

NICE support for commissioning for constipation in children and young people

Issue date: May 2014

1 Introduction

Implementing the recommendations from NICE guidance and other NICE-accredited guidance is the best way to support improvements in the quality of care or services, in line with the statements and measures that comprise the NICE quality standards. This report:

- Highlights the key actions that clinical commissioning groups (CCGs), NHS England area teams, local authorities and their partners should take to improve the quality of care for children and young people with constipation. Providers for the services outlined in this document are: GPs, health and social care workers in community services, school nurses and district general hospitals. Priority actions are outlined in [table 1](#).
- Identifies opportunities for collaboration and integration at a regional and local level.
- Identifies the benefits and potential costs and savings from implementing the changes needed to achieve quality improvement.
- Directs commissioners and service providers to other tools that can help them implement NICE and NICE-accredited guidance.

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. The statements draw on existing guidance, which provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement. For more information see [NICE quality standards](#).

NHS England's [CCG outcomes indicator set](#) is part of a systematic approach to promoting quality improvement. The outcomes indicator set provides CCGs and health and wellbeing boards with comparative information on the quality of health services commissioned by CCGs and the associated health outcomes. The set includes indicators derived from NICE quality standards. By commissioning services in line with the quality standards, commissioners can contribute to improvements in health outcomes, particularly by enhancing processes for assessment, treatment, review and referral.

Commissioners can use the quality standards to improve services by including quality statements and measures in the service specification of the standard contract and establishing key performance indicators as part of tendering. They can also encourage improvements in provider performance by using quality standard measures in association with incentive payments such as the [commissioning for quality and innovation \(CQUIN\) payment framework](#). NICE quality standards provide a baseline against which improvements can be measured and rewarded, enabling commissioners to address gaps in service provision, support best practice and encourage evidence-based care.

This report on the constipation in children and young people quality standard should be read alongside:

- [Constipation in children and young people](#). NICE quality standard 62 (2014).
- [Constipation in children and young people](#). NICE clinical guideline 99 (2010).
- [Paediatric continence service](#). NICE commissioning guide (2010).

2 Overview of constipation in children and young people

Constipation is the inability for a person to pass stools regularly or empty their bowels completely. It can also cause hard or lumpy stools that may be larger or smaller than usual. Idiopathic constipation is constipation that cannot be

explained by anatomical or physiological abnormalities. The exact cause of idiopathic constipation is not fully understood but factors that may contribute include pain, fever, dehydration, dietary and fluid intake, psychological issues, toilet training, medicines and family history of constipation. This document covers idiopathic constipation in children and young people aged from birth to 18 years.

Early diagnosis and treatment are important to prevent chronic constipation. However, people often do not recognise the signs and symptoms of constipation. If constipation is not treated early enough or is left untreated an acute episode may occur, which can lead to anal fissure and constipation can become chronic. Children and young people and their families and carers are often given conflicting advice and practice is often inconsistent, which can make treatment frustrating and less effective.

Services for children with continence difficulties vary across the UK. Many areas do not provide a community-based service that is led by a specialist paediatric continence adviser, and which covers all services.

2.1 *Epidemiology of constipation in children and young people*

Constipation is common in childhood. It is prevalent in between 5% and 30% of children, depending on the criteria used for diagnosis, and has peak prevalence in toddlers. It is estimated that 1% of children and young people aged between 11 and 18 years have idiopathic constipation. Some children and young people with physical disabilities, such as cerebral palsy, are more prone to idiopathic constipation as a result of impaired mobility. Children and young people with Down's syndrome or autism are also more prone to the condition. A higher prevalence also occurs in children and young people in local authority care.

Symptoms of constipation become chronic in more than one-third of children and young people, and constipation is a common reason for referral to secondary care. Morbidity may be under-reported because people may be too embarrassed to seek advice. The NICE [costing report](#) for constipation in

children and young people estimated that only 5% of children and young people with constipation present for treatment.

Inpatient data from hospital episode statistics in 2012/13 show that there were 13,135 finished consultant episodes for constipation in children and young people, of which 79% (10,400) were emergency admissions.

3 Summary of commissioning and resource implications

Children and young people with idiopathic constipation can present to a number of different health and social care professionals, such as GPs, pharmacists, school nurses, social workers, health visitors, practice nurses, continence advisors, paediatricians or staff at a specialist continence service. Establishing a paediatric continence service for children and young people aged 19 years and under could lead to a significant reduction in the number of admissions to secondary care for idiopathic constipation, by providing assessment and management of continence problems in primary and community settings.

The 2010 National audit of continence care for adults found that most continence services are poorly integrated across acute, primary and community settings, that training of healthcare professionals is inadequate and that there is no-one specifically responsible for commissioning and improving continence services. For good practice in paediatric continence services commissioners of health and social care services should commission an integrated paediatric continence service.

Current commissioning responsibilities for constipation in children and young people are as follows:

- CCGs are responsible for commissioning acute and community services, including continence services. CCGs are therefore largely responsible for commissioning **most** of the elements of care outlined in this document.
- NHS England area teams are currently responsible for commissioning aspects of public health, which include services for children from pregnancy

to age 5 years (the Healthy Child Programme: pregnancy and the first 5 years of life), including health visits and Family Nurse Partnership Programme (although the responsibility for children's public health from 0-5 years is due to transfer to local authorities in 2015).

- Local authorities are currently responsible for commissioning children's public health from 5-19 years (Healthy Child Programme for school-age children). This includes school nurses.

Table 1 summarises the priority commissioning actions and potential resource implications for commissioners working towards achieving this quality standard. See section 4 for more detail on commissioning and resource implications.

Table 1 Priority commissioning actions, provider implications and potential resource impact for constipation in children and young people

Quality improvement area	Commissioning actions	Provider implications	Resource impact
Assessment and treatment (Quality statements 1&2)	<p>CCGs, NHS England area teams and local authorities should seek assurance that:</p> <ul style="list-style-type: none"> • arrangements are in place for providers to carry out a full assessment before idiopathic constipation is diagnosed • protocols are in place to administer oral macrogols as a first-line treatment. <p>NHS England area teams should seek assurance that pharmacists are aware that oral macrogols are the most effective first line treatment.</p>	GP surgeries, community services, district general hospitals and school nurses should ensure that full assessments and protocols are in place in line with quality statements 1 and 2.	<p>Potential costs for training to allow staff to undertake a full assessment to diagnose constipation.</p> <p>Potential reduction in referrals to secondary care for diagnosis of constipation.</p> <p>Potential increase in prescribing oral macrogols.</p> <p>Potential reduction in referrals to secondary for treatment of constipation.</p>
Reviewing disimpaction and maintenance therapy (Quality statements 3&4)	CCGs and NHS England area teams should seek assurance that procedures for review and monitoring are in place in line with quality statements 3 and 4.	GP surgeries, community services, district general hospitals and school nurses should ensure that procedures for review and monitoring are in place.	<p>Potential costs from ensuring appropriate continence services for children and young people exist within primary care.</p> <p>Savings from a potential reduction in inappropriate use of secondary care services – see section 4.2</p>
Written information (Quality statement 5)	CCGs and NHS England area teams should seek assurance that providers can demonstrate that written information is	GP surgeries, community services, district general hospitals should ensure that appropriate written information is	No significant costs anticipated due to written information already being available. Providing written information may result in more

	provided about laxatives at the start of treatment.	available.	effective management of the condition.
Specialist referral (Quality statement 6)	CCGs and NHS England area teams should seek assurance that local contract monitoring is in place in order to ensure that providers in all settings adhere to the 3 month targets in line with quality statement 6.	GP surgeries, community services and district general hospitals should ensure that children and young people are referred to a healthcare professional with expertise in the problem after 3 months (if they do not respond to initial treatment).	Numbers of referrals are likely to be small; therefore no significant costs are anticipated.

4 Commissioning and resource implications

This section considers the commissioning implications and potential resource impact of implementing the recommendations to achieve the NICE quality standard for constipation in children and young people.

4.1 *Assessment and treatment*

Quality statement 1: Assessment

Children and young people with constipation receive a full assessment before a diagnosis of idiopathic constipation is made.

Quality statement 2: First-line treatment with laxatives

Children and young people with idiopathic constipation receive oral macrogols as first-line treatment.

A diagnosis of idiopathic constipation can only be made through a full assessment, including a detailed history and physical examination by a healthcare professional, for example by a paediatric continence service or a GP with a special interest. Key components of assessment can be found in

[tables 1–3](#) of Constipation in children and young people (NICE clinical guideline 99). It is anticipated that this can be delivered within existing resources, for example, it is usually carried out by a GP and would be funded under the GP Contract. If a child or young person has any 'red flag' symptoms, healthcare professionals should not treat them for constipation. Instead, they should be referred urgently to a healthcare professional with experience in the area of concern. 'Red flag' findings and diagnostic clues that indicate an underlying disorder or condition (not idiopathic constipation) are detailed in full in [tables 2 and 3](#) of Constipation in children and young people (NICE clinical guideline 99).

NHS England area teams, CCGs and local authorities all need to ensure that healthcare professionals can perform a full assessment described above. Where appropriate, CCGs, NHS England area teams and local authorities may wish to audit service providers for evidence of practice that children and young people receive a full assessment before a diagnosis of idiopathic constipation is made (for example, using the NICE [constipation in children and young people audit support](#)).

Expert opinion suggests that in current practice many children are seen by a GP, who then refers them on to secondary care for diagnosis of constipation. CCGs should seek assurance that only appropriate referrals are being made to secondary care. A review of referrals in this area may highlight an opportunity for CCGs to reduce costs- for example, a consultant outpatient attendance at a cost of £224¹.

Laxative treatment is effective for constipation. CCGs and NHS England area teams should ensure that all healthcare professionals, including pharmacists, are aware that macrogols are the first-line laxative of choice unless otherwise indicated. Children and young people should either start disimpaction therapy with an escalating dose regime or maintenance therapy, depending on the results of the physical examination.

¹ Per Reference Costs 2012/13– Consultant led outpatient attendance– specialty 251 Paediatric Gastroenterology £224.

[Analysis of prescribing data](#) for all prescriptions dispensed in the community from NHS prescription services for paediatric oral macrogols for the period 2009 to 2012 shows that prescribing has increased from 205,000 prescriptions at a cost of £1.4 million to 469,000 prescriptions at a cost of £3.1 million, a year-on-year increase of approximately 30%. Specific analysis of GP prescribing data from the IMS Disease Analyser database for all children with a diagnosis of constipation aged 0 to 18 years, showed an increase in the prescribing of macrogols of approximately 12% from 2009/10 to 2012/13. This analysis also showed that macrogols make up approximately 54% of the laxatives prescribed. While this is a substantial change in prescribing practice, expert opinion suggests that oral macrogols should be prescribed more widely for children and young people, and that some clinicians are unaware that oral macrogols should be the first-line treatment for constipation.

This suggests that there is further scope for an increase in prescribing of oral macrogols for children. The indicative costs of 3 months of treatment with oral macrogols and other laxatives are shown in appendices A and B. For every additional 10% switch in prescribing from lactulose to oral macrogols, there will be an estimated increase in costs of £585 per 100,000 population for 3-months treatment. For every 10% increase in the prescribing of oral macrogols (without a corresponding decrease in the prescribing of other laxatives) there will be an estimated cost of £800 per 100,000 population. Organisations need to check prescribing practice in their local area to assess the resource impact locally.

Expert opinion suggests that in approximately one-third of children and young people with constipation, the condition will become chronic. Early assessment and effective treatment in primary care may result in reduced referrals to secondary care for the treatment of constipation.

Commissioners and others may wish to refer to the [audit support](#) tool for NICE clinical guideline 99 on constipation in children and young people.

Further information can be found in section [1.1.1](#), [1.1.2](#) and [1.1.3](#) of the

NICE commissioning guide on constipation in children and young people.

Commissioners may wish to refer to [hospital episode statistics](#) for local figures relating to children admitted to hospital with constipation.

4.2 *Reviewing disimpaction and maintenance therapy*

Quality statement 3: Reviewing disimpaction therapy

Children and young people with idiopathic constipation starting disimpaction therapy have their treatment reviewed by a healthcare professional within 1 week.

Quality statement 4: Reviewing maintenance therapy

Children and young people with idiopathic constipation starting maintenance therapy have their first treatment review by a healthcare professional within 6 weeks.

Expert clinical opinion suggests that regular treatment reviews are not currently common practice. CCGs and NHS England area teams may wish to include 1- and 6-week treatment reviews in service specifications where necessary, in line with the above statements.

It is anticipated that this can be delivered within existing resources, for example, face-to-face appointments are not always needed and they can sometimes be carried out by telephone.

However, a lack of availability of appropriate paediatric continence services or services in primary care may mean that the review is carried out in secondary care. There may be costs involved in ensuring that there are appropriate continence services for children and young people in primary care. Due to wide variability in practice it is not possible to provide an indicative cost for a paediatric continence service, but the [paediatric continence service](#) NICE

commissioning guide may be used to assess costs at a local level. Availability of such services should avoid unnecessary use of secondary care services- for example, an unnecessary consultant outpatient attendance at a cost of £224.²

Commissioners and others may wish to refer to the [audit support](#) tool for NICE clinical guideline 99 on constipation in children and young people.

Further information can be found in section [1.1.1](#), [1.1.2](#) and [1.1.3](#) of the NICE commissioning guide on constipation in children and young people.

4.3 ***Written information***

Quality statement 5: Written information

Children and young people with idiopathic constipation starting laxative treatment, or their parents or carers, receive written information about laxatives.

CCGs and NHS England area teams should ensure that providers can demonstrate that written information about constipation and its management is provided for children and young people with idiopathic constipation who are undergoing laxative treatment.

Parents and carers play a key role in supporting the child or young person's self-management, so it is important that they are provided with clear information about the condition as appropriate, including how to take their medication and what to expect when taking laxatives. This information can be referred to, can act as a reminder of key information and can help to answer any queries.

² Per Reference Costs 2012/13– Consultant led outpatient attendance– specialty 251 Paediatric Gastroenterology £224.

The recommendations in Constipation in children and young people (NICE clinical guideline 99) also include a recommendation to ‘offer a point of contact with specialist healthcare professionals who can give ongoing support’ (recommendation 1.8.2), who would be able to provide additional advice and support and answer queries about treatment.

Parental or family education on understanding the aetiology, symptoms and principles of management are also important.

Expert opinion suggests that there is sufficient existing literature that can be provided to parents, carers, children and young people. They should also be signposted to other sources of useful information, for example [ERIC](#) (Education and Resources for Improving Childhood Continence) and encouraged to contact their specialist healthcare professionals for ongoing support. CCGs and NHS England area teams should seek assurance that healthcare professionals are aware of the importance of providing written information about laxatives (and explaining about their use) to children and young people and their parents or carers at the start of treatment.

Achieving this quality statement is not anticipated to have a significant resource impact, as this statement reinforces good clinical practice, and may result in improved adherence to treatment and more effective management of the condition.

Further information about what written information around laxatives should include can be found in NICE clinical guideline 99, recommendation [1.8.1](#).

See also NICE constipation in children and young people: [guide to resources](#).

4.4 Referral if no response to treatment

Quality statement 6: Referral if no response to treatment

Children and young people with idiopathic constipation that does not respond

to initial treatment within 3 months are referred to a healthcare professional with expertise in the problem.

CCGs and NHS England area teams should seek assurance that local contract monitoring is in place in order to ensure that providers, including community and continence services and GPs, adhere to the 3-month target in line with this statement.

CCGs and NHS England area teams may wish to consider requesting evidence of written protocols from continence services and GP surgeries that children and young people, who do not respond to initial treatment, are referred to a healthcare professional with expertise in the problem after a period of 3 months.

A healthcare professional with expertise in the problem may include, but is not limited to, a specialist continence nurse, community paediatrician or GP with a special interest. Wherever paediatric continence services are not in place, this is likely to occur in secondary care, with an estimated cost of £240 per referral. Numbers of referrals are likely to be small; therefore no significant costs are anticipated. Non-adherence to this statement may lead to expenditure on ineffective treatments.

5 Other useful resources

5.1 Policy documents

- Department of Health (2010) [National service framework for children, young people and maternity services – continence issues for a child with learning difficulties](#)
- Department of Health (2007) [National service framework for children, young people and maternity services – continence.](#)
- Department of Health (2004) [National service framework for children, young people and maternity services: core document](#)

5.2 Useful resources

- All Party Parliamentary Group for Continence Care (2013) [Continence care services in England](#)
- Royal College of Physicians (2010) [National audit of Continence Care, Combined Organisational and Clinical Report](#)
- [The Paediatric Continence Forum](#)
- [Association for Continence Advice](#)
- [PromoCon \(Promoting Continence and Product Awareness\)](#)

5.3 NICE implementation support.

- [Constipation in children and young people](#). NICE costing report (2010)
- [Constipation in childhood and nocturnal enuresis](#). BMJ learning and NICE online educational tool (2010)

5.4 NICE pathways

- [Constipation in children and young people](#)

Copyright

© National Institute for Health and Care Excellence 2014. All rights reserved. NICE copyright material can be downloaded for private research and study, and may be reproduced for educational and not-for-profit purposes. No

reproduction by or for commercial organisations, or for commercial purposes,
is allowed without the written permission of NICE.

Appendix A. Indicative costs of treatment with oral macrogols

Drug Name	Age group	Minimum daily dose ¹	Maximum daily dose ¹	Cost per sachet ²	Daily cost-minimum dose £	Daily cost-maximum dose £	Average of minimum and maximum daily costs £	Cost of 3 months treatment ⁴ £
Disimpaction								
Macrogol 3550 paediatric formula	Under 1 year	0.5	1	0.15	0.08	0.15	0.11	10.13
	1-5 years	2	8	0.15	0.30	1.20	0.75	67.50
	5-12 years	4	12	0.15	0.60	1.80	1.20	108.00
Macrogol 3550 adult formula ³	12-18 years	4	8	0.22	0.88	1.76	1.32	118.80
Ongoing maintenance								
Macrogol 3550 paediatric formula	Under 1 year	0.5	1	0.15	0.08	0.15	0.11	10.13
	1-6 years	1	4	0.15	0.15	0.60	0.38	33.75
	6-12 years	2	4	0.15	0.30	0.60	0.45	40.50
Macrogol 3550 adult formula ³	12-18 years	1	2	0.22	0.22	0.44	0.33	29.70
<p>1 Dosages taken from BNF for children online - accessed 06 March 2014 For ages under 12 years, based on Movicol Paediatric , for those 12 years and over, based on Movicol or Macrogol oral powder (same dosage for each)</p> <p>2 Cost per sachet taken from BNF online for Movicol Paediatric (for all ages up to the age of 12) or Movicol (for ages 12 and over)- accessed 06 March 2014 - as not listed in electronic drug tariff.</p> <p>3 Macrogol oral powder or Movicol - same doses for each per BNF for children</p> <p>4 Calculated as 90 days at the average of minimum and maximum daily dose costs</p>								

Appendix B. Indicative costs of treatment with other laxatives recommended in NICE clinical guideline 99

Drug Name	Age group	Daily dose ¹	Minimum daily dose	Maximum daily dose	Cost per Electronic Drugs Tariff ²	Daily cost- minimum dose £	Daily cost- maximum dose £	Average of minimum and maximum daily costs £	Cost of 3 months treatment ⁶ £
Lactulose	1 month to 1 year	2.5ml twice daily	5 ml	5 ml	3.1-3.7mg/5ml oral solution 500ml -£3.09	0.03	0.03	0.03	2.70
	1-5 years	2.5ml-10ml twice daily	5ml	20ml		0.03	0.12	0.08	6.75
	5-18 years	5-20ml twice daily	10 ml	40ml		0.06	0.24	0.15	13.50
Sodium picosulphate	1 month to 4 years	2.5-10mg once daily	2.5mg	10mg	Oral solution 5mg/5ml	0.05	0.20	0.13	11.25
	4-18 years	2.5-20mg once daily	2.5mg	20mg	300ml-£5.78	0.05	0.40	0.23	20.25
Bisacodyl	4-18 years	5-20mg once daily	5mg	20mg	5mg tablets 60 tablets - £2.47	0.04	0.16	0.10	9.00
Senna	1 month to 4 years	2.5-10ml once daily ⁵	2.5ml	10ml	7.5 mg/5ml oral solution	0.03	0.10	0.06	5.63
	4-18 years	2.5-20ml once daily ⁵	2.5ml	20ml	500ml -£2.69	0.03	0.20	0.11	10.13
Docusate sodium	6 months-2 years	12.5mg three times daily ³	37.5mg	37.5mg	Paediatric - 12.5mg/5ml oral solution 300ml-£5.29 ⁴	0.27	0.27	0.27	24.30
	2-12 years	12.5-25mg three times daily ³	37.5mg	75mg		0.27	0.54	0.41	36.45
	12-18 years	up to 500mg daily in divided doses	37.5mg	500mg	Adult - 50mg/5ml oral solution 300ml-£5.49 ⁴	0.09	0.90	0.50	44.55
<p>1 Dosages taken from BNF for Children online- accessed 06 March 2014</p> <p>2 Electronic drugs tariff (EDT), accessed 06 March 2014 . Available online at http://www.ppa.org.uk/ppa/edt_intro.htm</p> <p>3 Use paediatric oral solution</p> <p>4 Price for Docusol per Electroni cDrugs Tariff</p> <p>5 Doses for Senokot syrup</p> <p>6 Calculated as 90 days at the average of minimum and maximum daily dose costs</p>									