not consider it necessary to change the wording of the recommendation.

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						any proposed medication.' The following is also offered in support; Cochrane Database Systematic Review 2003;(3):CD002117. 'Tricyclic and related drugs for nocturnal enuresis in children.' Glazener CM, Evans JH, Peto RE. 'Although tricyclics and desmopressin and effective in reducing the number of wet nights while taking the drugs, most children relapse after stopping active treatment. In contrast, only half the children relapse after alarm treatment. Parents should be warned of the potentially serious side effects of tricyclic overdose when choosing treatment.	
SH	Citizens Commission on Human Rights	3	NICE	18	1.7.2	Reference 'the parents of carers are having difficulty coping with the burden of bedwetting'. CCHR would comment. The use of washable incontinence products has been successfully utilised in immediately reducing the knock-on	Thank you for your comment. We have included guidance on these issues which can be found in recommendations 1.2.2 and 1.2.3.

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						effects. This can, and has, been used in conjunction with an alarm option – either using the incontinence pants over underwear, or directly on the body. This would give an immediate, temporary alleviation whilst due consideration can be given fully.	
SH	Citizens Commission on Human Rights	4	NICE	24	1.10	The use of anticholinergics is wholly undesirable owing to their adverse side effects and withdrawal symptoms. Full disclosure to the patients/parents should be made to ensure that patients' rights are protected in terms of 'informed consent'. The following is given in support; 'Managing Anticholinergic Side Effects.' Joseph A. Lieberman, III, M.D.,M.P.H.Prim Care Companion J Clin Psychiatry.2004; 6(suppl 2): 20-23. 'Anticholinergic side effects can cause physical as well as mental impairment. While the peripheral side effects may not all appear serious, physicians should be wary	Thank you for your comment. Anticholinergics are recommended only for children not responding to other treatments.

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						because these side effects can lead to a plethora of medical complications. Complications can range fro ulceration of the gums and respiratory problems to hyperthermia and myocardial infarction.'	
SH	Citizens Commission on Human Rights	5	NICE	25	1.11	The use of Tricyclic Antidepressants, and specifically Imipramine is wholly undesirable owing to their adverse side effects and withdrawal symptoms. Full disclosure to the patients/parents should be made to ensure that patients' rights are protected in terms of 'informed consent'. The following is given in support; 'Evidence based management of nocturnal enuresis'. Jonathan HC Evans, consultant paediatric nephrologist BMJ.2001 November 17;323(7322):1167-1169. 'Imipramine has high frequency of serious adverse effects and should be used with great caution.'	Thank you for your comment. These drugs are recommended when children have not responded to other treatments and when children are assessed by specialists.
SH	Department of Health	1	Full	Gene ral		the Department of Health has no substantive comments to make, regarding this consultation.	Thank you for your comment.

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SH	Diabetes UK	1	Full	16	23	**Recommendation 1.2.8**: Please find below information relating to testing for diabetes, for consideration. The NICE Type 1 diabetes guideline (1) recommends that diagnosis is made in accordance with the WHO guidance (2) and criteria. The ISPAD guidelines (3) state "Diagnostic criteria for diabetes are based on blood glucose measurements **and** the presence or absence of symptoms….the diagnosis is usually confirmed quickly by measurement of a marked elevation of the blood glucose level." 1. www.nice.org.uk/cg15 2.http://whqlibdoc.who.int/publications/2006/9241594934_eng.pdf 3. Craig,M.E. Hattersley, A et al ISPAD Clinical Practice Consensus Guidelines 2009 Compendium: Definition, epidemiology and classification of diabetes in children and adolescents	Many thanks for your comment. IN the recommendations we have highlighted the importance of ruling out other comorbidities: "Assess whether the child has comorbidities or there are other factors to consider, in particular (..)diabetes mellitus" We have also added the following recommendation from the Type 1 diabetes guideline: *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*

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						Pediatric Diabetes 2009: 10(Suppl. 12): 3–12	*confirm diagnosis and to provide immediate care.*
SH	Diabetes UK	2	Full	16	23	**Recommendation 1.2.8**: Diabetes UK is aware of delays to, and the misdiagnosing of, Type 1 diabetes which can lead to potentially fatal complications such as DKA. Information in the NSF for Diabetes recommends education for health professionals to support early recognition of the condition, as a key intervention. To support these aims it would be useful for the guidance document to contain an appendix/ sign post to information about the symptoms and history that would indicate possible Type 1 diabetes. This would support practitioners using these guidelines and increase awareness of the signs	Many thanks for your comment. We have added the following recommendation from the Type 1 diabetes guideline: *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.* The NICE Type I diabetes guideline is also referenced in the guideline.

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						and symptoms of Type 1 diabetes. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4902159	
SH	ERIC	1	NICE	7	1.4.7	'Abnormal fluid intake' -this statement does not clearly identify what is normal or abnormal	Thank you for your comment. We have changed the recommendation to 'insufficient or excessive' fluid intake.
SH	ERIC	2	NICE	7	1.6.1	'Good levels of fluid' this statement does not clearly identify what a good level of fluid is	Thank you for your comment. We have changed this to 'recommended' levels of fluid.
SH	ERIC	3	NICE	7	1.8.1	An explanation that desmopressin does not work for all and does not induce improvement in bedwetting for all children needs to be included.	Thank you for your comments. These points are included in a further recommendation (1.9.10 in final draft)
SH	ERIC	4	NICE	7	1.9.1 2	'Specialist expertise in the management of bedwetting' – there is no explanation to identify to whom referrals from primary care should be made for this level of specialist intervention as this role is not clearly	Thank you for your comment. We have altered this phrase and indicated what we consider the health professional should do rather than who they are or the area of expertise we think they need. The

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						identified. This term is used throughout the documents but it is not clarified anywhere.	particular professional able to carry out the appropriate assessments or prescribing will vary according to local service configuration of services.
SH	ERIC	5	NICE	9	1.2.3	'Large volume of urine' is an unclear term, and needs to be clarified	Thank you for your comment. The GDG reviewed the wording of this recommendation and considered that health professionals would understand what is meant by 'volume' of urine. The term is not meant to be very precise but to distinguish a bed that is completely soaked from a small wet patch. We have changed wording of recommendation to clarify this.
SH	ERIC	6	NICE	9	1.2.3	'What times of the night does bedwetting occur'? This may be very difficult for a parent to determine.	Thank you for your comment. The GDG reviewed the wording of this recommendation and although acknowledged that some parents may find this difficult to answer it remained an important question to consider.
SH	ERIC	7	NICE	10	1.2.7	It would be useful to specify how long records should be taken. Current recommendations are for 4	Thank you for your comment. The GDG did not think it was possible to specify periods of time as these

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						days however it is not unknown for parents to be asked to keep records for a very long time e.g. 1-2 months with no clinical need. See also page 3 below for statement form parent re record taking.	would vary according to the particular symptoms the child had. We have added more information about this to the Full guideline
SH	ERIC	8	NICE	11	1.2.10	'Severe daytime symptoms' this statement does not identify what this means	Thank young for your comment. Daytime symptoms is defined both in the glossary to the Full guideline and in the section 'Guidance'. We reviewed the wording with the GDG who considered it would be understood by health professionals working in this area.
SH	ERIC	9	NICE	11	1.2.13	'Daytime symptoms predominate' this statement does not identify what this means	Thank you for your comment. The GDG reviewed the wording and considered that this statement would be understood by health care professionals seeing children with bedwetting.
SH	ERIC	10	NICE	11	1.12.14	What the child thinks is the problem and whether child thinks problem requires treatment – unsure what this means or seeks to determine	Thank you for your comment. The GDG considered that the child's view of the problem and the need for treatment is important. Use of rewards, drugs and alarms all require active involvement of child.

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SH	ERIC	11	NICE	14	1.3.7	Include an explanation of why bedwetting occurs for children, parents and carers. An understanding of the reasons why it occurs is fundamental for achieving a successful treatment outcome	Thank you for your comment. The GDG considered this was covered in recommendation 1.4.1
SH	ERIC	12	NICE	15	1.3.7	Add an explanation that medication does not work for every child	Thank you for your comment. This is a general recommendation and this information is included in the separate recommendations the medicines recommended in the guideline.
SH	ERIC	13	NICE	15	1.3.8	Parents often have concerns about whether pull ups or nappies at night will have an adverse effect. A statement to clarify this would be useful	Thank you for your comment. The GDG reviewed the wording and considered that pull ups are included as 'washable and disposable products.' They did not consider a separate recommendation appropriate.
SH	ERIC	14	NICE	16	1.4.1	'Adequate daily fluid intake' needs clarification. It would also be useful to explain why fluid intake is important	Thank you for your comment. We have changed the wording of the recommendation.
SH	ERIC	15	NICE	16	1.4.3	There is no explanation of why to avoid these drinks A suggestion that if a drink is suspected as having an effect it should be withdrawn to see if	Thank you for your comment. A recommendation does not normally provide an explanation. The recommendation has been changed

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						makes a difference and if not the drink can be reinstated could be helpful.	to refer to caffeine based drinks only. The GDG considered there are physiological reasons why these are detrimental for children with bedwetting.
SH	ERIC	16	NICE	16-17	1.5.2	Bullet points one and two and three appear to contradict each other – they need clarifying	Thank you for your comment. We have altered the wording of this recommendation to improve clarity.
SH	ERIC	17	NICE	17	1.6.1	'good levels of fluid' needs clarification	Thank you for your comment. We have altered the recommendations on fluid intake to improve clarity.
SH	ERIC	18	NICE	17	1.6.2	It is difficult to understand what this statement means. E.g. why would a child get a reward for incorrect behaviour or bedwetting?	Thank you for your comment. The wording of this recommendation was unclear and we have removed the end of this sentence for clarity.
SH	ERIC	19	NICE	17	1.6.3	This contradicts 1.6.1.	Thank you for your comment. The wording of the recommendation to indicate that this reward systems alone rather than in conjunction with other treatments should be used for young children.
SH	ERIC	20	NICE	18	1.7.2	'burden of bedwetting' this needs clarifying e.g. does this statement mean finding it difficult to cope emotionally or financially or dealing with the daily washing requirements etc	Thank you for your comment. We have changed this to clarify emotional difficulty.

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SH	ERIC	21	NICE	18	1.7.3	This contradicts 1.7.19	Thank you for your comment. The GDG considered it important to include a specific recommendation to inform parents that dry nights may be a late sign of response.
SH	ERIC	22	NICE	18	1.7.5	Assessment of 'how' the child and parent are using the alarm would be useful at this point	Thank you for your comment. We have added to this recommendation the necessity of considering motivation of child and parent/carer if continuing alarm. The GDG considered that assessment of how the alarm is being used is covered by the recommendations to provide adequate support when and advice when starting to use an alarm.
SH	ERIC	23	NICE	19	1.7.15	'Recognise the need to pass urine' the words 'when asleep' need to be added for clarification	Thank you for your comment. The GDG considered the wording you suggested and considered that adding 'when asleep' was not required.
SH	ERIC	24	NICE	20	1.7.19	Contradicts 1.7.3	Thank you for your comment. The GDG reviewed the wording of these recommendations and did not consider they contradicted each other.

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SH	ERIC	25	NICE	22	1.9	Clarify how long 'initial treatment' is before offering combination treatment bearing in mind 1.7.19	Thank you for your comment. Initial treatment will vary according as to whether this is alarm or desmopressin e.g. non-response to alarm would be evidence at 4 weeks.
SH	ERIC	26	NICE	24	1.9.1 2 /1.10. 1	Health care professional with specialist expertise – clarify what this means	Thank you for your comment. We have altered the recommendations to indicate that professionals should have expertise in treating children who have non responded to alarms and desmopressin. Who this will be will vary from area to area.
SH	ERIC	27	NICE	25	1.11. 4	Increase dose gradually (bullet point 4) needs to be clarified especially when followed by the overdose implications (bullet point 6)	Thank you for your comment. The GDG considered that health professionals prescribing imipramine would be aware of correct dosages.
SH	ERIC	28	NICE	26	1.15. 2	This should also involve an element of support as well as 'advice' - as parents who have not been able to potty train a child by age 5 may be having some difficulties.	Thank you for your comment. We have added another recommendation to highlight the need to explore why toilet training may not have been undertaken and any needs for support.
SH	ERIC	29	NICE	27	1.15. 3	Tailor the trial ….. to the success of the trial (bullet point 2) needs clarification	Thank you for your comment. We have altered the wording of this recommendation to clarify the meaning.

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SH	ERIC	30	NICE	27	1.15.3	Length of time being dry – needs clarification – perhaps add the words ' in the day'	Thank you for your comment. We have altered the wording of this recommendation.
SH	ERIC	31	NICE	27	1.15.6	Also a common cause of daytime wetting	Thank you for your comment. Daytime wetting is outside the scope of the guideline.
SH	ERIC	32	NICE	39		Very confusing algorithm – hard to understand	Thank you for your comment. The NICE editorial team will produce a Quick Reference Guide for use by health professionals.
SH	ERIC	33	NICE	40		Management algorithm not easy to follow	Thank you for your comment. The NICE editorial team will produce a Quick Reference Guide for use by health professionals.
SH	ERIC	34	NICE	40		There is no indication as to what happens to the child that does not have a response. There appears to be no indication of follow up or further support. This would create stress for families. There is also no indication of at which point families should be referred to the 'specialist health care professionals', who they are and what support /advice can be expected. Page 43 of Full guideline states 'management advice ….. who do not	Thank you for your comment. We have clarified the recommendation about referral of children who do not respond and indicated that they are likely to need review of bladder function/social and emotional factors and underlying disease. We found no evidence to specifically guide healthcare professionals for this group of patients.

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						respond to treatment' but does not suggest what this may involve.	
SH	ERIC	35	Full	22	9	Minimum fluid intake suggestion – it's not clear from where this figure is derived. There is also no maximum fluid intake suggested which could be potentially difficult	Many thanks for your comment. This recommendation has now been revised for clarification. The GDG considered the information provided by government bodies and experts and the most comprehensive source of information on water requirements is: Dietary reference intakes for water, potassium, sodium, chloride, and sulphate. Panel on Dietary Reference Intakes for Electrolytes and Water Standing Committee on the Scientific Evaluation of Dietary Reference Intakes Food and Nutrition Board. Institute of Medicine (U.S). 2004.
SH	ERIC	36	Full	22	10	Sugar and caffeine based drinks. It is unclear from where advice this derives. This is referred to on page 179 line 12. It may be helpful to suggest that if it is suspected that these types of drinks have an effect they are withdrawn for a period and	This recommendation has been revised for clarification. The GDGs view was it was important recommendation, and particularly useful to reiterate the message that these type of drinks not helpful in general as they are also diuretic.

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						if their withdrawal does not cause any change they may be reinstated.	
SH	ERIC	37	Full	22	19	Abnormal fluid intake – it is unclear what this statement means.	Many thanks for your comment. This recommendation has now been revised for clarification.
SH	ERIC	38	Full	23	4	It is unclear what the term 'older' means	The GDG used this term as a proxy to establish maturity. However, the GDG's view was that clinical judgement would be required to identify those children that would benefit or not from the intervention.
SH	ERIC	39	Full	23	12	It is unclear what the term good levels of fluid means	Many thanks for your comment. This recommendation has now been revised for clarification.
SH	ERIC	40	Full	23	19	The term 'younger children' needs clarifying.	The GDG used this term as a proxy to establish maturity. However, the GDG's view was that clinical judgement would be required to identify those children that would benefit from the intervention
SH	ERIC	41	Full	30	8	It is unclear who the specialist expertise in bedwetting may be.	Thank you for your comment. We have changed these recommendations to indicate what is required in these situation rather than who the person should be as

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							configuration of services will vary in different areas.
SH	ERIC	42	Full	33	12	'Tailor trial to …success of trial .' this needs clarifying	Thank you for your comment. This recommendation has been revised in light of stakeholder comments and for further clarity.
SH	ERIC	43	Full	33	13	'Length of time being dry .' need to clarify eg dry during day or night or both	Thank you for your comment. This recommendation has been revised in light of stakeholder comments and for further clarity.
SH	ERIC	44	Full	178	6	Minimum fluid intake suggestion – it's not clear from where this figure is derived. There is also no maximum fluid intake suggested which could be potentially difficult	Many thanks for your comment. This recommendation has now been revised for clarification.
SH	ERIC	45	Full	199	11	Clarify term 'older child'	The GDG used this term as a proxy to establish maturity. However, the GDG's view was that clinical judgement would be required to identify those children that would benefit or not from the intervention.
SH	ERIC	46	Full	833	13	This paragraph appears to suggest that for many children bedwetting occurs because children have not been successfully toilet trained.	Thank you for your comment. The experience of the GDG was that they do see children in this age group who have not been toilet trained. We have removed the term 'many' and

Type	*Stakeholder*	*Order No*	*Document*	*Page no.*	*Line no.*	*Comment*	*Response*
							changed to 'some' as this is a better reflection of GDG opinion.
SH	ERIC	47	Full	836	4	Insert word 'up'	This has been added.
SH	Ferring Pharmaceuticals Ltd	1	Full	General	General	In general, Ferring welcome these guidelines but feel that there is useful and relevant information in the full guidance that is missing from, or not adequately covered in the summary. More care should be taken to ensure that the summary fully reflects the main body of text. We feel that the summary of the document is weighted towards the use of the alarm as a first-line therapy. This is not reflective of current clinical practice or physiologically guided treatment. The table on pg 18 (of the full guidelines) seeks to identify a patient history in order to tailor the therapy appropriately; this should be reflected in the summary.	Thank you for your comment. The GDG considered that where possible alarms should be first line therapy and the recommendations are therefore worded in this way.

Type	Stakeholder	Order No	Document	Page no.	Line no.	Comment	Response
SH	Ferring Pharmaceuticals Ltd	2	Full	12 1.1.3	8	Ferring supports the key priority for implementation that younger children are not excluded from the management of bedwetting on the basis of age alone. In light of data produced by the ALSPAC study group we believe it is essential that those children with severe bedwetting are treated as early as possible with the appropriate intervention.	Thank you for your comment.
SH	Ferring Pharmaceuticals Ltd	3	Full	13 1.7.1	13	Ferring believes that the word “inappropriate”, when referring to alarm therapy as a treatment choice, should be defined. The meaning here and throughout the document (when relating to alarm treatment) appears to be within the context of social factors and not from a pathophysiological perspective. Certain clinical pictures exist where alarm therapy may be less appropriate. There is evidence to suggest that desmopressin is most effective in patients with nocturnal polyuria and normal bladder storage,	Thank you for your comment. We have merged two recommendations to make the intention clearer. The paper by Hunsballe et al (1998) is a detailed analysis of nocturnal urine output in a population of 23 people with mono-symptomatic enuresis who are aged 15-37 years and 9 controls aged 24-31 years. The paper describes them as adults with refractory enuresis and questions whether mechanisms for enuresis in childhood extend into adulthood. The paper does not

Type	Stakeholder	Order No	Document	Page no.	Line no.	Comment	Response
						whereas the alarm is most efficient in children without polyuria, with low voided volumes. Initiation of treatment should be based on this knowledge (Hunsballe et al 1998, Hjalmas et al 2004). By taking a useful clinical history, the most appropriate treatment targeted to the individual can be applied. This approach is in line with a rational choice of treatment, where it is stressed that treatment should be initiated based on the underlying factors causing enuresis (Butler and Holland, 2000). The recommendation of alarm as a first-line therapy unless inappropriate or undesirable is restrictive and does not adequately address the multiple factors which cause enuresis. As recommended in the full guideline (page 36, section 2.1.4) – "Identifying the likely underlying mechanism for the wetting may allow better 23 use of certain treatments."	provide evidence of effectiveness of intervention. The paper by Hjalmas et al is a review article and the evidence it suggests for response to desmopressin in the paper by Hunsballe et al (1998) as described above. The studies quoted do not provide evidence on efficacy of interventions. The GDG did not consider that the current evidence on interventions supported treating on a presumption of pathophysiological cause of wetting. The GDG included a research recommendation for further research on effectiveness of treatments including identification of subgroups.

Type	Stakeholder	Order No	Document	Page no.	Line no.	Comment	Response
SH	Ferring Pharmaceuticals Ltd	4	Full	13 1.8.1	15	We believe that this should read "offer desmopressin as a choice of first-line treatment to children for whom a rapid onset AND/OR short-term improvement in bedwetting is the priority of treatment". The needs for a rapid onset or a short-term improvement do not always arise together. It is not clear in the text that desmopressin can be used first-line for patients who require rapid onset or short term improvement in symptoms. Without the additional wording (as we suggest) it implies that the alarm must still be first-line prior to desmopressin in this setting.	Thank you for your comment. We have considered your suggestion and changed the recommendation to ' rapid onset and/or short term improvement' . We have also changed the wording of the recommendation of use of alarm to clarify the intention of the GDG.
SH	Ferring Pharmaceuticals Ltd	5	Full	13 1.8.1	15	As desmopressin is a widely prescribed and very well established therapy in the treatment of nocturnal enuresis we believe there should be an additional bullet point similar to point 1.8.2 on page 27 in this 'Key Priorities for Implementation' section. This is in-line with the management algorithm on page 52.	The GDG selected 10 KPIs according to criteria set out by the guidelines manual. The GDG individually ranked the recommendations and discussed any conflicts in ranking. The GDG did not rank recommendation 1.8.2 on page 27 as a KPI.

Type	*Stakeholder*	*Order No*	*Document*	*Page no.*	*Line no.*	*Comment*	*Response*
SH	Ferring Pharmaceuticals Ltd	6	Full	18 1.2.1 8	8 and table	Point 1.2.18. specifies that the findings of the history should be used to inform the diagnosis and management of bedwetting. However, there is no discussion on choosing appropriate interventions based on the findings of the history. For example, a high measured urine output, wetting soon after falling asleep and consistently large wet patches indicates a diagnosis of nocturnal polyuria. It is in this group of patients where a better response is observed with desmopressin treatment. Response to the alarm may be less good (Hjalmas 2004). If a child has a small bladder capacity, wets several times throughout the night in small volumes and exhibits signs of urgency and frequency throughout the day the cause may be bladder storage problem and would therefore be treated differently to nocturnal	Thank you for your comment. The GDG considered that the findings of the history may help in considering the appropriateness the interventions and understanding co-morbidities and family issues. The management of daytime wetting is outside the scope of the guideline and a recommendation is made that is these symptoms pre-dominate consideration should be given to treating these first. The GDG did not consider that the current evidence on interventions supported treating on a presumption of pathophysiological cause of wetting. The GDG included a research recommendation for further research on effectiveness of treatments including identification of subgroups.

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						polyuria. This detail should also be reflected in the management algorithm.	
SH	Ferring Pharmaceuticals Ltd	7	Full	21 1.3.9	10	We propose that other factors are included in this statement when deciding upon an alarm or pharmacological treatment. As mentioned in points 3 and 6, current clinical practice assesses a wider range of clinical signs when deciding upon treatment intervention. Deciding simply upon age of child, frequency of bedwetting and motivation and needs of child and family seems inadequate.	Thank you for your comment. This recommendation is asking healthcare professionals to consider whether or not it is appropriate to use either alarm or pharmacological treatment and not about which to use. Not all children will require alarm or pharmacological intervention and the factors included in the recommendation are some of those to consider.
SH	Ferring Pharmaceuticals Ltd	8	Full	24 1.7.1	3	We propose that this should read "Offer an alarm as *a choice* of first-line treatment".	The GDG considered that an alarm should be offered as first line treatment. The caveats are now clearer as we have combined recommendations 1.7.1.and 1.7.2.
SH	Ferring Pharmaceuticals Ltd	9	Full	27 1.8	7	We would like to propose an additional recommendation for desmopressin in this section for its use in children with confirmed	Thank you for your comment. The study by Rittig et al (1989) is a study examining diurnal rhythm of plasma vasopressin and urinary output in 15

Type	*Stakeholder*	*Order No*	*Document*	*Page no.*	*Line no.*	*Comment*	*Response*
						nocturnal polyuria. Reduced nocturnal vasopressin production is the cause of enuresis in a notable proportion of children. Since Rittig et al (1989) established that vasopressin levels in a proportion of bedwetting children do not increase at night compared with non-enuretic subjects it has been considered logical to replace this vasopressin with the synthetic analogue desmopressin. In line with the 3 systems model (Butler 2000) desmopressin has become one of the first-line treatments for nocturnal enuresis alongside alarms. Nocturnal polyuria can be confirmed through a detailed history and clinical signs. It is established that children with polyuria normally wet in the first third of the night and in large patches. Hjalmas (2004) confirms that in this group of patients (with polyuria) response is better with desmopressin and alarm response may be less good. This additional recommendation should be included	children aged 11-17 years with nocturnal enuresis and 11 controls aged 12-17 years. Hjalmas et al (2004) is a review and quotes other studies of pathphysiology such as Hunsballe et al (1998). The evidence review for the guideline did not provide convincing evidence for difference in approach to children with presumed differing underlying disorders.

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						in the management algorithm.	
SH	Ferring Pharmaceuticals Ltd	10	Full	27 1.8	General	We believe the wording –"as a first-line treatment" should be removed from this title to bring in line with the title for Alarms on page 24, 1.7, line 2. As stated in the 'Key Priorities for Implementation' section, desmopressin should be offered to children for whom a rapid onset and short term improvement is the priority. This would then warrant changes to point 1.8.1 as stated below.	Thanks you for your comment. We have revised the headings for treatment. .
SH	Ferring Pharmaceuticals Ltd	11	Full	27 1.8.1	8	To bring clarity to the point that desmopressin can be used as a first-line treatment in children for whom a rapid onset or short term improvement is priority we propose the text should read – "offer desmopressin as a choice of first-line treatment…" As mentioned in point 4, desmopressin can be used when a	Thank you for your comment. We have changed the wording in the headings in general. We changed the wording of the recommendation and changed this to 'rapid onset and/or short term improvement' and also changed the wording of the recommendation on alarms to clarify the intention of the GDG.

Type	*Stakeholder*	*Order No*	*Document*	*Page no.*	*Line no.*	*Comment*	*Response*
						rapid onset **and/or** when short term improvement is required. We propose that this line should read – "Offer desmopressin as a choice of first-line treatment to children for whom rapid onset **and/or** short term improvement in bedwetting is the priority of treatment."	
SH	Ferring Pharmaceuticals Ltd	12	Full	28 1.8.1 0	18	This point needs more clarification in terms of how long desmopressin can be used for. According to the licensed dosing schedule, the continued need for desmopressin should be assessed at 3 monthly intervals by the means of a one week break in treatment. If treatment is still warranted then desmopressin can be used for as long as symptom control is required with a 1 week break every three months in patients aged up to 65 years old. The wording in the guideline is vague and could suggest that treatment is limited to 3 months. The need for a 1 week break is also not included in this point.	Thank you for your comment. We have changed the wording of the recommendations to ensure that it is clear that recurring doses of desmopressin can be used indefinitely There is a separate recommendation concerning the need for break in treatment when desmopressin is being used in this way.

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SH	Ferring Pharmaceuticals Ltd	13	Full	30 1.9.1 0	1	Ferring feel this point should be more specific when referring to withdrawal times. As per the DesmoMelt and Desmotabs Summary of Product Characteristics (SPC) a treatment break of 1 week is recommended at 3 month intervals.	Thanks you for your comment. This has been revised accordingly.
SH	Ferring Pharmaceuticals Ltd	14	Full	32 1.11. 5	6	The wording here should be amended to fully reflect the Imipramine Summary of Product Characteristics (SPC). It is recommended that should a relapse occur (after 3 months), a further course of treatment should not be started until a **full physical examination** has been made. The wording of “regularly review” used in the guideline is not strict enough or reflect the requirements of the SPC.	Thanks you for your comment. This has been revised to read “perform a medical review”. The recommendation is not required to repeat the wording of the BNF or SPC.
SH	Malem Medical	1	Full	3	10	Desmopressing as first line treatment. The “first line treatment” should be removed as reading the	Thank you for your comment. We have changed the headings in the NICE and Full guidelines.

Type	*Stakeholder*	*Order No*	*Document*	*Page no.*	*Line no.*	*Comment*	*Response*
						table of contents will wrongly imply Desmopressing as FIRST LINE TREATMENT. No such phrase is used in the line above for "Alarms" which IS the first line treatment.	
SH	Malem Medical	2	Full	General		It is important for the guidelines to have a clear and concise summery/conclusion stating that for a high success rate and long term genuine cure, alarms, when appropriate, should always be the first line treatment. For temporary and short-term symptomatic relief at a vast expense or when alarms are inappropriate and having explained this to the child and parents/guardians, drugs can be used.	Thank you for your comment.
SH	Malem Medical	3	Full	General		It is important for the guidelines to clearly state, especially in this severe financial situation, the true cost of using an alarm to achieve a high rate of cure compared to the vast cost of using a drug for temporary and short term relief. After all the NHS should provide the best solution to the patient without	Thank you for your comment. As part of the NICE process the developed guidance includes a cost-effectiveness analysis.

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						unnecessary waste of precious financial resources.	
SH	Malem Medical	4	Full	13	13	This paragraph should clearly state that "For best long-term results, offer an alarm...."	Thank you for your comment. The format and wording of recommendations have to confirm to NICE requirements and recommendations do not usually include information.
SH	Malem Medical	5	Full	13	15	This paragraph should clearly start with " If the priority is for probable short-term reduction in quantity and frequency of wetting, offer desmopressin".	Thank you for your comment. The format and wording of recommendations have to confirm to NICE requirements and recommendations do not usually include information.
SH	Malem Medical	6	Full	14	16	I am surprised that the draft guidelines consider "90% improvement as a good response to an intervention. Surely the child is either 100% dry or not dry. You can not be 90% dry unless the guidelines are trying to accommodate the use of drugs.	Thank you for your comment. Percentage improvements are recognised outcomes used in studies of bedwetting and recommended by the International Children's Continence Society.
SH	Malem Medical	7	Full	24	2	Alarms. I suggest the phrase "Alarms should be first-line treatment" as heading.	Thank you for your comment. This has now been changed to Initial treatment-Alarms as heading.

Type	Stakeholder	Order No	Document	Page no.	Line no.	Comment	Response
SH	Malem Medical	8	Full	36	27	"The causes of bedwetting are not fully understood" This is not a true statement. Bedwetting is neither an illness nor a disease. We all start life as bedwetters. And we learn to become dry. Becoming dry is a skill that we acquire in the same way we learn to talk, walk or ride a bicycle. Children acquire these skills at different times. By the age of 13 years, about 98% of children are dry. It is clear that a bedwetting child has about 15% chance per year every year of becoming dry naturally. Yes, different factors at this early stage of life can delay dryness or reinitiate wetness.	Thank you for your comment. In the context of the guideline 'bedwetting' is used to describe 'bedwetting' which continues after dryness at night would be expected. The guideline is not suggesting it is an illness or disease. As with other areas such as speech or mobility, it is reasonable to consider why children do not achieve dryness at usual age and whether interventions will be helpful.
SH	Malem Medical	9	Full	25	19	Alarm treatment for bedwetting goes beyond the stated points as the child will sleep throughout the night without the need to hold on nor to wake spontaneously. The alarm help the child to achieve full dryness by speeding up the natural process. That is why the use of alarms is a permanent cure for bedwetting unlike using drugs.	Thank you for your comment

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SH	Malem Medical	10	Full	general		It should be emphasised and highlighted that most if not all “studies” on drugs, state the results while the child is receiving the drug and not after they stop taking the drug. That will falsely improve the results as most children (unless becoming naturally dry during the drug taking period) will revert to the original state of wetting.	Thank you for your comment. The detail of the studies in included in the data extraction tables and discussed in the chapter when relevant.
SH	Malem Medical	11	Full	general		The draft guidelines contain and refer to a large number of out of date and unscientific studies but appear to have overlooked a recent major and independent study by Cutting et al. from Australia. I strongly suggest closer examination and inclusion. Nocturnal Enuresis: Application of Evidence-Based Medicine in Community Practice. Journal of Paediatrics & Child Health 167-172 43 2007.	Thank you for your comment. The paper by Cutting et al reports the results of a cohort of children in a private paediatric practice in Australia who were diagnosed by the paediatirican to have mono-symptomatic nocturnal enuresis. The paper provides supportive evidence for the use of an alarm in the setting described but a randomised controlled trial (RCT) provides better evidence of the effectiveness of an intervention and RCTs were available to evaluate the use of alarms.

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SH	Malem Medical	12	Full	gener al		To avoid "conflict of interest", all professional experts contributing to the Guideline should assert their independence and impartiality by public written declaration within the guidelines stating any involvement/s, small or large, directly or indirectly, past or present, financial or otherwise with the pharmaceutical or medical device industries related to this subject. This is a legal requirement in the USA, Australia and other countries. I am sure it is in the UK as well.	Thank you for your comment. The Declarations of Interest of all GDG members are available in an appendix to the guideline and on the NICE website.
SH	Paediatric Continence Forum	1	NICE	8	4th para	Urinary incontinence – this is not a recognised definition for bedwetting	Thank you for your comment. The International Children's Continence Society (ICCS) consider nocturnal enuresis a form of intermittent urinary incontinence.
SH	Paediatric Continence Forum	2	NICE	9	1.2.3	Large volume of urine – large/"small" Needs to be clarified	Thank you for your comment. The GDG reviewed the wording of this recommendation and considered that the examples of questions given are appropriate and did not wish to add other examples

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SH	Paediatric Continence Forum	3	NICE	10	1.2.7	Why only use the word “consider” asking.. as this importantly assists and confirms diagnosis Also important to provide some guidance to practitioners on the minimum effective period to ask parents and children to keep records for assessment eg fluid intake, urine output, stool production – as the process can be intrusive and stressful if this is unnecessarily prolonged	Thank you for your comment. The GDG used the word consider as the collecting this information can be intrusive and onerous and would not be appropriate for all children and families. The GDG did not think it was possible to specify periods of time as these would vary according to the particular symptoms the child had. We have added more information about this to the Full guideline.
SH	Paediatric Continence Forum	4	NICE	15	1.3.8	Using bed protection – washable **and** disposable	Thank you for your comment. We have changed the wording.
SH	Paediatric Continence Forum	5	NICE	16	1.4.2	Fluid intake stated for 5 &10 yr olds: need clarity for the 10yr olds and older (2,000 mls for adults)	Thank you for your comment. We have changed this recommendation to provide more comprehensive advice.
SH	Paediatric Continence Forum	6	NICE	16	1.4.6	Toilet use 4-5 times a day? Recommended normal – 4-7 times a day	Thank you for your comment. We have altered the wording of this recommendation to say 4-7 times.
SH	Paediatric Continence Forum	7	NICE	18	1.7.6	Daytime symptoms: if the alarm is sounding more than once a night, is this appropriate treatment – as shouldn’t the underlying bladder issues be resolved first?	Thank you for your comment. The evidence supported use of alarms in children with bedwetting and day time symptoms. There is a separate recommendation indicating that

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							children with severe or predominant daytime symptoms may need this addressed first.
SH	Paediatric Continence Forum	8	NICE	19	1.7.16	They **need** to record progress. This is important, but why an imperative now when not at assessment 1.2.7	Thank you for your comment. The GDG consider that it was not appropriate that all children and families record fluid and toileting patterns as part of the assessment as this could be considered excessive and burdensome for some families. Part of the assessment for an alarm includes whether the family can cope with using the alarm and these families are therefore considered able to cope with recording.
SH	Paediatric Continence Forum	9	NICE	20	1.7.18	Alarm going off later and **fewer times per night.** Are you suggesting that it is appropriate for a child to be woken/have their sleep disturbed more than once per night? Is there not evidence that an overactive bladder needs resolving first?	Thank you for your comment. The GDG considered that waking more than once a night might occur but was not likely to continue for longer than a few weeks. We did not find evidence that overactive bladder needed to be treated first -the evidence reviews indicated that children with daytime symptoms and bedwetting can respond to alarms. The GDG made

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							a recommendation to consider treating daytime symptoms first if these predominate.
SH	Paediatric Continence Forum	10	NICE	20	1.7.20	Re-start alarm if wetting within 2 weeks of stopping alarm. **Why 2 weeks** and not 3-4-5-6 weeks?	Thank you for your comment. We have removed the time period in this recommendation.
SH	Paediatric Continence Forum	11	NICE	21	1.8.1	Not enough emphasis upon the longer term use of desmopressin ie as long as symptom control is needed	Thank you for your comment. This recommendation deals with initial prescription of desmopressin. Recommendations regarding continued prescription are in further section.
SH	Paediatric Continence Forum	12	NICE	21	1.8.5	Would you use 400 micrograms for a 5 year old?	Thank you for your comment. This is in line with BNF.
SH	Paediatric Continence Forum	13	NICE	24	1.9.12	All professionals treating children for bedwetting should have a specialist competency in the assessment and treatment of this condition. As a wide variety of types of professionals treat this condition these could be listed. It would not be unusual within a paediatric continence service to have one or more professionals who had an expertise in managing the more complex cases	Thank you for your comment. We agree with your comment about expertise available in continence services.

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SH	Royal College of Nursing	1	Full	General		The Royal College of Nursing welcomes this guideline, particularly as it recommends treatment from age five.	Thank you for your comment.
SH	Royal College of Nursing	2	NICE	8	4th Para	**Urinary incontinence** – this is not a recognised explanation / definition for Bedwetting	Thank you for your comment. The International Children's Continence Society (ICCS) consider nocturnal enuresis a form of intermittent urinary incontinence.
SH	Royal College of Nursing	3	NICE	9	1.2.3	Large volume of urine – large / '*small*' (large is a leading question)	Thank you for your comment. The GDG reviewed the wording of this recommendation and considered that the examples of questions given are appropriate and did not wish to add other examples.
SH	Royal College of Nursing	4	NICE	10	1.2.7	Recording information - **Consider** asking – Should this be a firmer wording – as this process assists and confirms diagnosis	Thank you for your comment. The GDG used the word consider as the collecting this information can be intrusive and onerous and would not be appropriate for all children and families.
SH	Royal College of Nursing	5	NICE	15	1.3.8	Using bed protection - washable & disposable	Thank you for your comment. We have changed the wording.
SH	Royal College of Nursing	6	NICE	16	1.4.2	Fluid intake stated for 5 & 10 yr olds: clarity for the 10 yr olds & older - (2000 mls – adults)	Thank you for your comment. We have changed this recommendation to provide more comprehensive

Type	Stakeholder	Order No	Document	Page no.	Line no.	Comment	Response
							advice.
SH	Royal College of Nursing	7	NICE	16	1.4.6	Toilet use: 4-5 times a day? Recommended / normal: 4-7 x a day	Thank you for your comment. We have altered the wording of this recommendation to say 4-7 times.
SH	Royal College of Nursing	8	NICE	18	1.7.6	Daytime symptoms: if alarm is sounding more than once a night, is this appropriate treatment: or resolve underlying bladder issues?	Thank you for your comment. The evidence supported use of alarms in children with bedwetting and day time symptoms. There is a separate recommendation indicating that children with severe or predominant daytime symptoms may need this addressed first.
SH	Royal College of Nursing	9	NICE	19	1.7.1 6	'they **need** to record progress' Why record now and not at assessment: 1.2.7	Thank you for your comment. The GDG consider that it was not appropriate that all children and families record fluid and toileting patterns as part of the assessment as this could be considered excessive and burdensome for some families. Part of the assessment for an alarm includes whether the family can cope with using the alarm and these families are therefore considered able to cope with recording.

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SH	Royal College of Nursing	10	NICE	20	1.7.18	'Alarm going off later and **fewer times per night**.' This seems to suggest that it is suitable for a child being woken more than once per night, should continue to have their sleep disturbed? Is this not evident that over active bladder needs resolving first or in conjunction?	Thank you for your comment. The GDG considered that waking more than once a night might occur but was not likely to continue for longer than a few weeks.
SH	Royal College of Nursing	11	NICE	20	1.7.20	Restart alarm if wetting within 2 weeks of stopping alarm. **Why 2 weeks** and not 3-4-5-6 weeks – it would be helpful to know the rationale for recommending two weeks?	Thank you for your comment. We have removed the time period in this recommendation.
SH	Royal College of Nursing	12	NICE	21	1.8.5	Is this recommending use of Desmopressin - 400 micrograms for a 5 year old?	Thank you for your comment. This is in line with BNF.
SH	Royal College of Nursing	13	NICE	21	1.8	Also it does not clearly say that desmopressin can be continued for as long as symptom control is required although it is implied that it can. Also it says that demopressin to be given for 3 months - this may be interpreted by some that it	Thank you for your comment. This recommendation deals with initial prescription of desmopressin. Recommendations regarding continued prescription are in further section.

Type	*Stakeholder*	*Order No*	*Document*	*Page no.*	*Line no.*	*Comment*	*Response*
						should ONLY be given for 3 months	
SH	Royal College of Nursing	14	FULL	12	8	This is unclear - thought the guideline was going to change age of treatment from 7 years to 5 years?	Thank you for your comment. The recommendation is saying that children under the age of 7 should not be excluded from consideration of treatment.
SH	Royal College of Nursing	15	FULL	14	20	Is 19 years appropriate here – think adolescents would not appreciate this, suggest the age reference should be in line with all other `child' policies.	Thank you for your comment. The age of 19 years is used as the guideline includes young people with and without special needs. Educational and social services commonly continue for children with special needs up to 19 years. The age range used was agreed with NICE following stakeholder comments on the scope.
SH	Royal College of Nursing	16	FULL	17	17	think `recommend' is more appropriate than `consider'	Many thanks for your comment. The GDG considered that in this particular recommendation, "consider" would be more appropriate.

Type	*Stakeholder*	*Order No*	*Document*	*Page no.*	*Line no.*	*Comment*	*Response*
SH	Royal College of Nursing	17	FULL	21	6 +	No recommendation about follow up – think this would be appropriate here	Thank you for your comment. Recommendations about follow up are included in the sections about interventions.
SH	Royal College of Nursing	18	FULL	22	9	It would be helpful to have the reference for these intake figures.	Thank you for your comment. We have added reference and further detail about GDG decision.
SH	Royal College of Nursing	19	FULL	22	16	This differs from the guidelines already published by ICCS – which state that 4-7 times is `normal' frequency (www.i-c-c-s.org); for consistency suggest that 4-5 times should be changed to 4-7	Many thanks for your comment. This recommendation has now been revised accordingly.
SH	Royal College of Nursing	20	FULL	25	2	Good – supports alarm use in under 7s – if appropriate	Thank you for your comment.
SH	Royal College of Nursing	21	FULL	21	38	Again – age 19 years – this does not seem to be consistent with any other `child and young person' guideline.	Thank you for your comment. The age of 19 years is used as the guideline includes young people with and without special needs. Educational and social services commonly continue for children with special needs up to 19 years. The age range used was agreed with NICE following stakeholder

Type	*Stakeholder*	*Order No*	*Document*	*Page no.*	*Line no.*	*Comment*	*Response*
							comments on the scope.
SH	Royal College of Paediatrics and Child Health	1	Full	General		The RCPCH supports this clinical guideline in principle, but we note that many of the included studies had serious limitations.	Thank you for your comment. The majority of studies were graded low or very low.
SH	Royal College of Paediatrics and Child Health	2	Full			We note there are quite a few spelling errors throughout the document.	Thank you for your comment. We will conduct a thorough check before publication of the guideline.
SH	Royal College of Paediatrics and Child Health	3	Full	General		We would like clarification on whether we will no longer use the three-systems model/term.	Thank you for your comment. No specific evidence was found regarding the 3 systems approach but the principle of the 3 systems can be found many of the recommendations.
SH	Royal College of Paediatrics and Child Health	4	Full	General		We note that nocturnal enuresis is common after cardiac transplantation. We suggest the GDG consider whether to include this condition, though rare. Leonard and Plant. Nocturnal enuresis is a common complication following cardiac transplantation. Arch Dis Child. 2003;88:1048-50.	Thank you for your comment. The GDG considered that the children with cardiac transplantation are a unique group who are likely to have complex problems including possible effects of both their condition and medication on renal function. They are covered by the recommendation suggesting that referral may be required for children with co-morbidities and the GDG did not

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							consider it appropriate to single this group out.
SH	Royal College of Paediatrics and Child Health	5	Full	Gene ral		We note that the management of nocturnal enuresis is variable across the world, within the UK, and among clinicians in the same hospital.	Thank you for your comment.
SH	Royal College of Paediatrics and Child Health	6	NICE	9	1.1.2	We note there is an impact from failed treatments. We agree with the removal of lower age limits as well as that alarms should be offered to all ages. Anecdotal experience supports that alarms should be used with caution in some families. The expectation is that the family and child should be fully assessed, but we do not think this is sufficiently emphasised in the NICE version (it is well set out in the full version). To make this clearer, we recommend changing to, "Offer support and appropriate **assessment and** treatment…"	Thank you for your comment. We have changed the recommendation in line with your suggestion.

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SH	Royal College of Paediatrics and Child Health	7	NICE	9	1.2	We note that measurement of blood pressure in secondary wetting is not mentioned. It may be a basic assessment of renal function but it is easily done by primary care.	Thank you for your comment. The GDG considered the suggestion to recommend BP measurement for children with secondary wetting but decided there was not adequate evidence to recommend this.
SH	Royal College of Paediatrics and Child Health	8	NICE	9	1.2	We note that ultrasound or assessment of residual volume is not included in the NICE version, though the use of this is discussed in the full version. While this is understandable given the evidence, we note that there is therefore little guidance on further investigation in select groups, e.g. treatment refractive children.	Thank you for your comment. The GDG did not consider the evidence supported any recommendations on investigation in children and considered that professionals would need to individualise the assessment when reviewing children who were not responding to treatment..
SH	Royal College of Paediatrics and Child Health	9	NICE	9	1.2.2	We would like clarification on the recommendation to enquire about bedwetting over the previous 6 months only. We suggest removing the word “recent” before the list of possible triggers, as children may present many months or years after a significant event with secondary wetting.	Thank you for your comment. We have removed the word ‘recent’ from this recommendation.

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SH	Royal College of Paediatrics and Child Health	10	NICE	9	1.2.4	We note that **infrequency** is not included as a consideration here or in the full version.	Thank you for your comment. This wording has been changed and infrequency included.
SH	Royal College of Paediatrics and Child Health	11	NICE	16	1.4	We recommend there be more explicit advice about the types of fluids that need to be avoided and those that should be encouraged (i.e. water).	Thank you for your comment. There is a recommendation about avoidance of high sugar and caffeine based drinks. The GDG did not consider it appropriate to recommend only water and this is potentially restrictive and not offer a realistic, pragmatic choice for children and families.
SH	Royal College of Paediatrics and Child Health	12	NICE Full	17 264	1.6.3 10.2. 2.3	We agree that rewards should relate to agreed behaviour not dry nights. However, we cannot find evidence to support the statement [bold emphasis our own], “Advise parents or carers to use reward systems alone for the initial treatment of bedwetting in previously **untreated younger children** who have some dry nights.”	Thank you for your comment. The wording of the recommendation was misleading and has been altered. We have removed ‘previously untreated’ from the recommendation.
SH	Royal College of Paediatrics and Child Health	13	NICE Full	21 385	1.8.3 12.2. 3.6	Anecdotal evidence supports that paediatricians would usually start these children on oxybutynin, with advice on drinks and regular toileting habits. The guideline also notes that	Thank you for your comment. This recommendation applies to the management of bedwetting symptom only. There is a separate recommendation indicating that

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						these children often are poor responders to desmopressin.	children with severe or predominant daytime symptoms may need this addressed first. The GDG considered that this group of children might have some benefit from desmopressin and it should be available for them if required.
SH	Royal College of Paediatrics and Child Health	14	NICE Full	21 477	1.8.7 13.2.3.7	Anecdotal evidence supports that tertiary specialists do not recommend desmopressin in these children except for short periods because of the risk of sickle cell crisis. We are concerned that standard methods that are often successful in managing nocturnal enuresis are unlikely to help children with sickle cell crisis; failure with an alarm may further deflate patient self esteem.	Thank you for your comment. We have changed the wording of the recommendation slightly. We found no evidence regarding children with sickle cell disease and the GDG were concerned that children miss out on treatments of benefit. The GDG considered that each child needs assessment as to their ability to cope with desmopressin but that it should be available as a treatment option for them.
SH	Royal College of Paediatrics and Child Health	15	NICE	22	1.8.10	Regarding the statements to inform the child and parents or carers, “of the importance of fluid restriction from 1 hour before until 8 hours after taking desmopressin” and “that it should be taken 1–2 hours before bed”.	Thank you for your comment. We have changed the wording in the recommendation to indicate that it should be taken at bedtime and a second recommendation to indicate that it may be taken earlier in therapy resistance.

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						We note that manufacturers Ferring state desmopressin should be given at bedtime. By giving 1-2 hours before bed extends the time of fluid restriction. We are aware that current evidence suggests desmopressin should be administered at least 1 hour before bed and up to 2 hours before bed in therapy resistance. De Guchtenaere, A et al. Evidence of partial anti-enuretic response related to poor pharmacodynamic effects of desmopressin nasal spray. Journal of Urology. 2009;181;302-9. Vande, Wall et al. Journal of Urology. 2006;97;603-9.	
SH	Royal College of Paediatrics and Child Health	16	NICE	22	1.9	From reading the full guideline, we understand that this is related to cost effectiveness, but note this will be difficult to remember and recommend the reason is included in the NICE version.	Thank you for your comment. This is related to clinical and cost effectiveness evidence. Recommendations do not usually provide explanation.

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SH	Royal College of Paediatrics and Child Health	17	NICE	22	1.9.2	We note the recommendation that those children who do who do not respond to a combination of alarm and desmopressin are offered desmopressin alone. We think this may be appropriate with a partial response but not if there has been no response.	Thank you for your comment. We have changed the wording and order of the recommendations to make the meaning clear.
SH	Royal College of Paediatrics and Child Health	18	NICE	25	1.11	Anecdotal evidence supports that we would not be very comfortable in using Imipramine.	Thank you for your comment. The recommendations are made following review of clinical evidence and imipramine is only recommended in children who have not responded to other treatments.
SH	Royal College of Paediatrics and Child Health	19	NICE	24	1.10.1 1.10.5	We are surprised by the recommendation to not use anticholinergics for bedwetting alone unless the child is assessed by healthcare professionals with specialist expertise (1.10.1), as well as that to consider use of an anticholinergic with desmopressin for children who have daytime symptoms once assessed by a healthcare professional with specialist expertises (1.10.5).	Thank you for your comment. Many children with bedwetting are managed within community and school services and not by paediatricians. The treatment of daytime wetting alone is outside the scope of the guideline. We have altered the recommendation to indicate what these children require rather than who they should see as this will vary by area.

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						We would like clarification on who these healthcare professionals with specialist expertise are. We note that the majority of these problems are managed by paediatricians in a district general hospital, and we are unsure of need for referral for daytime enuresis management. Anecdotal evidence supports that the use of an anticholinergic alone for day time enuresis works very well.	
SH	Royal College of Paediatrics and Child Health	20	NICE	Gene ral		I could not find any mention of ERIC or other parent /family support groups. I think it is helpful to define goals: for example in a child who is soaking through pullups every night- a reduction in urine volume so that all the wee is contained within the pull up- could be successful treatment- even if he continues to wet evry night. He won't need a complete shower and won't need a daily change of bedclothes. Identifying where/how families may	Thank you for your comment. The NICE implementation team will provide supporting materials for the guideline which will include details of support groups. We have recommendations for health professionals to explain the condition and treatments and clarify what the child and family expect from treatment. The GDG however considered that at least when treatment is initially sought children and families would aim to achieve dryness.

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						have access to nappies/pullups especially for older children. There are often issues about both availability AND cost. Butler identified that about 1/3 of children with nighttime wetting wake up and go back to sleep again. This group may respond to incentives- but clearly the trial should be short. I think a short trial of incentives is always worthwhile because if it does work – great and if it does not it can be soon stopped without affecting the child- especially if the child is involved. Emphasize the negative impact of wetting on children and families and the benefits of treatment.	
SH	Royal College of Paediatrics and Child Health	21	NICE	9	1.2.3	Knowing how many times a night a child wets can be helpful.	Thank you for your comment. We have added this question.
SH	Royal College of Paediatrics and Child Health	22	NICE	10	1.2.7	Measuring bladder volume is useful. Ultrasound estimation seems less useful – and fun- than measuring wees in a jug. The simple measurement will overlook those children with	Thank you for your comment. The GDG considered that measurement of bladder volume can be useful but evidence did not support a recommendation for routine measurement of bladder volume.

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						inadequate emptying.	
SH	Royal College of Paediatrics and Child Health	23	NICE	16	1.5	Waking gets a bad press. If it keeps a child dry- why not- especially in families that don't want medication- or as an adjunct to medication. It will not teach dryness but that is tru of desmopressin too.	Thank you for your comment. The recommendation has been reworded slightly and now states that waking by parents or carers, either at regular times or randomly, should be used only as a practical measure in the short-term management of bedwetting'
SH	Royal College of Paediatrics and Child Health	24	NICE	18	1.7.6	Alarms are less useful in the presence of daytime symptoms- OAB unless you are thinking about day alarms.	Thank you for your comment. The evidence supported use of alarms in children with bedwetting and day time symptoms. There is a separate recommendation indicating that children with severe or predominant daytime symptoms may need this addressed first
SH	Royal College of Paediatrics and Child Health	25	NICE	21	1.8.5	Desmopressin does not have a cumulative effect. If it is going to work it will work straight away- why wait 2 weeks to increase the dose.	Thank you for your comment. We have amended this recommendation to say 1-2 weeks. The GDG considered that it may take longer to adequately ascertain side effects and tolerability than efficacy and therefore recommend some delay in increasing dose.

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SH	Royal College of Paediatrics and Child Health	26	NICE	21	1.8.1 0	Mention avoiding drinking after desmopressin as risk of hyponatraemia. Treatment would be dependent on families wishes- some may only want it for special events but most prefer to take it continuously. It should be stopped every 3 months or so to see if natural dryness has developed	Thank you for your comment. The recommendation includes a bullet point about fluid restriction.
SH	Royal College of Paediatrics and Child Health	27	NICE	22	1.9	If treatment fails- go back to first principles- constipation/daytime drinking/weeing/ changes at home/school	Thank you for your comment. The GDG considered that this would be part of assessment routine when assessing treatment result but did not think it merited a separate recommendation.
SH	Royal College of Paediatrics and Child Health	28	NICE	23	1.9.6	There is no cumulative effect of desmopressin so cannot reduce it gradually- also as it comes in tabs/melts there is practically little way of wening medication- its one or nothing!	Thank you for your comment. The GDG considered that slow withdrawal by e.g. breaking tablets or taking alternate nights is possible.
SH	Shropshire County PCT	1	Full	15	1.1.3	My comments regarding Section 1 – Guidance are: I welcome that those under 7 years should not be excluded on the basis	Thank you for your comment. The GDG did not consider that routine medical examination was required for all children with enuresis

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				15 – 18 27 - 28	1.2 1.8	of age alone. Assessment of children by discusses enquiring, assessing, investigating and considering give guidance to the assessor. I do however seek further clarification on the need or not for routine baseline medical examination for all children with enuresis. I am developing an enuresis care pathway for Shropshire and medical examination of children with enuresis appears to differ with each area. There does not appear to be research included in the consultation to show any evidence or recommendations of the value of a routine baseline medical. I do welcome the evidence that many children with nigh time problems also have associated daytime symptoms. Some practitioners feel they are unable to give advice to children and their families if daytime symptoms are present. Clear referral / investigation	but that any examination should be directed by the history. We have changed the recommendation regarding timing of desmopressin. It is recommended to take this at bedtime but a trial of taking it earlier is recommended in children who have had a partial or no response

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						guidance is also welcomed I welcome that desmopressin can be offered to children between 5 and 7 but seek further clarification on 1.8.10 that desmopressin should be taken 1-2 hours before bed. Pharmaceutical guidelines recommend taking the medication at bedtime.	
SH	Shropshire County PCT	2	Full	51	2.9	Care pathways, assessment and management. These are welcomed though staff found them difficult to follow and asked for a more simplified version	Thank you for your comment. We will work with NICE to produce a Quick Reference Guide at the time of publication of the guideline which will be easier to follow by professionals.
SH	Shropshire County PCT	3	Full	Gene ral		Guidelines promote best practice based on extensive research. As a school nurse and enuresis lead for Shropshire I welcome the guidelines as they will help shape services and ensure practice is evidence based. All care should be in partnership with children and their families and the guidelines will ensure all are able to make informed decisions about their	Thank you for your comment.

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						care and treatment.	
SH	The Portland Hospital	1	NICE	12	8	I thought the guideline was going to change age of treatment from 7 years to 5 years.	Thank you for your comment. There was no lower limit for inclusion in guideline and recommendations are made for each age according to evidence and consensus of the GDG.
SH	The Portland Hospital	2	NICE	14	20	I do not think 19 years is appropriate – no adolescent would appreciate this, I believe the age should be 16 as it is for all other `child' policies	Thank you for your comment. The age of 19 years is used as the guideline includes young people with and without special needs. Educational and social services commonly continue for children with special needs up to 19 years. The age range used was agreed with NICE following stakeholder comments on the scope.
SH	The Portland Hospital	3	NICE	17	17	I think `recommend' is more appropriate than `consider'	We cannot locate which recommendation this is referring to.
SH	The Portland Hospital	4	NICE	21	6 + (1.8.3)	No recommendation about follow up – I think this would be appropriate here	Thank you for your comment. We have added bullet points about the use of desmopressin long term and the evidence of early response.

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SH	The Portland Hospital	5	NICE	22	9	Do you have the reference for these intake figures?	Thank you for your comment. We presume you are referring to the figures regarding intake of fluids. The figures come from an Amercian survey of intake. Full details have been added to the Full guideline.
SH	The Portland Hospital	6	NICE	22	16	This differs from the guidelines already published by ICCS – they state that 4-7 times is `normal' frequency (www.i-c-c-s.org; for consistency I think 4-5 times should be changed to 4-7	Thank you for your comment. The reference appears incorrect. We have changed the wording of the recommendation regarding frequency of urine.
SH	The Portland Hospital	7	NICE	25	2	Good – supports alarm use in under 7's – if appropriate	Thank you for your comment
SH	The Portland Hospital	8	NICE	21	38	Again – age 19 years – not consistent with any other `child and young person' guidline	Thank you for your comment. The age of 19 years is used as the guideline includes young people with and without special needs. Educational and social services commonly continue for children with special needs up to 19 years. The age range used was agreed with NICE following stakeholder comments on the scope.