

National Institute for Health and Care Excellence

NICE Quality Standards Consultation – Constipation in children and young people

Closing date: 5pm – Tuesday 14 January 2014

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| Organisation   | <b>Paediatric Continence Forum</b>   |
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| <b>Please note:</b> comments submitted on the draft quality standard are published on the NICE website.  |  |
| Would your organisation like to express an interest in endorsing this quality standard? x <input type="checkbox"/> <b>Yes</b>  |  |
| For information about endorsing quality standards please visit <a href="http://www.nice.org.uk/guidance/qualitystandards/indevelopment">http://www.nice.org.uk/guidance/qualitystandards/indevelopment</a> |  |

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Please provide comments on the draft quality standard on the form below, putting each new comment in a new row. When feeding back, please note the section you are commenting on (for example, section 1 Introduction). If commenting on a specific quality statement, please indicate the particular sub-section (for example, statement, measure or audience descriptor). If your comment relates to the standard as a whole then please put 'general'.

In order to guide your comments, please refer to the general points for consideration on the NICE website as well as the specific questions detailed within the quality standard.

Please add rows as necessary.

| Section  | Comments   |
|--|--|
| e.g. Section 1 Introduction or quality statement 1 (measure) | e.g. Comment about quality statement 1.  |
| General  | <p>The Paediatric Continence Forum (PCF) welcomes the development of this quality standard for constipation in children and young people, which we hope we help address the significant challenges of supporting those children and young people concerned. As the NICE guideline indicates, between 5% and 30% of children and young people are affected, and it is more common amongst those with physical disabilities.</p> <p>The PCF is a national group of patient representatives and healthcare professionals which campaigns for improved services for children with continence problems. It was established in 2003, and works closely with the national charities ERIC (Education and Resources for Improving Childhood Continence) and PromoCon (Promoting Continence through Product Awareness). One of the key goals of the PCF is for every area in the UK to have a proper community-based integrated paediatric continence treatment service, led by an expert paediatric continence professional, with a clear system of referral and care pathways across primary and secondary NHS care, education and social services.</p> <p>There is evidence that clinical outcomes are higher when a service is integrated (Royal College of Physicians</p> |

| Section     | Comments  |
|-------------|---|
|             | National Audit of Continence Care 2010). NICE 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 (NICE Commissioning Guide 2010). Emergency admissions for constipation in England are currently being measured by CHIMAT.   |
| General     | The PCF would like to reiterate that continence problems occur at a formative time for children, which influence their health, wellbeing, and emotional development. There is evidence that they are associated with emotional and behavioural problems, including a strong association with bullying, both as recipients and perpetrators. Continence problem, including constipation, can also reduce self-esteem at a crucial time during a child's emotional development, risking their exclusion from normal social interaction (e.g. school trips or sleepovers). |
| General     | In response to evidence that paediatric continence services are not being properly commissioned, the PCF has written a Commissioning Guide for Paediatric Continence, which is currently being considered for accreditation by NICE.  |
| Question 1  | PCF agrees that this draft quality standard accurately reflects the key areas for quality improvement.  |
| Statement 3 | PCF believes this quality statement should be amended to state that the healthcare professional must be "appropriately trained", by which PCF means a healthcare professional, trained in paediatrics, who has a good level of understanding of the range of continence issues. Such an individual should be able to fully understand the implications of constipation/soiling on an individual's health and wellbeing, and manage the situation with the appropriate sensitivity and empathy.  |
| Statement 5 | PCF recommends that upon referral, children and young people 0-19 years with idiopathic constipation should be treated by professionals within the context of community based paediatric services that also treat other conditions such as daytime incontinence and nocturnal enuresis, plus advice on toilet training. The service should include working with children and young people with learning difficulties and physical disabilities.   |

**Closing date:** Please forward this electronically by 5pm on **Tuesday 14 January 2014** at the very latest to [QSconsultations@nice.org.uk](mailto:QSconsultations@nice.org.uk)

**PLEASE NOTE:** The Institute reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of the Institute, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.