

Faecal incontinence

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Introduction

This 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). For more information see the <u>Faecal incontinence topic overview</u>.

Why this quality standard is needed

Faecal incontinence is a symptom, rather than a diagnosis. For many people faecal incontinence is the result of a complex interplay of contributing factors. 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 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. Nearly two-thirds of people with faecal incontinence also have urinary incontinence (known as double incontinence) although management, including any specialist input, may be quite distinct. Faecal incontinence has remained a largely hidden problem, with many people feeling too embarrassed to describe their symptoms to health and social care practitioners, or even to family and friends. People with faecal incontinence often experience social exclusion, and frequently suffer from stress, anxiety and depression. 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.

How this quality standard supports delivery of outcome frameworks

NICE quality standards are a concise set of prioritised statements designed to drive measureable quality improvements within a particular area of health or care. They are derived from high-quality guidance, such as that from NICE or other sources accredited by NICE. This quality standard, in conjunction with the guidance on which it is based, should contribute to the improvements outlined in the following 3 outcomes frameworks published by the Department of Health:

- The Adult Social Care Outcomes Framework 2013–14
- NHS Outcomes Framework 2014–15
- Improving outcomes and supporting transparency: a public health outcomes framework for England 2013–2016, Part 1 and Part 1A.

Tables 1–3 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 The Adult Social Care Outcomes Framework 2013-14

Domain	Overarching and outcome measures
1 Enhancing quality of	Overarching measure
ife for people with care	1A Social care-related quality of life*
and support needs	Outcome measures
	People manage their own support as much as they wish, so that are in control of what, how and when support is delivered to match their needs.
	1B Proportion of people who use services who have control over their daily life
	Carers can balance their caring roles and maintain their desired quality of life.
	1D Carer-reported quality of life
	People are able to find employment when they want, maintain a family and social life and contribute to community life, and avoid loneliness or isolation.
	1G Proportion of adults with a learning disability who live in their own home or with their family**
	1I Proportion of people who use services and their carers, who reported that they had as much social contact as they would like*

2 Delaying and reducing the need for care and support	Overarching measures 2A Permanent admissions to residential and nursing care homes per 1000 population
	Outcome measures
	2F Dementia – a measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life**

Aligning across the health and care system

- * Indicator complementary
- ** Indicator shared

Table 2 NHS Outcomes Framework 2014–15

Domain	Overarching indicators and improvement areas
2 Enhancing quality of life for	Overarching indicator
people with long-term conditions	2 Health-related quality of life for people with long-term conditions**
	Improvement areas
	Ensuring people feel supported to manage their condition
	2.1 Proportion of people feeling supported to manage their condition**
	Improving functional ability in people with long-term conditions
	2.2 Employment of people with long-term conditions***
	Enhancing quality of life for carers
	2.4 Health-related quality of life for carers**
	Enhancing quality of life for people with dementia
	2.6ii A measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life (Placeholder)**

Alignment across the health and social care system

- ** Indicator complementary with Adult Social Care Outcomes Framework
- ***Indicator shared with Public Health Outcomes Framework

Table 3 Public health outcomes framework for England, 2013-2016

Domain	Objectives and indicators
1 Improving the wider determinants of health	Objective Improvements against wider factors that affect health and wellbeing and health inequalities
	Indicators
	1.6 Adults with a learning disability/in contact with secondary mental health services who live in stable and appropriate accommodation
	1.18 Social isolation (Placeholder)
	1.8 Employment for those with long-term health conditions including adults with a learning disability or who are in contact with secondary mental health services

Coordinated services

The quality standard for faecal incontinence specifies that services should be commissioned from and coordinated across all relevant agencies encompassing the whole faecal incontinence care pathway. A person-centred, integrated approach to providing services is fundamental to delivering high-quality care to adults with faecal incontinence in all settings.

The Health and Social Care Act 2012 sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services, as part of a general duty to secure continuous improvement in quality. Commissioners and providers of health and social care should refer to the library of NICE quality standards when designing high-quality services. Other quality standards that should also be considered when choosing, commissioning or providing a high-quality faecal incontinence service are listed in Related NICE quality standards.

Training and competencies

The quality standard should be read in the context of national and local guidelines on training and competencies. Health and social care practitioners involved in identifying, assessing, caring for and treating adults with faecal incontinence should have sufficient and appropriate training and competencies to deliver the actions and interventions described in the quality standard.

Role of families and carers

Quality standards recognise the important role families and carers have in supporting people with faecal incontinence. If appropriate, health and social care practitioners should ensure that family members and carers are involved in the decision-making process about investigations, treatment and care. Because of the sensitive nature of the condition and the stigma attached to it, it is particularly important that people give their agreement before family members and carers are involved.

^[1] Faecal incontinence. NICE clinical guideline 49 (2007).

List of quality statements

<u>Statement 1</u>. Adults in high-risk groups for faecal incontinence are asked in a sensitive way, at the time the risk factor is identified and then at times according to local care pathways, whether they have bowel control problems.

<u>Statement 2</u>. Adults 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.

<u>Statement 3</u>. Adults 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.

<u>Statement 4</u>. Adults with faecal incontinence have an initial management plan that covers any specific conditions causing the incontinence, and diet, bowel habit, toilet access and medication.

<u>Statement 5</u>. Adults who continue to experience episodes of faecal incontinence after initial management are offered referral for specialised management.

Quality statement 1: Identification in high-risk groups

Quality statement

Adults in high-risk groups for faecal incontinence are asked in a sensitive way, at the time the risk factor is identified and then at times according to local care pathways, whether they have bowel control problems.

Rationale

Faecal incontinence is distressing and can have a big effect on everyday life. Many people are embarrassed to talk about faecal incontinence with doctors and nurses, and their family and friends. Others may report symptoms of diarrhoea to avoid talking about the condition directly. Faecal incontinence can have many different causes. However, once identified there are treatments that can help manage or sometimes cure it. There are also strategies to help people discuss the condition openly and to cope with it. To ensure that everyone with faecal incontinence has access to this management, including people who find it difficult to talk about, it is important that enquiry about symptoms is pro-active and sensitive. How often questions should be asked will vary for each person and will depend on the level of risk and individual circumstances. This might happen at annual review for example, but as a minimum, questions should be asked at the time a risk factor is identified.

Quality measures

Structure

a) Evidence of identification of locally relevant groups at high risk of faecal incontinence from those listed in NICE clinical guideline 49 recommendation <u>1.1.2</u>.

Data source: Local data collection.

b) Evidence of local initiatives for raising awareness of faecal incontinence among staff working with groups at high risk, including training in talking openly and sensitively about the condition.

Data source: Local data collection.

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c) Evidence of local arrangements to ensure that when the risk factor for faecal incontinence is

identified, staff ask adults in high-risk groups whether they have bowel control problems.

Data source: Local data collection. The National Audit of Continence Care (NACC) collects data

on whether organisations ask a screening question(s) relating to bladder and bowel problems as

part of initial assessment.

d) Evidence that local care pathways relevant to the groups at high risk of faecal incontinence

include prompts to ask about bowel control problems (for example, at annual review).

Data source: Local data collection.

Process

Proportion of adults in locally relevant groups at high risk of faecal incontinence (from those

listed in NICE clinical guideline 49 recommendation <u>1.1.2</u>) who have been asked whether they

have bowel control problems.

Numerator – the number of people in the denominator who have been asked whether they have

bowel control problems.

Denominator – the number of adults in identified locally relevant groups at high risk of faecal

incontinence (from those listed in NICE clinical guideline 49 recommendation 1.1.2).

Data source: Local data collection. The National Audit of Continence Care (NACC) collects data

on how faecal incontinence was identified for each person in the audit.

Outcome

a) Feedback from adults who have been asked about whether they have bowel control problems,

on whether this was done in a sensitive way.

Data source: Local data collection.

b) Incidence of faecal incontinence.

Data source: Local data collection.

What the quality statement means for service providers, health and social care practitioners, and commissioners

Service providers ensure that systems are in place for the identification of locally relevant groups at high risk of faecal incontinence from those listed in NICE clinical guideline 49 recommendation <u>1.1.2</u> and that local pathways for care of adults in these groups include prompts to ask about bowel control problems (for example, at annual review). Providers should also raise awareness of faecal incontinence among staff working with groups at high risk, and provide training on talking openly and sensitively about the condition.

Health and social care practitioners ensure that they ask adults in identified locally relevant groups at high risk of faecal incontinence, in a sensitive way, at the time the risk factor is identified and then at times according to local care pathways, whether they have bowel control problems.

Commissioners ensure that they commission services that identify key people who are responsible for raising awareness of faecal incontinence and promoting continence and commission from providers that can demonstrate they have systems in place for the identification of locally relevant groups at high risk of faecal incontinence from those listed in NICE clinical guideline 49 recommendation <u>1.1.2</u> and that local pathways for care of adults in these groups include prompts to ask about bowel control problems (for example, at annual review). Providers should also raise awareness of faecal incontinence among staff working with groups at high risk, and provide training on talking openly and sensitively about the condition.

What the quality statement means for patients, service users and carers

Adults who are at risk of faecal incontinence (certain groups of people are more likely to have this than others) are asked in a sensitive way by health or social care staff whether they have problems controlling their bowels.

Source guidance

 Faecal incontinence (NICE clinical guideline 49), recommendation <u>1.1.2</u> (key priority for implementation).

Definitions of terms used in this quality statement

Faecal incontinence

This is any involuntary loss of faeces that is a social or hygiene problem [NICE clinical guideline 49, scope].

High-risk groups for faecal incontinence

These include:

- frail older people
- people with loose stools or diarrhoea from any cause (for example, inflammatory bowel disease)
- women following childbirth (especially after obstetric anal sphincter injury)
- people with neurological or spinal disease or injury (for example, spina bifida, stroke, multiple sclerosis, spinal cord injury)
- people with severe cognitive impairment
- people with urinary incontinence
- people with pelvic organ prolapse and/or rectal prolapse
- people who have had colonic resection or anal surgery
- people who have undergone pelvic radiotherapy
- people with perianal soreness, itching or pain
- people with learning disabilities.

[Adapted from NICE clinical guideline 49, recommendation 1.1.2 (key priority for implementation)]

Sensitive

Sensitive enquiry about faecal incontinence includes not asking more often than is appropriate for the person's level of risk. [Expert opinion]

Equality and diversity considerations

Risk of faecal incontinence relates closely to many of the protected characteristics that are covered by the Equality Act 2010, including age, disability, sex, and pregnancy and maternity. The consequences may also impact on others, including religion and belief. If people at risk are not asked about faecal incontinence, and if the condition is not effectively managed and treated, some people covered by the Act could be adversely affected. These people may have more than one protected characteristic or be affected by socioeconomic factors. Faecal incontinence may itself be counted as a disability if it occurs over the long term and has a substantial adverse effect on day-to-day activities. Sensitively asking people at risk about faecal incontinence promotes dignity and respect and is an important first step in removing any unequal access to care. Any enquiry about faecal incontinence should take into account the person's religion and belief and be culturally appropriate. People with faecal incontinence may also be unable to work. Providing assessment, effective management and treatment is likely to allow increased participation in society and public life, promoting equality of opportunity. If the person at risk of faecal incontinence lacks capacity, input from carers should be sought.

Quality statement 2: Baseline assessment

Quality statement

Adults 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.

Rationale

Faecal incontinence may have different underlying causes and contributing factors. There is a risk that healthcare professionals could make assumptions that faecal incontinence is related to a pre-existing condition or disability (such as a neurological condition or cognitive impairment) without carrying out a full assessment. 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. Correct identification of contributing factors will promote better access to care and ensure that appropriate management can be planned.

Quality measures

Structure

a) Evidence of local pathways for accessing full baseline assessments when adults report bowel control problems.

Data source: Local data collection. The <u>National Audit of Continence Care (NACC)</u> collects data on whether services have a protocol or pathway that is initiated when a patient reports that they have a bladder or bowel problem. The audit also collects data on whether services have a written protocol on providing basic assessments for people who have problems with urinary and/or faecal incontinence. The <u>APPG Continence Care survey</u> includes a question on what pathways are available for people with incontinence within the organisation.

b) Evidence of local initiatives to raise awareness of factors contributing to faecal incontinence so that healthcare professionals carrying out full baseline assessments do not assume that symptoms are caused by existing conditions or disabilities.

Data source: Local data collection.

Process

Proportion of adults reporting bowel control problems who receive a full baseline assessment.

Numerator – the number of people in the denominator receiving a full baseline assessment.

Denominator – the number of adults reporting bowel control problems.

Data source: Local data collection. Also contained in NICE audit support for <u>Faecal incontinence</u> (NICE clinical guideline 49), criterion 2. The <u>National Audit of Continence Care (NACC)</u> collects data on whether an assessment focusing on finding the cause(s) of faecal incontinence was performed, and specifically on cognitive assessments, rectal examination, medication review and impact on quality of life. The 2010 <u>National Audit of Continence Care</u> collected data on documented evidence of a bowel history.

Outcome

Feedback from adults with faecal incontinence (or their carers) that symptoms were properly assessed and not assumed to be caused by any pre-existing conditions or disabilities.

Data source: Local data collection.

What the quality statement means for service providers, health and social care practitioners, and commissioners

Service providers ensure that local pathways are in place for accessing full baseline assessments when adults report bowel control problems. Providers should also raise awareness among healthcare professionals carrying out the assessments of the many forms and causes of faecal incontinence.

Health and social care practitioners to whom adults with bowel control problems report symptoms, but who are not competent to carry out a full baseline assessment themselves, refer the person for assessment according to local pathways.

Healthcare professionals who are competent to carry out a full baseline assessment themselves ensure that they offer adults reporting bowel control problems (or refer for) a full baseline assessment, which they carry out without assuming that symptoms are caused by any existing conditions or disabilities.

Commissioners ensure that they commission services with capacity and expertise to provide full baseline assessments for adults reporting bowel control problems.

What the quality statement means for patients, service users and carers

Adults who report bowel control problems are offered a full assessment, which includes a physical examination and questions about their medical history, medication, diet and how the bowel problems affect their day-to-day life. Healthcare professionals should not assume that the problems are caused by conditions or disabilities that people already have.

Source guidance

• Faecal incontinence (NICE clinical guideline 49), recommendations <u>1.1.6</u>, <u>1.2.1</u> and <u>1.2.2</u> (key priorities for implementation).

Definitions of terms used in this quality statement

Faecal incontinence

This is any involuntary loss of faeces that is a social or hygiene problem [NICE clinical guideline 49, scope].

Baseline assessments

These are ideally carried out when symptoms are reported and include medical history, physical examination (including anorectal examination) and medication review [adapted from NICE clinical guideline 49, recommendation 1.2.2]. Examples of specific questions to ask as part of a baseline assessment are available in table 1 of NICE clinical guideline 49. Coping strategies should also be provided at the time of assessment (see quality statement 3) [NICE clinical guideline 49 recommendation 1.3.11]

Medical history

This includes:

- history of bowel habit (including warning signs for lower gastrointestinal cancer such as rectal bleeding and change in bowel habit, as defined in section 1.5 of <u>Referral guidelines for</u> <u>suspected cancer</u> [NICE clinical guideline 27])
- previous medical history
- medication review (see below)
- diet and fluid history
- consequences of faecal incontinence
- impact of symptoms on quality of life.

Physical examination

This includes:

- general examination (as indicated)
- cognitive and behavioural assessment (if indicated)
- assessment of person's ability to use the toilet
- anorectal examination
 - visual inspection of anus
 - assessment of perineal descent
 - digital rectal examination for anal tone and ability to squeeze anal sphincter voluntarily
 - assessment of faecal loading.

Medication review

This considers whether the person with faecal incontinence is taking any drugs that may exacerbate faecal incontinence (see <u>table 4</u> of NICE clinical guideline 49) and the effectiveness of any alterations already made.

Equality and diversity considerations

Faecal incontinence is associated with many protected characteristics that are covered by the Equality Act 2010, including age, disability, sex, and pregnancy and maternity. The consequences may also impact on others, including religion and belief. If people with faecal incontinence do not have assessments that take account of individual factors, and if healthcare professionals assume that faecal incontinence is caused by an underlying condition, effective management and treatment may not be provided. This may adversely affect people whose condition is associated with a protected characteristic. Undertaking detailed baseline assessments for each person with faecal incontinence is an important step in removing any unequal access to the most effective care. Extra steps may need to be taken to ensure physical access to clinics and allow extra time to meet the needs of all disabled people, including people with learning disabilities. It may sometimes be appropriate for carers to be involved in the assessment process (for example, helping people to answer questionnaires).

Quality statement 3: Coping with symptoms

Quality statement

Adults 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.

Rationale

Faecal incontinence can be depressing, demoralising and detrimental to everyday life and it is important that people are able to cope with symptoms. Because some interventions may take time to be effective, people have to cope with symptoms while undergoing baseline assessment and sometimes during the period of initial management, while waiting for specialist referral, or while undergoing specialist assessment or management. People for whom specialist management has not been effective and people who do not wish to pursue active treatment also have to cope with symptoms. Access to support, advice and appropriate coping strategies, including a choice of appropriate products, can allow people with faecal incontinence to lead active lives with as much independence as possible.

Quality measures

Structure

a) Evidence of local provision of ongoing practical support and advice on coping with symptoms of faecal incontinence.

Data source: Local data collection.

b) Evidence of local pathways (which are known to healthcare professionals carrying out baseline assessments for adults reporting bowel control problems) for accessing practical support and advice on coping with symptoms of faecal incontinence.

Data source: Local data collection. The <u>APPG Continence Care survey</u> includes a question on what pathways are available for people with incontinence within the organisation.

c) Evidence that a choice of appropriate products for faecal incontinence is available locally.

Data source: Local data collection. The <u>APPG Continence Care survey</u> includes a question on whether a choice of products within a range is offered after assessment.

Process

a) Proportion of adults reporting bowel control problems and their carers who receive support and advice at the time of baseline assessment for coping with symptoms.

Numerator – the number of people in the denominator for whom they and their carers receive support and advice at the time of baseline assessment for coping with symptoms.

Denominator – the number of adults with faecal incontinence.

Data source: Local data collection. The <u>National Audit of Continence Care (NACC)</u> collects data on the information available to people with faecal incontinence and their carers.

b) Proportion of adults reporting bowel control problems who are given a choice of appropriate products at the time of baseline assessment for coping with symptoms.

Numerator – the number of people in the denominator who are given a choice of appropriate products at the time of baseline assessment for coping with symptoms.

Denominator – the number of adults with faecal incontinence.

Data source: Local data collection. The <u>National Audit of Continence Care (NACC)</u> collects data on the NHS continence products that people can access.

Outcome

Feedback from adults with faecal incontinence that they receive ongoing support and advice and a choice of appropriate products for coping with symptoms.

What the quality statement means for service providers, health and social care practitioners, and commissioners

Service providers have local pathways (which are known to healthcare professionals carrying out baseline assessments) for accessing ongoing practical support, advice and a choice of appropriate products to help adults and their carers cope with symptoms of faecal incontinence.

Health and social care practitioners ensure that they offer adults with faecal incontinence and their carers (or refer for) practical support, advice and a choice of appropriate products to help them cope with symptoms during the period of assessment and for as long as symptoms persist. This includes up-to-date information about product choice and provision.

Commissioners ensure that they commission services with access to ongoing practical support, advice and a choice of appropriate products to help adults and their carers cope with symptoms of faecal incontinence.

What the quality statement means for patients, service users and carers

Adults with faecal incontinence and their carers are offered advice, support and a choice of products (such as pads, plugs, skincare products and disposable gloves) to help them deal with bowel control problems for as long as there are symptoms.

Source guidance

• Faecal incontinence (NICE clinical guideline 49), recommendations <u>1.1.5</u>, <u>1.3.11</u>, <u>1.3.12</u> and <u>1.6.1</u>.

Definitions of terms used in this quality statement

Faecal incontinence

This is any involuntary loss of faeces that is a social or hygiene problem [NICE clinical guideline 49, scope].

Practical support and advice

This includes written information, opportunities for discussion and access to appropriate services covering:

- where to get emotional and psychological support, including counselling or psychological therapy or support groups, as appropriate, to foster acceptance and positive attitudes
- · how to talk to friends and family about incontinence and its management
- strategies such as planning routes for travel to facilitate access to public toilets, and carrying
 a toilet access card (available from <u>Crohn's and Colitis UK</u> and <u>Bladder and Bowel</u>
 <u>Foundation</u>) or RADAR key (available from <u>Disability Rights UK</u>) to allow access to 'disabled'
 toilets in the National Key Scheme.
- skin-care advice
- advice on odour control and laundry needs.

[Adapted from NICE clinical guideline 49 recommendations 1.1.5 and 1.3.11].

Appropriate products

These are continence or bowel management products that are appropriate to the person's circumstances, taking into account their preferences. These may include:

- disposable body-worn pads in a choice of styles and designs, and disposable bed pads if needed
- pads in quantities sufficient for the person's continence needs (it is inappropriate to limit the number of pads given)
- anal plugs (for people who can tolerate them)
- disposable gloves
- cleansing and barrier products for skincare.

Information should be given about product choice, supply sources and use. Reusable absorbent products are not generally recommended for managing faecal incontinence.

[Adapted from NICE clinical guideline 49 recommendations 1.3.11, 1.3.12 and 1.3.13].

Equality and diversity considerations

Faecal incontinence is associated with many protected characteristics that are covered by the Equality Act 2010, including age, disability, sex, and pregnancy and maternity. The consequences may also impact on others, including religion and belief. Without access to individually tailored coping strategies (including continence products), some people with faecal incontinence who have protected characteristics under the Act could be adversely affected. Failure to make reasonable adjustment to take account of disabilities is a particular concern. Providing access to individually tailored coping strategies for people with faecal incontinence and their carers enables them to participate more fully in society and is an important step in preventing discrimination and promoting equality of opportunity.

Quality statement 4: Initial management

Quality statement

Adults with faecal incontinence have an initial management plan that covers any specific conditions causing the incontinence, and diet, bowel habit, toilet access and medication.

Rationale

Most symptoms of faecal incontinence can be improved, and many resolved, with initial management. Considering simple management options that may improve or resolve symptoms, in addition to providing support and advice on coping, should lead to the biggest improvements in quality of life for people with faecal incontinence. Effective initial management may reduce the risk of skin conditions and falls, and reduce the number of referrals to some specialist services. It can also help carers to cope, preventing carer breakdown and potentially delaying the need for domiciliary or residential care. People for who early specialist referral is indicated should also be offered initial management during any period of waiting.

Quality measures

Structure

a) Evidence of local capability to provide interventions for initial management of faecal incontinence.

Data source: Local data collection.

b) Evidence of local pathways (which are known to healthcare professionals carrying out baseline assessments for adults reporting bowel control problems) for accessing interventions for initial management of faecal incontinence.

Data source: Local data collection. The <u>APPG Continence Care survey</u> includes a question on what pathways are available for people with incontinence within the organisation.

Process

Proportion of adults with faecal incontinence who have had a baseline assessment and have an initial management plan that covers any specific conditions causing symptoms, and diet, bowel habit, toilet access and medication.

Numerator – the number of people in the denominator with an initial management plan that covers specific conditions that are causing symptoms, and diet, bowel habit, toilet access and medication.

Denominator – the number of adults with faecal incontinence who have had a baseline assessment.

Data source: Local data collection. The <u>National Audit of Continence Care (NACC)</u> collects data on whether there is a treatment plan, whether condition-specific interventions have been given or planned and whether the person's own goals and decisions for treatment and care have been documented.

What the quality statement means for service providers, health and social care practitioners, and commissioners

Service providers ensure there are local pathways (which are known to healthcare professionals carrying out baseline assessments) for accessing initial management for adults with faecal incontinence and that staff have the knowledge, skills and attitudes to develop initial management plans that cover specific conditions that are causing symptoms, and diet, bowel habit, toilet access and medication.

Health and social care practitioners offer adults with faecal incontinence (or refer for) an initial management plan that covers specific conditions causing symptoms, and diet, bowel habit, toilet access and medication.

Commissioners ensure they commission services that provide access to interventions for initial management of faecal incontinence.

What the quality statement means for patients, service users and carers

Adults with faecal incontinence have their bowel control problems managed in the first instance as set out in a plan that covers any specific conditions causing the problems, diet, medication and getting to the toilet. The plan should be adapted to individual needs and preferences.

Source guidance

• Faecal incontinence (NICE clinical guideline 49), recommendation <u>1.3.1</u>.

Definitions of terms used in this quality statement

Faecal incontinence

This is any involuntary loss of faeces that is a social or hygiene problem [NICE clinical guideline 49, scope].

Initial management plan

This outlines the initial intervention(s) that have been discussed and agreed with the person with faecal incontinence (and carers, as appropriate), tailored to their individual needs and preferences. Interventions may include addressing specific conditions causing the incontinence and addressing diet, bowel habit, toilet access and medication needs [Adapted from NICE clinical guideline 49 recommendations 1.3.1 to 1.3.15].

Specific conditions

Specific conditions that might cause faecal incontinence and require condition-specific interventions include:

- faecal loading
- potentially treatable causes of diarrhoea (for example, infective, inflammatory bowel disease and irritable bowel syndrome)

- warning signs for lower gastrointestinal cancer, such as rectal bleeding and change in bowel habit, as defined in recommendations 1.5.4 to 1.5.10 of <u>Referral guidelines for suspected</u> <u>cancer</u> [NICE clinical guideline 27]
- rectal prolapse or third-degree haemorrhoids
- acute anal sphincter injury including obstetric and other trauma
- acute disc prolapse/cauda equina syndrome.

[NICE clinical guideline 49 recommendation 1.2.3]

The initial management plan will also incorporate coping strategies (<u>statement 3</u>) and the findings of the baseline assessment (<u>statement 2</u>) [Adapted from <u>NICE clinical guideline 49</u> recommendations 1.3.1 and 1.3.11].

Medication

Managing medication includes reviewing medication and considering alternatives to drugs that are contributing to faecal incontinence (see <u>table 4</u> of NICE clinical guideline 49), as well as prescribing anti-diarrhoeal drugs for people with loose stools and associated faecal incontinence [Adapted from <u>NICE clinical guideline 49</u> recommendations 1.3.6 and 1.3.7].

Equality and diversity considerations

Faecal incontinence is associated with many protected characteristics that are covered by the Equality Act 2010, including age, disability, sex, and pregnancy and maternity. The consequences may also impact on others, including religion and belief. Without access to individually tailored initial management plans, appropriate care and treatment could be restricted for some people with faecal incontinence and protected characteristics. Effective management is likely to promote equality of opportunity by allowing increased participation in society and public life. An individually tailored initial management plan for people with faecal incontinence is therefore important for removing any unequal access to the most effective care.

Quality statement 5: Specialised management

Quality statement

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

Rationale

Some people will continue to have episodes of faecal incontinence after initial management and may benefit from specialised assessment and management, which can both identify the cause of symptoms and indicate further treatment options. These people should have the opportunity to discuss the possibility of referral and agree a course of action that meets their needs and preferences; some people will choose not to pursue active treatment. There are a number of specialist conservative, medical and surgical interventions that can help, and these are likely to be provided by different specialists. Access to the most appropriate specialist management will improve the quality of life for some people with faecal incontinence.

Quality measures

Structure

Evidence of local referral pathways for all options for specialised management of faecal incontinence.

Data source: Local data collection. The <u>National Audit of Continence Care (NACC)</u> collects data on whether services have clear pathways for referral between providers. The <u>APPG Continence Care survey</u> includes a question on what pathways are available for people with incontinence within the organisation.

Process

Proportion of adults continuing to experience episodes of faecal incontinence after initial management who are offered referral for specialised management.

Numerator – the number of people in the denominator who are offered referral for specialised management.

Denominator – the number of adults continuing to experience episodes of faecal incontinence after initial management.

Data source: Local data collection. Also contained in NICE audit support for <u>Faecal incontinence</u> (NICE clinical guideline 49), criterion 5. The <u>National Audit of Continence Care (NACC)</u> collects data on further investigations and referrals to a specialist or another service for people with a treatment plan.

What the quality statement means for service providers, healthcare professionals, and commissioners

Service providers have local referral pathways for all options for specialised management of faecal incontinence and ensure that staff providing initial management are aware of them.

Healthcare professionals ensure that they are aware of local referral pathways for all options for specialised management of faecal incontinence and offer referrals in accordance with these to adults who continue to experience episodes of faecal incontinence after initial management.

Commissioners ensure that they commission services with expertise and capacity for specialised management of faecal incontinence.

What the quality statement means for patients, service users and carers

Adults who still have symptoms after the first steps in managing faecal incontinence are offered a referral for specialist advice and possible further treatment.

Source guidance

• Faecal incontinence (NICE clinical guideline 49), recommendations <u>1.4.1</u> (key priority for implementation) and <u>1.4.2</u>.

Definitions of terms used in this quality statement

Faecal incontinence

This is any involuntary loss of faeces that is a social or hygiene problem [NICE clinical guideline 49, scope].

Initial management

This involves adjusting the person's fluid intake, diet and medication separately and ensuring that they complement each other (see <u>statement 4</u>). [NICE clinical guideline 49, <u>full guideline</u>].

Specialised management

This consists of conservative, medical or surgical interventions provided by a specialist continence service or secondary care specialists and may include:

- pelvic floor muscle training
- bowel retraining
- specialist dietary assessment and management (this is a detailed specialist intervention, separate to the basic dietary advice offered as part of initial management)
- biofeedback
- rectal irrigation
- electrical stimulation
- · anorectal physiology studies
- endoanal ultrasound (if this is not available, magnetic resonance imaging, endovaginal ultrasound and perineal ultrasound should be considered)
- other tests, including proctography, as indicated
- surgery (for example, sphincter repair, sacral nerve stimulation, stoma).

[Adapted from NICE clinical guideline 49, recommendations 1.4.1 and 1.5.1].

Equality and diversity considerations

Faecal incontinence is associated with many protected characteristics that are covered by the Equality Act 2010, including age, disability, sex, and pregnancy and maternity. The consequences may also impact on others, including religion and belief. Not all interventions offered by specialist services will be suited to all people with faecal incontinence. For example, some treatments may not be suitable for people who are unable to understand or adhere to treatment instructions, and interventions such as pelvic floor muscle training may not be suitable for people with neurological or spinal conditions. The key consideration is to ensure that people with protected characteristics covered by the Act can access specialised management if it is appropriate for them, and that assumptions are not made about suitability of the intervention. Adjustment should be made to both specialist assessment and treatment options when possible. This may mean giving extra support and time, especially to disabled people. Improving access to specialist services for all people with faecal incontinence is an important step in removing any unequal access to the most effective care. Effective management is likely to promote equality of opportunity by allowing increased participation in society and public life.

Using the quality standard

Quality measures

The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of care in areas identified as needing quality improvement. They are not a new set of targets or mandatory indicators for performance management.

We have indicated if current national indicators exist that could be used to measure the quality statements. These include indicators developed by the Health and Social Care Information Centre through its <u>Indicators for Quality Improvement Programme</u>. If there is no national indicator that could be used to measure a quality statement, the quality measure should form the basis for audit criteria developed and used locally.

See NICE's <u>What makes up a NICE quality standard?</u> for further information, including advice on using quality measures.

Levels of achievement

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, NICE recognises that this may not always be appropriate in practice, taking account of safety, choice and professional judgement, and therefore desired levels of achievement should be defined locally.

Using other national guidance and policy documents

Other national guidance and current policy documents have been referenced during the development of this quality standard. It is important that the quality standard is considered by commissioners, providers, health and social care practitioners, patients, service users and carers alongside the documents listed in Development sources.

Information for commissioners

NICE has produced <u>support for commissioning</u> that considers the commissioning implications and potential resource impact of this quality standard. This is available on the NICE website.

Information for the public

NICE has produced <u>information for the public</u> about this quality standard. Patients, service users and carers can use it to find out about the quality of care they should expect to receive; as a basis for asking questions about their care, and to help make choices between providers of social care services.

Diversity, equality and language

During the development of this quality standard, equality issues have been considered and <u>equality assessments</u> are available.

Good communication between health and social care practitioners and adults with faecal incontinence is essential in all settings. Treatment, care and support, and the information given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. Adults with faecal incontinence should have access to an interpreter or advocate if needed.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to avoid unlawful discrimination and to have regard to promoting equality of opportunity. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

Development sources

Further explanation of the methodology used can be found in the quality standards <u>Process</u> <u>quide</u> on the NICE website.

Evidence sources

The documents below contain recommendations from NICE guidance or other NICE-accredited recommendations that were used by the Quality Standards Advisory Committee to develop the quality standard statements and measures.

• Faecal incontinence. NICE clinical guideline 49 (2007).

Policy context

It is important that the quality standard is considered alongside current policy documents, including:

- All Party Parliamentary Group (2011) Cost-effective commissioning for continence care.
- Department of Health (2001) National service framework for older people.
- Department of Health (2000) Good practice in continence services.

Definitions and data sources for the quality measures

- All Part Parliamentary Group for Continence Care (2013) <u>Continence care service England</u> 2013 <u>survey report</u>.
- Royal College of Physicians (2012) <u>National audit of continence care (NACC) Pilot audit</u> evaluation report.
- Royal College of Physicians (2010) <u>National Audit of Continence Care, Combined</u> <u>Organisational and Clinical Report</u>
- NICE audit support for faecal incontinence. NICE clinical guideline 49 (2007).

Related NICE quality standards

Published

- Patient experience in adult NHS services. NICE quality standard 15 (2012).
- Service user experience in adult mental health. NICE quality standard 14 (2012).

Future quality standards

This quality standard has been developed in the context of all quality standards referred to NICE. The NICE library of quality standards (published, in development and for future development) covers many topics for which faecal incontinence may be relevant.

Quality Standards Advisory Committee and NICE project team

Quality Standards Advisory Committee

This quality standard has been developed by Quality Standards Advisory Committee 4. Membership of this committee is as follows:

Professor Damien Longson (Chair)

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Ms Alison Allam

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About this quality standard

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. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

The methods and processes for developing NICE quality standards are described in the <u>quality</u> <u>standards process guide</u>.

This quality standard has been incorporated into the NICE pathway for faecal incontinence.

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