National Institute for Health and Care Excellence

Stakeholder comments proforma – engagement exercise for quality standard on nocturnal enuresis

Please enter the name of your registered stakeholder organisation below. NICE is unable to accept comments from non-registered organisation or individuals. If you wish your comments to be considered please register via the NICE website or contact the registered stakeholder organisation that most closely represents your interests and pass your comments to them.	
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Please note: comments submitted are published on the NICE website.	
Would you like to express an interest in endorsing this quality standard? ☐ **Yes**	

Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
Separately list each key area for quality improvement that you would want to see covered by this quality standard. **EXAMPLE: Pulmonary rehabilitation for chronic obstructive**	EXAMPLE: There is good evidence that appropriate and effective pulmonary rehabilitation can drive significant improvements in the quality of life and health status of people with COPD. Pulmonary rehabilitation is recommended within NICE guidance. Rehabilitation should	EXAMPLE: The National Audit for COPD found that the number of areas offering pulmonary rehabilitation has increased in the last three years and although many people are offered referral, the quality of pulmonary rehabilitation and its availability is still limited in the UK. Individual programmes differ in the precise exercises used, are of different duration, involve variable amounts of home exercise and have different referral criteria.	EXAMPLE: Please see the Royal College of Physicians national COPD audit which highlights findings of data collection for quality indicators relating to pulmonary rehabilitation. http://www.rcplondon.ac.uk/resources/chronic-obstructive-pulmonary-disease-audit

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pulmonary disease (COPD)	be considered at all stages of disease progression when symptoms and disability are present. The threshold for referral would usually be breathlessness equivalent to MRC dyspnoea grade 3, based on the NICE guideline.		
Key area for quality improvement 1 Services for treating nocturnal enuresis should be commissioned as part of an integrated service.	The Paediatric Continence Forum (PCF) recommends that children and young people (0-19 years) with nocturnal enuresis should be treated by appropriately paediatric trained professionals within the context of community-based paediatric services that also treat conditions such as daytime incontinence, constipation/soiling, plus advice on toilet training. This service should include children with learning difficulties and physical disabilities. PCF would add that as part of this it is essential to work with commissioners to educate them on the value and greater cost-effectiveness of integrated services.	Treating NE within an integrated service means that children and young people would receive the support of specialist practitioners in a clinically effective and cost-effective setting. In 2011 PCF carried out a project, based on freedom of information requests, identifying how paediatric continence services were being run in primary care trusts. Of the 72 PCTs that responded, 49% were not running “joined up” services, i.e. those that treat all continence problems. NICE’s paediatric continence service commissioning guide states that an effective, integrated paediatric continence service could “lead to up to an 80% reduction in the number of emergency admissions to secondary care, by providing assessment and management of continence problems (constipation urinary tract infections which often present as acute abdominal pain) in primary and community settings”. This is currently being used as a quality measure by CHIMAT.	The PCF has led on producing a commissioning guide for paediatric continence services and is currently submitting the guide to NICE for accreditation. CHIMAT Needs Assessment Report: *Continence in children for local authorities* http://atlas.chimat.org.uk/IAS/profiles/profile?profileId=45&geoTypeId=4 Royal College of Physicians *National Audit of Continence Care* (2010). http://www.rcplondon.ac.uk/resources/national-audit-continence-care NICE paediatric continence service commissioning guide (2010) http://www.nice.org.uk/usingguidance/commissioningguides/paediatriccontinenceservice/home.jsp

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		Effective integrated paediatric services lead to fewer outpatient appointments (for UTIs and constipation). While we understand the present difficulty in using this as a quality measure, PCF believes that this should be worked towards.	
Key area for quality improvement 2 Recognition of the impact of continence problems on children.	NICE estimates that 900,000 children and young people in the UK are affected by bladder or bowel dysfunction (around 11%). Half of all children with a physical disability may have a continence problem.	Continence problems occur at a formative time for children, influencing their health, wellbeing and emotional development. NICE clinical guidelines recognise the association with emotional and behavioural problems – including particularly with bullying. Nocturnal enuresis is not the child's "fault", and children and parents should be educated to understand this. It is essential that children are not punished for wetting accidents, which can result in a "vicious cycle" of increased stress, more accidents, potentially leading to harsher chastisement and a risk of child abuse. Issues of safeguarding need to be addressed.	NICE clinical guidelines 99 and 111. Goodinge S (1998) *Removing Barriers for Disabled Children: Inspection of Services to Disabled Children and their Families*. Social Service Inspectorate.
Key area for quality improvement 3 A focus on the importance of appropriate treatment for children under the age of seven.	There should be clear recommendations for treating children under the age of seven reflecting the added importance of addressing nocturnal enuresis and its effect on behaviour, wellbeing and social life at a young age.	PCF agrees that a key priority for implementation is not excluding younger children from the management of bedwetting on the basis of age alone. While the existing clinical guideline contains treatment recommendations PCF feels these are ambiguous, particularly in relation to the use of	NICE clinical guideline 111, p7-8 and p22.

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		desmopressin which is licensed from age five. The key priorities for implementation (p8 says "offer desmopressin to children and young people over 7 years", but does not discuss those who are younger. However, the guidance goes on to suggest consideration of desmopressin for those aged 5-7 on p 22.	
Key area for quality improvement 4 Clarity around first line treatment.	Children and young people should only receive alarm treatment under appropriate circumstances, as reflected in guidance.	NICE's guidance is clear that alarm treatment should be the first line treatment under certain circumstances(p18-19). While alarm treatment is often successful, the guidance should not be interpreted to mean that alarm treatment should have been tried and failed with all children and young people before commencing treatment with desmopressin. This is particularly important given the limited availability of alarms and the lengthy waiting list for children and young people.	Through its membership the PCF has been made aware of anecdotal evidence from clinicians, that children and young people have to try the alarm first before they can treat with desmopressin.
Key area for quality improvement 5			

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Closing date: Friday 10 January 2014 5pm