NICE National Institute for Health and Care Excellence

Appendix B: Stakeholder consultation comments table

2018 surveillance of Bedwetting in under 19s (2010)

Consultation dates: 26 September 2018 to 9 October 2018

Do you agree with the proposal not to update the guideline?			
Stakeholder	**Overall response**	**Comments**	**NICE response**
Cambridge Community Services NHS Trust	No	I am in agreement with the proposed changes highlighted in the consultation document	Thank you for your comment.
Leeds Teaching Hospitals NHS Trust	Yes	The surveillance review is helpful and I agree with the proposals. Could the review be posted alongside the guideline for reference?	Thank you for your comment. After consultation on the proposal we will consider the comments received and make any necessary changes to the decision. We will then publish on the NICE website, the final surveillance report containing the decision, the summary of the evidence used to reach the decision, and responses to comments received in consultation.
NHS England		There are no comments from NHS England.	Thank you.

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 recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees

Royal College of Nursing		The guideline on Bedwetting in under19s has been reviewed by our members and we have no comments to submit at this stage	Thank you.
Royal College of Paediatrics and Child Health	No	No comments	Thank you.
Public Health England	No	Public Health England recommends that the proposal is updated to reflect the comments below.	Thank you for your comment.
Paediatric Continence Forum	No	**Appendix A: Summary of evidence from surveillance** We fully agree with the views of topic experts on p3 – the main areas for update. These in our view should merit a full update Specifically and additionally:- 1.1.3 Should state consider treatment from the age of 5 years 1.3.10 Why state and limit to "severe" daytime symptoms – this should be **any** bowel or bladder symptoms. The statement contradicts Table 1 (1.3.19) which doesn't use the term "severe" 1.8.10 should include a caveat that alarms are more effective for children over 7 years 1.10.1 Why not just offer desmopressin for children from 5 years of age? This 5-7 years age grouping just encourages	Thank you for your comment. Recommendation 1.1.3 Recommendation 1.1.3 explicitly states: 'Do not exclude younger children (for example, those under 7 years) from the management of bedwetting on the basis of age alone'. Recommendation 1.3.10 With regards to recommendation 1.3.10, the assessment and treatment of daytime wetting is outside the scope of the guideline but at the time of guideline publication the GDG (Guideline Development Group) considered that there is such overlap between these symptoms that health care professionals needed to only consider minimal changes to guideline recommendations when a child or young person has significant daytime symptoms. Recommendation 1.8.10 The caveat that alarms are more effective for children over 7 years was considered in recommendation 1.8.8 that states: 'Consider an alarm for the treatment of bedwetting in children under 7 years,

		clinicians (and Commissioning Groups) to delay treatment/services until 7 years – for CCGs/ Local Authorities as a cost saving! P42/3 We disagree with the Impact Statement that there is not enough good evidence to include Electrical Nerve Stimulation in the Guideline. 4.5 (P45) Bedwetting in Adolescents. There are good studies in this area post 2010 that have not been identified in the Surveillance process: Effects of urinary incontinence on psychosocial outcomes in adolescence. **Grzeda** MT, Heron J, von Gontard A, **Joinson** C. Eur Child Adolesc Psychiatry. 2017 Jun;26(6):649-658. doi: 10.1007/s00787-016-0928-0. Epub 2016 Dec 10. It would also be useful to include the findings that show that children with persistent bedwetting and with daytime wetting have much poorer outcomes in adolescence than those with bedwetting alone. The details of the paper are: Trajectories of urinary incontinence in childhood and bladder and bowel symptoms in adolescence: prospective cohort study. Heron J1, Grzeda MT1, von Gontard A2, Wright A3, Joinson C1. **BMJ Open. 2017 Mar 14;7(3):e014238. doi: 10.1136/bmjopen-2016-014238.**	depending on their ability, maturity, motivation and understanding of the alarm'. Recommendation 1.10.1 We are sorry that there is a view that the recommendation 1.10.1 has been misinterpreted. However, recommendation 1.10.2 clearly states: 'Consider desmopressin for children aged 5–7 years if treatment is required and:-rapid-onset and/or short-term improvement in bedwetting is the priority of treatment-or -an alarm is inappropriate or undesirable'. This implies that children can be treated with desmopressin from age of 5 but that the decision to prescribe depends on the individual patient assessment. At present, we do not believe that the wording of these recommendations needs clarification. However, for interpretation of the guideline, users of NICE guidance should refer to the NICE Pathway which brings together all of the nocturnal enuresis recommendations in a clear pathway that is easy to follow. Electrical nerve stimulation Studies indicated that electrical nerve stimulation leads to fewer wet nights compared with control. However, the studies found in this surveillance review were small and no psychological effects were investigated. These studies will be shared with the interventional procedures team. See reviewing and updating interventional procedures guidance in the interventional procedures programme manual for information on reviewing this type of guidance. Ongoing studies that we identify, or receive notification about, will be assessed for the potential to impact on the guideline. We will track studies meeting this criterion and check for publication on a regular basis. If new evidence with an impact on recommendations

		Also, the paper examining parental strategies to overcome bedwetting would be relevant: **Examining the effectiveness of parental strategies to overcome bedwetting: an observational cohort study.** **Grzeda MT, Heron J, Tilling K, Wright A, Joinson C. BMJ Open. 2017 Jul 13;7(7):e016749. doi: 10.1136/bmjopen-2017-016749.** P4 and p7 **Correction** Can you please credit the Paediatric Continence Commissioning Guide to the **Paediatric Continence Forum (** not to Paediatric continence services). Just to note to say that our Commissioning Guide is currently being updated (2018/ early 2019).	is identified at any time, we may decide bring forward the next update of the guideline. Thank you for the additional references. We have assessed the studies as follows: Grzeda et al. (2016) provides evidence of the association between daytime wetting/bedwetting in childhood and increased psychosocial problems in adolescence. It does not inform management of the condition, so has no impact on current recommendations. The guideline considered that bedwetting can be associated with emotional behavioural problems and attention to these problems may be the appropriate course of action for some children and young people rather than concentrating on treatments for bedwetting. The guideline also considered that these children and young people need psychological or behavioural treatment as appropriate to their problem (recommendation 1.3.15) Heron et al. (2017) provides evidence that trajectories of childhood urinary incontinence are differentially associated with adolescent bladder and bowel symptoms. It does not inform management of the condition, so has no impact on current recommendations. Grzeda et al. (2017) was identified and included in current surveillance. The study provides evidence that common strategies used by parents (including lifting, restricting drinks before bedtime, regular daytime toilet trips, rewards, and using protection pants) to overcome bedwetting in 7½-year-olds appeared not to be effective in reducing the risk of bedwetting at age 9½. This provides additional support for the existing recommendations and no impact on current recommendations was anticipated.

			An amendment will be made to credit the Paediatric Continence Commissioning Guide to the Paediatric Continence Forum in consultation document.

Do you have any comments on areas excluded from the scope of the guideline?			
Stakeholder	**Overall response**	**Comments**	**NICE response**
Cambridge Community Services NHS Trust	Yes	I wonder if there is the possibility to consider Nocturnal Enuresis in young adults. I am occasionally using a slightly higher dose of desmopressin 0.6mg tablet (0.36mg Melt) in very big teenagers. I am also using Mirabegron for bladder instability in my older girls rather than Oxybutynin or Tolterodine	Thank you for your comment. Assessment and treatment of adult bedwetting (over 19s) is outside the scope of the guideline. NICE has produced evidence-based recommendations on mirabegron (Betmiga) for treating overactive bladder in adults: Mirabegron for treating symptoms of overactive bladder
Leeds Teaching Hospitals NHS Trust	No	No, seems appropriate in scope	Thank you for your comment.
NHS England	Not answered	No comments provided	
Royal College of Nursing	Not answered	No comments provided	
Royal College of Paediatrics and Child Health	No	No comments	Thank you.

Public Health England	Yes	There should be consideration of body shape distortion, if applicable, when treating people with disabilities or movement difficulties. Constipation can be a consequence of body shape distortion and this is avoidable with the right postural care. A holistic approach beyond treating acute need(s) should be adopted and consideration given to postural needs. This could be added to section 1.3.9. See the Public Health England postural care guidance for more information and references https://www.gov.uk/government/publications/postural-care-services-making-reasonable-adjustments/postural-care-and-people-with-learning-disabilities. The document mentions both learning disabilities and learning difficulties, it is not clear if this is deliberate or whether those terms are being used interchangeably. The document should clarify as they have different meanings. Ensuring co-ordinated commissioning of integrated local pathways for prevention, identification of needs, early intervention and specialist services will offer support to children with additional health needs or long-term conditions and disabilities, including clinical support for enuresis or diabetes. Further details can be found in 'Best start in life and beyond: Improving public health outcomes for children, young people and families'. Guidance to support the commissioning of the Healthy Child Programme 0-19: Health visiting and school nursing services can be seen via the following link: https://www.gov.uk/government/publications/healthy-child-programme-0-to-19-health-visitor-and-school-nurse-commissioning	Thank you for your comment. Postural care is outside the scope of the guideline. The guideline does recommend that assessment, investigation and/or referral should be considered when bedwetting is associated with comorbidities and other risk factors such as constipation and/or soiling. Furthermore, it states that children or young people with soiling or constipation should be investigated and treated in line with the Constipation in children guideline (CG99). Failure to follow these guideline recommendations is an implementation issue that should be addressed at the local level. However, for interpretation of the guideline, pathways for both nocturnal enuresis and constipation should be referred to as these bring together recommendations in an easy to follow manner. To address the concern about lack of service provision for children with bedwetting following the move of school nursing to Public Health, NICE accredited a commissioning guide (Paediatric Continence Commissioning Guide) by Paediatric Continence Forum to address service provision. This commissioning guide provides support for the local implementation of NICE guidance through commissioning and should be read together with CG111. Thank you for pointing out the use of the terms 'learning disabilities' and 'learning difficulties' in the guideline. We have asked members of the original guideline development committee and they noted that there was no clear recognised definition when the guideline was developed and they used the terms interchangeably. However, their discussions and recommendations incorporated children and young people with both learning disabilities and learning difficulties. But we will note this issue for consideration when an update of the guideline is necessary.

Paediatric Continence Forum	Yes	The role of night time absorbent pants (pull-ups, nappies) is not clear and there is not enough clear guidance for parents or clinicians – yet many parents use these to manage bedwetting for under and over 5s. The scope of the 2010 NICE Guideline did not include a literature review in this area. The only statement was for under 5s (Section 1.16.3) which was based upon the views and experience of GDG members. See above ref**: Grzeda (2017) plus, for example:-** **Kushnir J et al Night time diaper use and sleep in children with enuresis. Sleep med 2103, 14: 1013-6**	Thank you for your comment. With regards to recommendation 1.16.3, the experience of the original GDG was that some children who are continuing to wet the bed at 5 years have not been toilet trained during the day. Parents and carers also use nappies or pull-ups at night and so children do not learn to either hold on or to react to feeling bladder fullness. Children who have been toilet trained and carry out the appropriate toileting behaviours such as going to toilet, sitting appropriately and are not able to stay dry and clean may have underlying problem that needs further assessment. No new evidence relevant to the night time absorbent pants was found and no ongoing studies were identified at the current surveillance review. Kushnir et al. (2013) was identified and assessed through the surveillance review. The study aimed to assess the association between night diapers use and sleep quality of children with enuresis. It does not inform management of bedwetting and assessment of the abstract of this small observational study showed no impact on current recommendations.

Do you have any comments on equalities issues?			
Stakeholder	**Overall response**	**Comments**	**NICE response**
Cambridge Community Services NHS Trust	No	No comments provided	

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 recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees

Leeds Teaching Hospitals NHS Trust	No	No comments provided	
NHS England	Not answered	No comments provided	
Royal College of Nursing	Not answered	No comments provided	
Royal College of Paediatrics and Child Health	No	No comments	Thank you.
Public Health England	Yes	See response to question 2.	Thank you for your comment.
Paediatric Continence Forum	Yes	A “Postcode lottery” on the provision of community- based paediatric continence services mean that many children are disadvantaged in terms of access to treatment	Thank you for your comment. Inequalities in access to paediatric continence services and local service redesign are addressed in a NICE-accredited commissioning guide (Paediatric Continence Commissioning Guide) by Paediatric Continence Forum. This commissioning guide provides support for the local implementation of NICE guidance through commissioning and should be read together with NICE guideline CG111.