NICE support for commissioning for faecal incontinence

February 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 NHS England area teams, Clinical Commissioning Groups, Local Authorities and their partners should take to improve the care of people with faecal incontinence. Priority actions are outlined in table 1.
- Identifies opportunities for collaboration and integration at a local and regional level.
- Identifies the benefits and potential costs or savings from implementing the changes needed to achieve quality improvement.
- Directs commissioners and service providers to support 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
Clinical Commissioning Groups (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.

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 Using 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.

It is likely that continence services will be commissioned in an integrated way, therefore this report on the faecal incontinence quality standard should be read alongside:

- **Faecal incontinence.** NICE quality standard 54 (2014).
- **Patient experience in adult NHS services.** NICE quality standard 15 (2012).
- **Lower urinary tract symptoms in men.** NICE quality standard 45 (2013)
- **Faecal incontinence.** NICE clinical guideline 49 (2007).
- **Irritable bowel syndrome.** NICE clinical guideline 61 (2008).
- **Lower urinary tract symptoms in men.** NICE clinical guideline 97 (2010).
- **Urinary incontinence in neurological disease.** NICE clinical guideline 148 (2012).
- **Urinary incontinence in women.** NICE clinical guideline 171 (2013).
2 Overview of faecal incontinence

Faecal incontinence is a symptom, rather than a diagnosis. For many people, faecal incontinence is the result of a complex interplay of contributing factors, many of which can co-exist. The quality standard covers the management of faecal incontinence, defined as any involuntary loss of faeces that is a social or hygiene problem, in adults (18 years and older) in the community (at home and in care homes) and in hospital (all departments).

Effective management depends on identifying the factors causing faecal incontinence for each person, and finding a combination of interventions that is acceptable to the person and that gives best control of their incontinence. Faecal incontinence can be stigmatising and people can be reluctant to disclose symptoms without specific enquiry. In most cases, symptoms can at least be improved or even resolved.

Typically, a baseline assessment in people with faecal incontinence leads to either condition-specific interventions or initial management for faecal incontinence. Initial management addresses reversible factors and can include advice about diet, bowel habit, toilet access and medication. Initial, conservative management is likely to take place in primary care. People who continue to have episodes of faecal incontinence after initial management are considered for specialised management, which may involve referral to a specialist continence service.

Healthcare professionals involved in the management of faecal incontinence include GPs, specialist continence nurses, physiotherapists, colorectal surgeons, gastroenterologists, neurologists and care of the elderly specialists. Specialised management may consist of specialist assessment, pelvic floor muscle training, bowel retraining, specialist dietary assessment and management, biofeedback, electrical stimulation, rectal irrigation or surgery.

Appropriate care for people with faecal incontinence should lead to improvements in quality of life. For some people with faecal incontinence (such as people with neurological injury or severe cognitive impairment, or
frail older people) better management may also eliminate or delay the need for residential care.

2.1 Epidemiology of faecal incontinence

Between 1 and 10% of adults are affected by faecal incontinence, depending on the definition used. It is likely that 0.5–1.0% of adults experience regular faecal incontinence that affects their quality of life. Faecal incontinence has remained a largely hidden problem, with many people feeling too embarrassed to describe their symptoms to healthcare professionals, or even to family and friends. Cultural and religious factors can also exacerbate this issue. People with faecal incontinence often experience social exclusion, and frequently experience stress, anxiety and depression. Faecal incontinence is closely associated with age (prevalence is about 15% in adults aged 85 years living at home) and is even more common in residential and nursing homes (prevalence ranges from 10 to 60%).

There is no consensus on methods of classifying the symptoms and causes of faecal incontinence. It is most commonly classified according to:

- Symptom: for example, whether the person experiences an urge before leakage (urge faecal incontinence) or has no sensation (passive soiling).
- Character of the leakage: for example, solid, liquid, mucus or flatus (‘anal incontinence’ is the term most often used to include gas incontinence).
- Patient group: for example, people with neurological conditions, frail older people, women with obstetric injuries.
- Presumed primary underlying cause: for example, damage or weakness to the internal or external anal sphincter, faecal loading, neurological motor or sensory impairment, cognitive impairment, problems with toilet access, rectal capacity, gut motility or stool consistency.

Nearly two-thirds of people with faecal incontinence also have urinary incontinence (known as double incontinence). For more information on urinary incontinence, see the NICE clinical guidelines on urinary incontinence in

women, lower urinary tract symptoms in men and urinary incontinence in neurological disease.

3 Summary of commissioning and resource implications

The cost of meeting the quality standard for faecal incontinence depends on current local practice and the progress organisations have made in implementing NICE and NICE-accredited guidance.

Services should be commissioned from and coordinated across all relevant agencies encompassing the whole faecal incontinence care pathway. The main commissioner will be CCGs, but will also include NHS England area teams, who are responsible for commissioning primary care services, and Local Authorities, who commission many residential care homes.

Faecal continence services should be provided as part of an integrated continence service and people with faecal incontinence should be offered care by health and social care professionals who have the relevant skills, training and experience. A person-centred, integrated approach to providing services is fundamental to delivering high-quality care to adults with faecal incontinence in all settings. The National audit of continence care concluded that most continence services are poorly integrated across acute, medical, surgical, primary, care home and community settings, resulting in disjointed care for patients and carers.

Expert opinion suggests that there is considerable under-recognition of faecal incontinence in adults over 18, in particular among those with multiple comorbidities. Using more focused case-finding may result in an increase in the detection rate of faecal incontinence in the community and in hospitals. Because faecal incontinence is under-reported, the estimation of this potential increase is subject to a high degree of uncertainty.

Poor management of faecal incontinence may increase the risk of skin conditions and falls. Effective initial management may reduce the number of referrals to some specialist services. It can also help carers to cope, helping
to prevent carer breakdown and potentially delaying the need for domiciliary or residential care. According to the All Party Parliamentary Group for Continence Care Report 2011, incontinence is a significant factor for initiating care home admission.

Implementing more robust initial management of faecal incontinence through the use of baseline assessments, advice and support and individual management plans could contribute towards providing the best possible outcomes for people with faecal incontinence and their carers. Best possible outcomes could mean: alleviating symptoms of faecal incontinence; preserving dignity, independence and mobility; reducing urinary tract infections, falls, social isolation and depression; reducing inappropriate and costly reliance on disposable pads and other containment products; and reducing inappropriate referrals to specialised services.

Commissioners can use the commissioning and budgeting tool to estimate the level of service needed locally and the cost of commissioning baseline assessments and specialised management.

Table 1 summarises the commissioning and resource implications for commissioners working towards achieving this quality standard. See section 4 for more detail on commissioning and resource implications.
**Table 1 Potential commissioning and resource implications of achieving the quality standard for faecal incontinence**

<table>
<thead>
<tr>
<th>Area of care</th>
<th>Commissioning implications</th>
<th>Estimated resource impact</th>
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<tbody>
<tr>
<td>Identification in high-risk groups</td>
<td>NHS England area teams, CCGs and Local Authorities should all ensure that healthcare professionals have been briefed to sensitively ask people in high-risk groups whether they have bowel control problems. This information may also need to be recorded and monitored as appropriate.</td>
<td>No additional costs are expected.</td>
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<tr>
<td>Baseline assessment, coping with symptoms and initial management</td>
<td>CCGs and NHS England area teams should specify and request evidence of practice by monitoring the proportion of people who are offered baseline assessments, coping strategies and initial management plans. CCGs and NHS England area teams may also wish to work collaboratively to ensure that healthcare professionals have relevant, up-to-date training to carry out these initial management steps.</td>
<td>Costs are expected from increasing the proportion of people offered baseline assessments. No costs are anticipated from offering coping strategies and initial management plans because they are expected to be delivered as part of an existing consultation.</td>
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<tr>
<td>Specialised management</td>
<td>CCGs should monitor the number of people who are offered referral for appropriate specialised management after receiving initial management for faecal incontinence.</td>
<td>There may be costs at a local level if commissioners need to increase the capacity of existing continence services or referrals to secondary care.</td>
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**4 Commissioning implications and cost impact**

This section considers the commissioning implications and potential resource impact of implementing the recommendations to achieve the NICE quality standard for faecal incontinence.
## 4.1 Identification in high-risk groups

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<tr>
<th>Quality statement 1: Identification in high-risk groups</th>
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<tbody>
<tr>
<td>People in high-risk groups for faecal incontinence are asked in a sensitive way, when the risk factor is identified and then according to local care pathways, whether they have bowel control problems.</td>
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Faecal incontinence may have many different causes but can have a significant negative impact on quality of life, and is under-reported because of embarrassment and fear of stigma. Some people may report symptoms in a less direct way, for example by reporting symptoms of diarrhoea. Faecal incontinence (NICE clinical guideline 49) states that active case-finding will often be needed. Case-finding upon presentation in various healthcare settings (mainly, but not limited to, primary care) is likely to be the biggest opportunity to improve quality of life for people with faecal incontinence.

People considered at risk of faecal incontinence include frail older people, women following childbirth, people with neurological or spinal disease or injury, people with severe cognitive impairment, people with urinary incontinence, people who have undergone pelvic radiotherapy, people with pelvic organ prolapse and/or rectal prolapse, people with perianal soreness, itching or pain and people with learning disabilities. It is expected that healthcare professionals will ask at-risk groups as they present (and in a sensitive way), at appropriate points in local care pathways. For example, this may be done at GP appointments, social care assessment, during hospital admission or as care plans are put in place in residential care (for further information, see NICE support for commissioning for mental wellbeing of older people in care homes).

NHS England area teams, Clinical Commissioning Groups and Local Authorities may wish to work together to think about how to raise awareness among healthcare professionals of the potential benefits of asking at-risk groups, in a sensitive way, whether they have bowel control problems. Once
faecal incontinence has been identified, there are treatments that can help manage or sometimes cure it, as well as strategies to help people cope with the condition and discuss it openly.

It is anticipated this identification would take place within an existing consultation, for example a GP appointment or during annual review, therefore no additional costs are expected.

4.2 Initial management

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<th>Quality statement 2: Baseline assessment</th>
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<tbody>
<tr>
<td>People reporting bowel control problems are offered a full baseline assessment, which is carried out by healthcare professionals who do not assume that symptoms are caused by any existing conditions or disabilities.</td>
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<tr>
<th>Quality statement 3: Coping with symptoms</th>
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<tr>
<td>People with faecal incontinence and their carers are offered practical support, advice and a choice of appropriate products for coping with symptoms during the period of assessment and for as long as they experience episodes of faecal incontinence.</td>
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<th>Quality statement 4: Initial management</th>
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<tbody>
<tr>
<td>People with faecal incontinence have an initial management plan that covers any specific conditions causing the incontinence, diet, bowel habit, toilet access and medication.</td>
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A baseline assessment is carried out to confirm symptoms, to identify the causes and contributing factors of faecal incontinence, and to ensure that people get the most appropriate treatment. Because faecal incontinence is a symptom (rather than a diagnosis) there is a risk that healthcare professionals could make assumptions about causes in people with pre-existing conditions or disabilities (such as a neurological condition or cognitive impairment). Faecal incontinence may have different contributing factors in people with the
same long-term condition. A baseline assessment that takes account of the individual person, rather than assuming incontinence is related to a pre-existing condition, is therefore essential. Baseline assessments can help to prevent discrimination in access to appropriate care by ensuring that the contributing factors to faecal incontinence are properly identified, so that appropriate management can be planned. CCGs and NHS England area teams should request and monitor evidence of practice from providers that people reporting bowel control problems are offered a full baseline assessment.

Some interventions for faecal incontinence can take time to be effective, so it is important that people are able to cope with symptoms while appropriate management is planned and while symptoms persist. Access to appropriate coping strategies can allow people with faecal incontinence to lead active lives. Most symptoms of faecal incontinence can be improved, and many resolved, with initial conservative management. Considering simple management options that may improve or resolve symptoms, as well as providing support and advice on coping, should lead to the biggest improvements in quality of life for people with faecal incontinence. Initial, conservative management options can include provision of a choice of continence products (such as disposable pads, devices or gloves and skin care products) and information about use.

CCGs and NHS England area teams may wish to seek assurances that the relevant healthcare professionals are sufficiently trained to offer baseline assessments, to provide advice, support and a choice of appropriate products, and to offer initial management plans to people presenting with faecal incontinence. Healthcare professionals should also have up-to-date knowledge of health promotion such as the National Key Scheme (NKS). Radar NKS keys cost around £4.50 each from Disability Rights UK.

Costs are expected from increasing the proportion of people offered baseline assessments, which are estimated to cost around £22 each (based on an hour of band 6 nursing time). The commissioning and budgeting tool estimates that 0.65% of the population will be offered a baseline assessment.
This is based on prevalence data obtained from The Health Improvement Network (THIN) database. Local costs can be estimated using the associated commissioning and budgeting tool for this document. No additional costs are anticipated from offering coping strategies and initial management plans because they are expected to be delivered as part of an existing consultation.

4.3 Specialised management

Quality statement 5: Specialised management

People who continue to experience episodes of faecal incontinence after initial management are offered referral for specialised management.

Some people will continue to have episodes of faecal incontinence after initial management. If they choose to pursue active management, they may benefit from specialised assessment and management. This may include access to specialist diagnostic tests as well as treatment.

Access to the most appropriate specialist management will improve the quality of life for some people with faecal incontinence.

Specialist management will be provided by healthcare professionals who have undertaken further study and training to acquire the skills needed for more comprehensive assessment of faecal incontinence. These healthcare professionals will have access to specialised equipment for assessment and treatment (such as rectal irrigation). CCGs may wish to note that there is a potential shortage of specialist continence nurses; the Continence care services England 2013 survey report highlights that the number of continence nurse specialists has actually fallen in the past 12 months in 27% of primary care sites and 18% of acute sites, whereas the clinical audit showed that continence nurse specialists are delivering the most continence care. CCGs may therefore wish to consider working with providers at a local level to incentivise training programmes for continence nurse specialists.
There may be costs at a local level if commissioners need to increase the capacity of existing continence services or referrals to secondary care. The associated commissioning and budgeting tool for faecal incontinence allows calculation of costs associated with specialised management in both secondary care and the community. The tool assumes that 10% of the people offered a baseline assessment are referred for specialised continence management. The tool should be amended to reflect local circumstances.

5 Other useful resources

5.1 Policy documents


5.2 Useful resources


5.3 NICE implementation support

- Faecal incontinence. NICE audit support (2007).
- Faecal incontinence. NICE slide set (2007).

5.4 NICE pathways

- Faecal incontinence.