

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Health and social care directorate

### Quality standards and indicators

#### Briefing paper

**Quality standard topic:** Faecal incontinence

**Output:** Prioritised quality improvement areas for development.

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# 1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for faecal incontinence. It provides the Committee with a basis for discussion when prioritising quality improvement areas for developing quality statements and measures. The draft quality standard will be subject to public consultation.

## Structure

This briefing paper includes an overview of the topic and a summary of the suggested quality improvement areas with supporting information.

Where relevant, guideline recommendations from the key development source below are presented to help the Committee in considering potential quality statements and measures.

## Development source

Unless otherwise stated, the key development source referred to in this briefing paper is as follows:

- [Faecal incontinence](#). NICE clinical guideline 49 (2007).

# 2 Overview

## 2.1 *Focus of quality standard*

This quality standard will cover 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).

## 2.2 *Definition*

Faecal incontinence is a sign or a symptom, rather than a diagnosis. 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' being the term most often used to include gas incontinence))
- patient group
- presumed primary underlying cause.

For many people faecal incontinence is the result of a complex interplay of contributing factors, many of which can co-exist. The guideline development group for NICE clinical guideline 49: faecal incontinence (CG49) considered that the majority of people with faecal incontinence were likely to fall into one or more of the following groups:

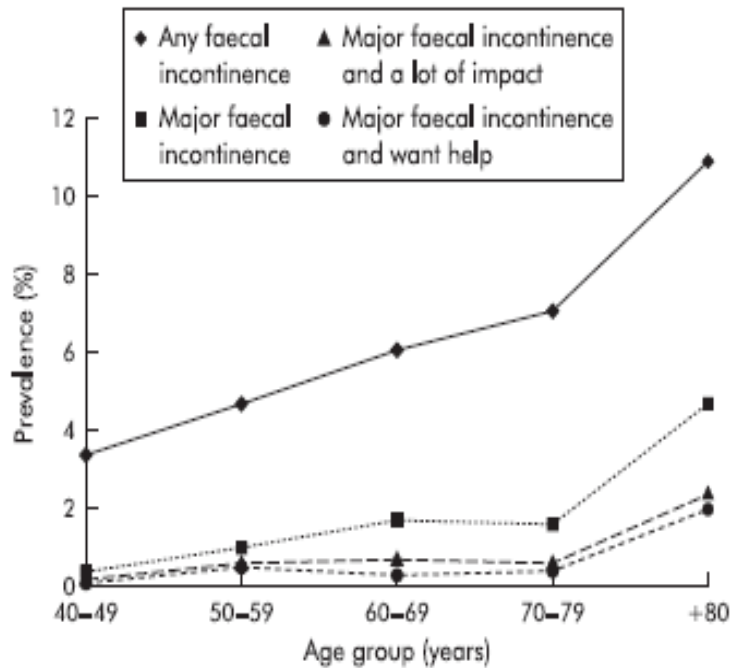
- structural ano-rectal abnormality (for example, sphincter trauma, sphincter degeneration, perianal fistula, rectal prolapse)
- neurological disorders (for example, multiple sclerosis, spinal cord injury, spina bifida, stroke, other)
- constipation/faecal loading (for example, diet, medication, megarectum)
- cognitive and/or behavioural dysfunction (for example, dementia, learning disabilities)
- loose stools (for example, gastrointestinal problems such as inflammatory bowel disease (IBD), or irritable bowel syndrome (IBS))
- disability related (for example, people who are frail, acutely unwell, or have chronic/acute disabilities)
- idiopathic (for example, self caring adults with faecal incontinence and none of the above).

### **2.3      *Incidence and prevalence***

Between 1% and 10% of adults are affected by faecal incontinence, depending on the definition and frequency of faecal incontinence used. It is likely that 0.5–1.0% of adults experience regular faecal incontinence that affects their quality of life. While faecal incontinence can affect people of any age (section 2.2), prevalence does increase with age (Figure 1). Nearly two thirds of people with faecal incontinence also have urinary incontinence (known as double incontinence).

Faecal incontinence has remained a largely hidden problem, with many people feeling too embarrassed to admit their symptoms to healthcare professionals, or even to family and friends. People with faecal incontinence often experience social exclusion, and frequently suffer from stress, anxiety and depression, which can cause them to delay seeking help.

**Figure 1 Prevalence (%) of faecal incontinence in adults aged 40 years or more living in the community, stratified by severity, impact and request for help<sup>1</sup>**



High quality care for people with faecal incontinence should lead to improvements in quality of life and may also eliminate or delay the need for residential care for older people affected by faecal incontinence.

## 2.4 Management

Faecal incontinence is a stigmatising condition and people are reluctant to disclose symptoms without specific enquiry. Effective management usually depends on identifying a complex interaction of factors causing symptoms for each individual, and in finding a combination of interventions that gives best control of those symptoms. In most cases, symptoms can at least be improved or even resolved.

A baseline assessment of people with faecal incontinence is carried out leading to either condition-specific interventions (for faecal loading, rectal prolapse for example) or initial management for faecal incontinence. Initial management addresses reversible factors using a conservative approach that includes advice about diet, bowel habit and medication. Conservative treatment 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

<sup>1</sup> Perry S, Shaw C, McGrother C et al. (2002). Prevalence of faecal incontinence in adults aged 40 years or more living in the community. *Gut* 50 (4):480-484.

management of faecal incontinence include 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.

People with continuing symptoms of faecal incontinence require long-term management that incorporates advice, support and review.

See Appendix 2 for key priority for implementation recommendations from CG49.

## **2.5 National audit of continence care**

Commissioned by the Healthcare Quality Improvement Partnership (HQIP), the Royal College of Physicians (RCP) has conducted three full rounds of the National Audit of Continence Care (NACC), publishing reports in 2005, 2006 and 2010. Results from a smaller, pilot round of the audit were published in 2012, including a separate survey of patients' experience of NHS continence services. Findings from the two most recent audits (2010 and the 2012 pilot) are presented in the current practice sections of this briefing paper, where they relate to a quality improvement area. The audits consist of three components: an organisational audit, a bladder clinical audit and a bowel clinical audit.

The 2010 report describes care given to 3,982 adults with faecal incontinence problems across 150 NHS Acute Trusts, 31 Mental Healthcare Trusts, 117 Primary Care Trusts, and 122 care homes<sup>2</sup>. For the 2012 pilot, 83 NHS organisations (60 Acute Hospitals, 23 Primary Care Trusts) and 9 care homes submitted data on 218 faecal incontinence cases<sup>3</sup>. For the patient experience pilot, volunteer continence services distributed questionnaires to patients who had been through their continence (bladder and bowel) services and 99 questionnaires were returned. Because of the relatively small numbers participating in the pilot audits, no firm conclusions can be drawn. The data is still included however, being the most current information available.

## **2.6 National outcome frameworks**

The table below shows indicators from the outcomes frameworks that the quality standard could contribute to:

- [The NHS Outcomes Framework 2013/14](#)

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<sup>2</sup> Royal College of Physicians (2010) [National Audit of Continence Care, Combined Organisational and Clinical Report](#)

<sup>3</sup> Royal College of Physicians (2012) [National audit of continence care \(NACC\) Pilot audit evaluation report](#).

- [The Adult Social Care Outcomes Framework 2013/14](#)
- [Improving Outcomes and Supporting Transparency – Part 1: A Public Health Outcomes Framework for England, 2013-2016](#)

<b>NHS Outcomes Framework 2013/14</b>	
Domain 2: Enhancing quality of life for people with long-term conditions.	<p><b>Overarching indicator</b> Health-related quality of life for people with long-term conditions<sup>4</sup></p> <p><i>Improvement areas</i> Ensuring people feel supported to manage their condition 2.1 Proportion of people feeling supported to manage their condition<sup>1</sup> Enhancing quality of life for carers 2.4 Health-related quality of life for carers<sup>1</sup> Enhancing quality of life for people with dementia 2.6 ii <i>A measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life</i><sup>5</sup></p>
Domain 3: Helping people to recover from episodes of ill health or following injury	<p><i>Improvement areas</i> Improving recovery from stroke 3.4 Proportion of stroke patients reporting an improvement in activity/lifestyle on the Modified Rankin Scale at 6 months.</p>
<b>Adult Social Care Outcomes Framework 2013/14</b>	
Domain 1: Enhancing quality of life for people with care and support needs	<p><b>Overarching measure</b> 1A. Social care-related quality of life<sup>6</sup></p> <p><i>Outcome measures</i> 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<sup>3</sup> 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<sup>7</sup>. 1I. Proportion of people who use services and their carers, who reported that they had as much social contact as they would like<sup>4</sup>.</p>
Domain 2: Delaying and reducing the need for care and support.	<p><b>Overarching measures</b> 2A. Permanent admissions to residential and nursing care homes per 1,000 population</p> <p><i>Outcome measures</i> 2F: Dementia –a measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life<sup>8</sup>.</p>

<sup>4</sup>Indicator complementary with Adult Social Care Outcomes Framework

<sup>5</sup>Indicator shared with Adult Social Care Outcomes Framework

<sup>6</sup>Indicator complementary with NHS Outcomes Framework

<sup>7</sup>Indicator shared with Public Health Outcomes Framework

<sup>8</sup>Indicator shared with NHS Outcomes Framework

Public Health Outcomes Framework	
Domain 1: Improving the wider determinants of health	Indicators 1.6 People with mental illness or disability in settled accommodation <sup>9</sup> 1.18 <i>Social connectedness (placeholder)</i> <sup>6</sup>

### 3 Summary of suggestions

#### 3.1 Responses

Six stakeholders responded to the 2-week engagement exercise (26 April – 13 May 2013), five of which submitted suggestions for quality improvement (one stakeholder submitted a ‘no comment’ response). Suggestions were also provided by specialist committee members.

**Table 1 Summary of suggested quality improvement areas**

Stakeholders were asked to suggest up to five areas for quality improvement. These have been merged and summarised in the table below for consideration by the Committee (incorporating stakeholder and specialist committee member suggestions). Only improvement areas which are specific and patient-centred are presented, in line with the approach to quality standard development. The Committee is asked to note that broader comments on service delivery (for example integrated services and multidisciplinary teams), structural issues (for example staff training), equitable access to assessment and treatment and the scope of the quality standard (to include children and young people) were also received. The full detail of the suggestions is provided in Appendix 3 for information.

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<sup>9</sup> Indicator shared with Adult Social Care Outcomes Framework

<b>Suggested area for improvement</b>	<b>Stakeholder</b>
<u>Identification and assessment</u> <ul style="list-style-type: none"> <li>• Case finding</li> <li>• Diagnostic overshadowing</li> <li>• Baseline assessment</li> </ul>	RCOG UUGC SCMs A, B & D
<u>Initial management</u>	UUGC SCMs A, B & C
<u>Specialised management</u>	Coloplast UUGC SCMs B, C & D
<u>Specialist assessment</u>	BSGAR RCOG SCM A
<u>Surgery</u>	RCOG UUGC
<u>Continuity of care</u>	SCMs A & B

**Table 2 Stakeholder details (abbreviations)**

The details of stakeholder organisations who submitted suggestions are provided in the table below.

<b>Abbreviation</b>	<b>Full name</b>
BSGAR	British Society of Gastrointestinal and Abdominal Radiology
RCN <sup>10</sup>	Royal College of Nursing
RCOG	Royal College of Obstetricians and Gynaecologists
RCPCH	Royal College of Paediatrics and Child Health
UUGC	Urology User Group Coalition
[No abbreviation]	Coloplast
SCM(s)	Specialist Committee Member(s)

<sup>10</sup> Submitted 'no comment' response.



## **4 Suggested improvement area: Identification and assessment**

### **4.1 *Summary of suggestions***

#### **Case finding**

A number of stakeholders report a need to enquire specifically about the presence of faecal incontinence in high-risk groups. This is because the condition is currently underreported due to embarrassment and fear of stigma. It is suggested that nearly three-quarters of people with irritable bowel disease may have faecal incontinence, for example and the major negative impact on quality of life is noted. It is suggested that case finding in primary care is likely to be the biggest opportunity to improve quality of life for people with faecal incontinence. Ensuring that staff are trained in appropriate questions to ask, and who to ask, is highlighted along with 'screening' for impaction or diarrhoea in care home residents.

#### **Diagnostic overshadowing**

The importance of clinicians being appropriately trained in faecal incontinence, and not making assumptions about primary contributing factors to faecal incontinence symptoms in people with long term conditions or disabilities such as neurological conditions or cognitive disorders, is stated. It is felt that false assumptions lead to many people with faecal incontinence not receiving the care they need.

#### **Baseline assessment**

Rectal examination and documentation of bowel function are noted as specific outcomes. A lack of understanding among care home staff resulting in faecal overflow leakage is raised, in addition to identification of people who need specialist referral (see section 6).

### **4.2 *Selected recommendations from development source***

Recommendations from the development source relating to the suggested improvement areas have been provisionally selected and are presented below to inform the Committee's discussion.

## **Case finding**

### NICE CG49 – Recommendation (key priority for implementation) 1.1.2 (Good practice in managing faecal incontinence)

Because faecal incontinence is a socially stigmatising condition, healthcare professionals should actively yet sensitively enquire about symptoms in high-risk groups:

- frail older people
- people with loose stools or diarrhoea from any cause
- women following childbirth (especially following third- and fourth- degree obstetric injury)
- people with neurological or spinal disease/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.

### NICE CG49 - Recommendation 1.1.3 (Good practice in managing faecal incontinence)

Local clinical teams should work as appropriate with local and national organisations to:

- raise public awareness of the causes, prevalence and symptoms of faecal incontinence and the resources needed to treat it
- aid mutual support between people with faecal incontinence
- decrease the taboo surrounding faecal incontinence
- encourage people with faecal incontinence to seek appropriate help.

## **Diagnostic overshadowing**

### NICE CG49 – Recommendation (key priority for implementation) 1.1.6 (Good practice in managing faecal incontinence)

When assessing faecal incontinence healthcare professionals should:

- be aware that faecal incontinence is a symptom, often with multiple contributory factors for an individual patient
- avoid making simplistic assumptions that causation is related to a single primary diagnosis ('diagnostic overshadowing').

## NICE CG49 – Recommendation 1.7.1 (Management of specific groups)

Pay special attention to recommendation 1.1.6 about diagnostic overshadowing.

### **Baseline assessment**

## NICE CG49 – Recommendation 1.2.1 (Baseline assessment)

Healthcare professionals should ensure that people who report or are reported to have faecal incontinence are offered:

- a focused baseline assessment to identify the contributory factors before any treatment is considered
- all appropriate initial management including, where appropriate, condition-specific interventions before any specialised treatment.

## NICE CG49 – Recommendation (key priority for implementation) 1.2.2 (Baseline assessment)

Healthcare professionals should carry out and record a focused baseline assessment for people with faecal incontinence to identify the contributory factors. This should comprise:

- relevant medical history (see [table 1](#))
- a general examination
- an anorectal examination (see [table 1](#))
- a cognitive assessment, if appropriate.

## NICE CG49 – Recommendation (key priority for implementation) 1.2.3 (Baseline assessment)

People with the following conditions should have these addressed with condition-specific interventions before healthcare professionals progress to initial management of faecal incontinence:

- faecal loading (see also section 1.7.3)
- potentially treatable causes of diarrhoea (for example, infective, inflammatory bowel disease and irritable bowel syndrome)
- warning signs for lower gastrointestinal cancer<sup>11</sup>
- rectal prolapse or third-degree haemorrhoids
- acute anal sphincter injury including obstetric and other trauma
- acute disc prolapse/cauda equina syndrome.

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<sup>11</sup> See the NICE clinical guideline on referral for suspected cancer ([www.nice.org.uk/CG27](http://www.nice.org.uk/CG27))

## **4.3 Current UK practice**

### **Case finding**

Consensus of topic experts suggests considerable under-recognition and recording of faecal incontinence in primary care, in particular among those with multiple comorbidities<sup>12</sup>. Incidence of faecal incontinence has been estimated at 10%<sup>13</sup>.

In the 2012 NACC pilot, around half of all audited cases were identified by routine provider screening within NHS Trusts. There were a number of missed or undiagnosed cases: in acute settings, 27% of cases were only identified as a result of the audit. Nearly all organisations (including care homes) in 2010 and 2012 reported their practice being to ask a screening question(s) relating to bladder and bowel problems as part of an initial assessment.

### **Diagnostic overshadowing**

The 2010 NACC found that only half of older people in NHS Trusts had types or causes of bowel problem documented. The rate was higher for younger people at around two thirds across settings. Less than a third of patients in mental health care had a clear diagnosis, and records were frequently unavailable in care homes. In the 2012 pilot audit, documentation of the cause(s) of faecal incontinence existed in just over half of all cases across acute and primary care.

The Disability Equality Duty requires health professionals to take disability and consequent diagnostic overshadowing into account, as highlighted in CG49<sup>14</sup>.

### **Baseline assessment**

The 2010 NACC reported that some type of cognitive assessment was documented for the majority (71%) of older patients across all settings. Just under half of people under 65 received this. In the 2012 pilot, function and cognition was assessed in 81% of patients across acute and primary care.

In both the 2010 and 2012 audits, digital rectal examination as part of a basic examination was documented in around one half of all cases although a higher proportion of sites had a written protocol to provide basic assessments.

Overflow from constipation was documented as a type/cause of faecal incontinence in 38% of all cases in 2012.

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<sup>12</sup> [Faecal continence service for the management of faecal incontinence in adults](#). NICE Commissioning guide 15 (2010).

<sup>13</sup> [Faecal incontinence: costing report](#). NICE costing report (2007).

<sup>14</sup> Disability Rights Commission. (2005) The duty to promote disability equality: statutory duty of practice, England and Wales. Stratford upon Avon: Disability Rights Commission.

## 5 Suggested improvement area: Initial management

### 5.1 Summary of suggestions

Stakeholders describe a current misperception that little can be done to help people with faecal incontinence, and the need to tailor management to the individual. Stakeholders refer to documenting patients' personal goals for care outcomes; appropriate loperamide prescribing, including advice about safe use; the importance of assisting patients with odour control; and skin care advice. Stakeholders raise the need to understand that this support should be contained within first line or conservative management (in addition to medication and product provision).

Education of healthcare professionals in the full range of management options and available products is highlighted, including relevant support for people with faecal incontinence and their family and carers regarding their chosen management options. It is felt that many people with faecal incontinence do not receive regular support and care, are given no choice over the products they receive, and that some people are prescribed inappropriate products. Regular review for people with faecal incontinence is also cited. Issues around medicines management in care homes, which can result in people experiencing faecal overflow leakage, are raised. The importance of quality of life outcomes are also mentioned, with people being more likely to be able to live independently and participate in public and social life with dignity by meeting these individual needs.

### 5.2 Selected recommendations from development source

Recommendations from the development source relating to the suggested improvement areas have been provisionally selected and are presented below to inform the Committee's discussion.

*The Committee is asked to note that the published quality standard on '[Patient experience in adult NHS services](#)' includes generic statements on discussion, patient choice, understanding treatment options and shared decision-making.*

#### NICE CG49 – Recommendation (key priority for implementation) 1.1.1 (Good practice in managing faecal incontinence)

People who report or are reported to have faecal incontinence should be offered care to be managed by healthcare professionals who have the relevant skills, training and experience and who work within an integrated continence service<sup>15</sup>.

*The Committee is asked to note it is expected that quality standards be read in the context of national and local guidelines on training and competencies. All*

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<sup>15</sup> See Section 3, 'Good practice in continence services' and 'National service framework for older people' ([www.dh.gov.uk](http://www.dh.gov.uk)).

*professionals involved in the care of people with faecal incontinence should be sufficiently and appropriately trained and competent to deliver the actions and interventions described in the quality standard.*

#### NICE CG49 – Recommendation 1.1.5 (Good practice in managing faecal incontinence)

Healthcare professionals should ensure that people with faecal incontinence and their carers:

- are kept fully informed about their condition and have access to appropriate sources of information in formats and languages suited to their individual requirements
- are offered access to or made aware of appropriate support groups (which may include alerting people with faecal incontinence to the possibility of family and friends having similar experiences, or suggesting community groups or more formal organisations). Consideration should be given to the individual's cognition, gender, physical needs, culture and stage of life
- have the opportunity to discuss assessment, management options and relevant physical, emotional, psychological and social issues. The views, experiences, attitudes and opinions of the individual with faecal incontinence about these issues should be actively sought.

#### NICE CG49 – Recommendation 1.3.1 (Initial management)

Healthcare professionals should explain to people with faecal incontinence that a combination of initial management interventions is likely to be needed. The specific management intervention(s) offered should be based on the findings from the baseline assessment, tailored to individual circumstances and adjusted to personal response and preference.

#### NICE CG49 – Recommendation 1.3.6 (Initial management – medication)

When reviewing medication, healthcare professionals should consider alternatives to drugs that might be contributing to faecal incontinence. (see [table 4](#))

#### NICE CG49 – Recommendations 1.3.7-10 (Initial management – medication)

[Recommendations on antidiarrhoeal medication]

#### NICE CG49 – Recommendations 1.3.11 (Initial management – coping strategies)

During assessment and initial management healthcare professionals should offer people with faecal incontinence advice on coping strategies including:

- the use of continence products and information about product choice, supply sources and use
- where to get emotional and psychological support, including counselling or psychological therapy, where 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 conveniences, carrying a toilet access card<sup>16</sup> or RADAR key<sup>17</sup> to allow access to 'disabled' toilets in the National Key Scheme.

#### NICE CG49 – Recommendations 1.3.12 (Initial management – coping strategies)

People with faecal incontinence should be offered:

- disposable body-worn pads in a choice of styles and designs and disposable bed pads if needed
- pads in quantities sufficient for the individual's continence needs – it is inappropriate to limit the number of pads given
- anal plugs (for people who can tolerate them)
- skin-care advice that covers both cleansing and barrier products
- advice on odour control and laundry needs
- disposable gloves.

#### NICE CG49 – Recommendations 1.3.13 (Initial management – coping strategies)

The use of reusable absorbent products in the management of faecal incontinence is not generally recommended.

#### NICE CG49 – Recommendation 1.3.14 (Initial management – review of treatment)

After each intervention healthcare professionals should ask the person whether the faecal incontinence has improved. People continuing to experience symptoms should be:

- involved in discussions about further treatment options (including effectiveness and adverse effects) or alternative coping strategies
- asked if they wish to try further treatments.

#### NICE CG49 – Recommendation 1.3.15 (Initial management – review of treatment)

The options for long-term management should be considered for people who prefer symptomatic management to more invasive measures (see recommendation in section 1.6).

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<sup>16</sup> These are available from National Association for Colitis and Crohn's disease (NACC) ([www.nacc.org.uk](http://www.nacc.org.uk)), Incontact ([www.incontact.org](http://www.incontact.org)) or the Continence Foundation ([www.continence-foundation.org.uk](http://www.continence-foundation.org.uk)).

<sup>17</sup> These are available from RADAR ([www.radar.org.uk/radarwebsite/tabid/41/default.aspx](http://www.radar.org.uk/radarwebsite/tabid/41/default.aspx)).

### NICE CG49 – Recommendation (key priority for implementation) 1.6.1 (Long-term management)

Healthcare professionals should offer the following to symptomatic people who do not wish to continue with active treatment or who have intractable faecal incontinence:

- advice relating to the preservation of dignity and, where possible, independence
- psychological and emotional support, possibly including referral to counsellors or therapists if it seems likely that a person's attitude towards and ability to manage and cope with his or her faecal incontinence could improve with professional assistance
- at least 6-monthly review of symptoms
- discussion of any other management options (including specialist referral)
- contact details for relevant support groups
- advice on continence products and information about product choice, availability and use
- advice on skin care
- advice on how to talk to friends and family

### NICE CG49 – Recommendation 1.8.9 (Surgery)

People who have an implanted sacral nerve stimulation device, stimulated graciloplasty or an artificial anal sphincter should be offered training and ongoing support at a specialist centre. These people should be monitored, have regular reviews and be given a point of contact.

*The Committee is asked to note that [NICE clinical guideline 148: Urinary incontinence in neurological disease](#) (CG148) was identified by a stakeholder as a potential development source: "Most people with neurological conditions have concurrent bowel dysfunction resulting in faecal incontinence if not managed. The same basic principles should apply."*

### NICE CG148<sup>18</sup> – Recommendation (key priority for implementation) 1.2.1 (Information and support)

Offer people with neurogenic urinary tract dysfunction, their family members and carers specific information and training. Ensure that people who are starting to use, or are using, a bladder management system that involves the use of catheters, appliances or pads:

- receive training, support and review from healthcare professionals who are trained to provide support in the relevant bladder management systems and are knowledgeable about the range of products available
- have access to a range of products that meet their needs
- have their products reviewed, at a maximum of 2 yearly intervals.

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<sup>18</sup> [Urinary incontinence in neurological disease](#) NICE clinical guideline 148 (2012).



## 5.3 **Current UK practice**

### *Information provision*

Three-quarters of organisations in the 2012 NACC pilot reported availability of evidence-based information on bladder and bowel care for patients, residents, families and carers. In 2010, this was available in 90% NHS organisations and 72% of care homes.

### *Continence products*

In the 2010 NACC, over half of all care homes reported a daily limit for continence products (bowel and bladder care). This was the case in around one-third of NHS Trusts in both 2010 and 2012. Despite this, only 8-12% of organisations (including care homes) said that products were supplied on the basis of cost rather than need.

In 2012, patient choice in types of products was restricted in more than one-half of all participating organisations. In 2010, over half of NHS Trusts and more than two thirds of care homes confirmed that views of patients/carers were sought in selecting the range of products to be supplied. A national survey of continence services published in 2013 found that 63% (39/62) offer a choice of products within a range<sup>19</sup>. A small (n=98) patient satisfaction survey on prescribing practice in relation to continence products (urinary and faecal) during 2007-08 suggested difficulties associated with products impacting on both physical and psychological wellbeing, and that knowledge of continence products is poor<sup>20</sup>.

### *Medication*

In the 2012 NACC pilot, medication reviews (to assess whether they may be worsening faecal incontinence) were carried out in 60% of cases with just over half of these having drug alterations made as a result. In 2010, around one-third of older patients across settings were on medications that may exacerbate faecal incontinence. The rate was notably lower (18%) for younger patients in acute hospitals. The majority of patients had medication altered or reviewed so it could not be further minimised, but up to a quarter of patients had no action relating to medication.

In 2012, 14% of cases had anti-diarrhoeal medication documented as a treatment for faecal incontinence. In 2010, this was around one-fifth across settings.

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<sup>19</sup> All Party Parliamentary Group For Continence Care (2013) [Continence Care Services England 2013 Survey report](#)

<sup>20</sup> Mangnall J, Midgley K., Lakin S. et al. (2010) Improving service provision for patients who are prescribed continence products. *British Journal of Community Nursing* 15 (4): 158-164.

### *Quality of life*

Despite a large number of organisations reporting in the 2012 pilot NACC that they monitor patient experience, the impact of faecal incontinence on quality of life was assessed in only one third of cases across settings. In 2010, half of cases in participating NHS Trusts and over a quarter of care home residents did not have a record of impact of symptoms on quality of life. In the patient experience pilot of the NACC<sup>21</sup>, nearly all (91 out of 99) people reported that they had been asked how their continence (bladder and bowel) problem affects them.

### *Personal goals*

In 2012, documenting patients' own goals and decisions on treatment was evident in one third of NHS patients (although a lower rate in acute care may partly be due to case-mix as there was no exclusion option for those with cognitive impairment). In care homes, almost all patients were recorded as not being able to decide on their own goals, but 3 out of 4 of those that could, had their choices recorded. In 2010, patient goals for treatment were recorded for more than half of care home residents able to partake in decision-making. The rate for NHS patients was similar to 2012, at 39%.

### *Review*

Plans for follow up and review were documented for less than half of NHS patients in 2012 although for those receiving long-term management/advice, this included periodic review of symptoms in most (50/57) of cases. Plans for follow up or review were documented for 15 out of 16 of care home residents, with 9 of the 16 having a follow up or review date documented in the care plan. In the patient experience arm of the survey, most people (86/99) felt their (bladder or bowel) treatment was reviewed regularly to meet their needs. In 2010, around half of NHS patients had periodic review of symptoms documented as part of long-term management. This figure was 85% in care homes. For people who had a documented continence care plan (from almost all care home residents to just one-third of acute sector cases), most of these had been reassessed within 6 months.

### *Long-term advice/support*

In the 2012 NACC pilot, long-term management/advice for NHS patients included advice on skin care in around two-thirds of cases (39/57) and advice on psychological and emotional support in half of these cases. Contact details for relevant support groups/helplines were provided in a third of these same cases. All 16 care home plans stated how to provide skin care, and 12 of the 16 stated how to provide psychological and emotional support. In the patient experience section of the

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<sup>21</sup> [National audit of continence care \(NACC\) Capturing patients' experience of NHS continence services](#) Pilot phase evaluation report. Royal College of Physicians (2012)

survey, the majority of people (59/99) were not given information about local user support groups.

In 2010, long-term management included advice on skin care in just one third of NHS cases but 89% care home residents. Across all cases, just 11% of NHS patients received, or had planned, advice on skin care and odour control. This was 39% in care homes. All measures of coping strategies in the context of long-term management were lowest in acute care, and highest in care homes where over 80% of patients received psychological and emotional support. Outside care homes less than 20% received contact details for relevant support groups. Not all people would necessarily require or accept the offer of psychological and emotional support.

The NICE costing report produced in 2007 to support implementation of the clinical guideline, notes that discussions with clinicians working in this area suggest that access to psychological and emotional support services is likely to be very limited, if available at all, and that following basic assessment and management about 10% of patients may benefit from such support<sup>22</sup>.

## **6 Suggested improvement area: Specialised management**

### **6.1 Summary of suggestions**

Stakeholders emphasise the benefits of referral to specialist services (including 'bowel centres') when community interventions alone are not helping. Specialist services offer appropriate skills, resources and knowledge of all management options. It is suggested that GPs are reluctant to refer people to specialist care, with a lack of available services and specialist clinicians in some areas (consultants, specialist physiotherapists, anorectal physiologists and specialist nurses). Stakeholders indicate long waiting times for specialist nurse/physiotherapist appointments. It is noted that the right care can transform the lives of people with faecal incontinence and their families or carers, and can reduce reliance on community services.

Stakeholders highlight transanal irrigation as a management option for people with neurogenic bowel dysfunction, and point out that with training many individuals can take control of their own bowel management using this method. Stakeholders also suggest that transanal irrigation can help prevent accidents related to faecal incontinence, reduce urinary tract infections and help to prevent blockages in people with constipation. Stakeholders note that CG 49 does not include guidance on the

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<sup>22</sup> [Faecal incontinence: costing report](#). NICE costing report (2007).

circumstances in which transanal irrigation would be appropriate or effective and signpost to more recent publications in this area. Details on relevant products and a scoring system to assess whether transanal irrigation might be appropriate in an individual (by assessing bowel function and quality of life) is provided. Stakeholders also highlight a lack of people qualified to teach patients how to perform this method of irrigation.

Stakeholders suggest targeted and structured guidance based on faecal incontinence subtypes, including proactive bowel management in neurological bowel patients.

## **6.2 Selected recommendations from development source**

Recommendations from the development source relating to the suggested improvement areas have been provisionally selected and are presented below to inform the Committee's discussion.

### NICE CG49 - Recommendation (key priority for implementation) 1.1.1 (Good practice in managing faecal incontinence)

People who report or are reported to have faecal incontinence should be offered care to be managed by healthcare professionals who have the relevant skills, training and experience and who work within an integrated continence service<sup>23</sup>.

### NICE CG49 – Recommendation (key priority for implementation) 1.4.1 (Specialised management)

People who continue to have episodes of faecal incontinence after initial management should be considered for specialised management. This may involve referral to a specialist continence service, which may include:

- pelvic floor muscle training
- bowel retraining
- specialist dietary assessment and management
- biofeedback
- electrical stimulation
- rectal irrigation.

Some of these treatments might not be appropriate for people who are unable to understand and/or comply with instructions. For example, pelvic floor re-education programmes might not be appropriate for those with neurological or spinal disease/injury resulting in faecal incontinence.

### NICE CG49 – Recommendation 1.4.2 (Specialised management)

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<sup>23</sup> See Section 3, 'Good practice in continence services' and 'National service framework for older people' ([www.dh.gov.uk](http://www.dh.gov.uk)).

Healthcare professionals should consider in particular whether people with neurological or spinal disease/injury resulting in faecal incontinence, who have some residual motor function and are still symptomatic after baseline assessment and initial management, could benefit from specialised management (see also section 1.7).

NICE CG49 – Recommendation (key priority for implementation) 1.7.2 (Management of specific groups)

Healthcare professionals should take a proactive approach to bowel management for specific groups of people:

- people with faecal loading or constipation
- people with limited mobility
- hospitalised patients who are acutely unwell and who develop acute faecal loading and associated incontinence.
- people with cognitive or behavioural issues
- people with neurological or spinal disease/injury resulting in faecal incontinence
- people with learning disabilities
- severely or terminally ill people
- people with acquired brain injury

NICE CG49 – Recommendation 1.7.10 (Management of specific groups)

Healthcare professionals should discuss the following management options with people unable to achieve reliable bowel continence after a neurological bowel management programme:

- coping and long-term management strategies for symptomatic individuals (see recommendations in sections 1.3.11 and 1.6)
- rectal irrigation if appropriate
- other surgical options (including stoma) if faecal incontinence or the time taken for bowel emptying imposes major limits on their lifestyle.

NICE CG49 – Various recommendations in section 1.7 (Management of specific groups):

- people with faecal loading
- people with limited mobility
- people using enteral tube feeding and reporting faecal incontinence
- people with severe cognitive impairment
- people with neurological or spinal disease/injury
- people with learning disabilities
- severely or terminally ill people)

### **6.3 Current UK practice**

The 2010 NACC found that 95% of PCTs commissioned services with clear referral pathways for patients between providers. Although 69% of sites reported access to an integrated continence service, only 4 services across the country fulfilled all of the requirements set out in [Good practice in continence services](#)<sup>24</sup> (and reiterated in [National service framework for older people](#)<sup>25</sup>).

In the 2012 pilot NACC, where a treatment plan existed, around one-third included referral to another specialist or service. Participating care homes reported the majority of cases (5/8) waiting 1-2 weeks from referral to being seen for an assessment visit by a continence nurse specialist. One case in the audit waited 8-18 weeks.

In 2013, a national survey of continence services (urinary and faecal) found that nearly three quarters had a waiting list in place for patients to receive a clinical assessment and that the most common length of time to wait was 4–8 weeks<sup>26</sup>. The RCP patient experience pilot audit for continence care found that 88% (87/99) of people felt they were seen soon enough to be helped. 8 patients said that it took a great deal of time to be referred or seen by a doctor, supported by qualitative comments with one patient saying that they had to ‘battle’ to be referred. Reasons given for the delay included lack of knowledge about treatment options, communication delays and treatment in progress that caused a delay in referral.

Around 5% of cases in the 2010 NACC had rectal irrigation recorded as a treatment method. This figure was higher in the under 65 group. It is not known how many people might have benefited from this intervention. No data on rectal irrigation was collected in the 2012 pilot.

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<sup>24</sup> [Good practice in continence services](#). Department of Health (2000).

<sup>25</sup> [National service framework for older people](#). Department of Health (2001)

<sup>26</sup> All Party Parliamentary Group For Continence Care (2013) [Continence Care Services England 2013 Survey report](#)

## **7 Suggested improvement area: Specialist assessment**

### **7.1 Summary of suggestions**

Stakeholders highlight specialised diagnostic tests including anorectal physiology, endoanal ultrasound, transperineal ultrasound and MRI, as well as clinical assessment. Stakeholders emphasise the need for multidisciplinary interaction and integration across colorectal, gynaecology, urology, clinical scientists (physiology), radiology and physiotherapy.

Endoanal ultrasound (specifically 3D endoanal ultrasound in one case) is referenced as the gold standard for assessment of the sphincter complex, and it was felt that any specialist centre should have this service available with appropriate equipment and skilled practitioners. This investigation was noted to be particularly important for women with obstetric anal sphincter injury, either during investigation of faecal incontinence or in advising women of risks of developing incontinence when contemplating mode of delivery in a subsequent pregnancy.

### **7.2 Selected recommendations from development source**

Recommendations from the development source relating to the suggested improvement areas have been provisionally selected and are presented below to inform the Committee's discussion.

#### NICE CG49 – Recommendation (key priority for implementation) 1.1.1 (Good practice in managing faecal incontinence)

People who report or are reported to have faecal incontinence should be offered care to be managed by healthcare professionals who have the relevant skills, training and experience and who work within an integrated continence service<sup>27</sup>.

#### NICE CG49 - Recommendation 1.5.1 (Specialist assessment)

People with continuing faecal incontinence after specialised conservative management should be considered for specialist assessment, including:

- 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.

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<sup>27</sup> See Section 3, 'Good practice in continence services' and 'National service framework for older people' ([www.dh.gov.uk](http://www.dh.gov.uk)).

*The Committee is asked to note that RCOG green-top guideline 29: Third- and fourth-degree perineal tears, management (NICE-accredited) was identified by a stakeholder as a potential development source.*

RCOG green-top guideline 29<sup>28</sup> - Section 10, recommendation 6 (Postoperative care)

If a woman is experiencing incontinence or pain at follow-up, referral to a specialist gynaecologist or colorectal surgeon for endoanal ultrasonography and anorectal manometry should be considered. A small number of women may require referral to a colorectal surgeon for consideration of secondary sphincter repair.

### **7.3 Current UK practice**

Around 40% of all cases in the 2010 NACC underwent bowel imaging of some kind. Across acute and primary care settings, around 6% of people received anorectal manometry and/or endoanal ultrasound. This rate was higher in the younger (<65) cohort. In the 2012 pilot NACC, 3 and 4 out of 202 patients received endoanal ultrasound and anorectal physiology respectively. It is not known how many were eligible for these tests.

The 2010 NACC found that a significant proportion of continence services appeared to lack access to specialist imaging and diagnostics required for the provision of integrated services. Less than half reported having access to anorectal physiology, for example. In 2012, 70% of sites reported having facilities for anorectal physiology.

## **8 Suggested improvement area: Surgery and interventional procedures**

### **8.1 Summary of suggestions**

Stakeholders suggest that current access to the most up to date interventions is limited, giving examples of percutaneous posterior tibial nerve stimulation (PTNS) and sacral nerve stimulation (SNS) not being widely available.

The importance of multidisciplinary team management (urogynae-colorectal) for women with faecal incontinence in association with uterovaginal prolapse is also raised to maximise the potential for surgical and non-surgical management.

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<sup>28</sup> [Third- and fourth-degree perineal tears, management](#) (2007) Royal College of Obstetricians and Gynaecologists green-top guideline 29.



Stakeholders specifically highlight sphincter repair for obstetric anal sphincter trauma. This includes a focus on larger defects only and urging caution in later onset incontinence. It is suggested that – even with adequate identification and primary repair – 20-40% of women with obstetric anal sphincter trauma (occurring in approximately 1% of vaginal deliveries) describe incontinence of flatus or faecal urgency.

## **8.2        *Selected recommendations from development source***

Recommendations from the development source relating to the suggested improvement areas have been provisionally selected and are presented below to inform the Committee's discussion.

## **Access to surgery**

### NICE CG49 - Recommendation (key priority for implementation) 1.8.1 (Surgery)

All people with faecal incontinence considering or being considered for surgery should be referred to a specialist surgeon to discuss:

- the surgical and non-surgical options appropriate for their individual circumstances
- the potential benefits and limitations of each option, with particular attention to long-term results
- realistic expectations of the effectiveness of any surgical procedures under consideration.

### NICE CG49 - Recommendation 1.8.2 (Surgery)

People with a full-length external anal sphincter defect that is 90° or greater (with or without an associated internal anal sphincter defect) and faecal incontinence that restricts quality of life should be considered for sphincter repair. They should be given a realistic expectation of what this operation can achieve and information about possible adverse events, in both the short and long terms.

### NICE CG49 - Recommendation 1.8.6 (Surgery)

A trial of temporary sacral nerve stimulation should be considered for people with faecal incontinence in whom sphincter surgery is deemed inappropriate<sup>29</sup>. These may be patients with intact anal sphincters, or those with sphincter disruption. In those with a defect, contraindications to direct repair may include atrophy, denervation, a small defect, absence of voluntary contraction, fragmentation of the sphincter or a poor-quality muscle.

### NICE CG49 - Recommendation 1.8.7 (Surgery)

All individuals should be informed of the potential benefits and limitations of this procedure and should undergo a trial stimulation period of at least 2 weeks to determine if they are likely to benefit. People with faecal incontinence should be offered sacral nerve stimulation on the basis of their response to percutaneous nerve evaluation during specialist assessment, which is predictive of therapy success. People being considered for sacral nerve stimulation should be assessed and managed at a specialist centre that has experience of performing this procedure.

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<sup>29</sup> See NICE interventional procedures guidance on sacral nerve stimulation ([www.nice.org.uk/IPG099](http://www.nice.org.uk/IPG099)).

RCOG green-top guideline 29<sup>30</sup> - Section 10, recommendation 6 (Postoperative care)

If a woman is experiencing incontinence or pain at follow-up, referral to a specialist gynaecologist or colorectal surgeon for endoanal ultrasonography and anorectal manometry should be considered. A small number of women may require referral to a colorectal surgeon for consideration of secondary sphincter repair.

*The Committee is asked to note that PTNS is not covered in CG49. [NICE interventional procedures guidance 395](#)<sup>31</sup> concluded that evidence on percutaneous tibial nerve stimulation (PTNS) for faecal incontinence raises no major safety concerns and that there is evidence of efficacy in the short term in a limited number of patients. The NICE interventional procedures guidance 395 recommends that this procedure should only be used with 'special' arrangements for clinical governance, consent and audit or research. A 'special' arrangements recommendation is often made within interventional procedures guidance when the procedure is considered to be emerging practice in the NHS.*

### **8.3 Current UK practice**

In the 2010 NACC, around one-fifth of cases in acute and primary care settings had been referred to a colorectal surgeon, with 10% of cases receiving surgery. It is not known how many patients may have been eligible for surgery. Of the Acute and Primary Care Trusts reporting access to an integrated continence service, just under half had designated referral pathways with colorectal surgery. This figure was lower for mental health and care home settings. In the 2012 NACC pilot, 8% of cases included anorectal surgery within documented treatment.

2% of people across primary and acute care settings received SNS in 2010. It is not known for how many people this procedure was indicated. 71% of Primary Care and Acute Trusts reported that surgeons operating on people with urinary incontinence work as part of the multidisciplinary team (no data for faecal continence multidisciplinary working). A designated clinical surgical lead for continence and prolapse surgery existed in two-thirds of Trusts.

Where the type or causes(s) of faecal incontinence was documented in the notes, obstetric-related anal sphincter damage represented 6% of cases in the 2012 NACC pilot.

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<sup>30</sup> [Third- and fourth-degree perineal tears, management](#) (2007) Royal College of Obstetricians and Gynaecologists green-top guideline 29.

<sup>31</sup> [Percutaneous tibial nerve stimulation \(PTNS\) for faecal incontinence](#). NICE interventional procedures guidance 395 (2011).

## 9 Suggested improvement area: Continuity of care

### 9.1 Summary of suggestions

Stakeholders suggest the use of standardised documentation for recording continence status in high-risk groups, and continence care more generally, to support standardised practice and audit. A need for continuing support with bowel management methods during hospital admissions is noted to prevent faecal incontinence. It is noted that, for example, people with spinal cord injuries report nursing staff refusing to carry out manual evacuation when they are admitted to hospitals away from their spinal injury unit.

### 9.2 Selected recommendations from development source

Recommendations from the development source relating to the suggested improvement areas have been provisionally selected and are presented below to inform the Committee's discussion.

#### NICE CG49 - Recommendation (key priority for implementation) 1.1.1 (Good practice in managing faecal incontinence)

People who report or are reported to have faecal incontinence should be offered care to be managed by healthcare professionals who have the relevant skills, training and experience and who work within an integrated continence service<sup>32</sup>.

*Continuity of care is not directly covered in NICE clinical guideline 49. The Committee is asked to note that the published quality standard on 'Patient experience in adult NHS services' includes a generic statement on coordinated care through the exchange of patient information.*

### 9.3 Current UK practice

In a cross-sectional descriptive survey of intensive care units across Germany, Italy, Spain and the UK (962 questionnaires, 232 from UK), nearly half had no hospital protocol or guideline for managing acute faecal incontinence with diarrhoea<sup>33</sup>. Among UK responders, 26% of physicians and 38% of nurses cited high awareness (as opposed to moderate or low awareness) of the clinical challenges associated with this. 16% and 19% of physicians and nurses respectively reported low priority given to its management (as opposed to high or moderate priority).

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<sup>32</sup> See Section 3, 'Good practice in continence services' and 'National service framework for older people' ([www.dh.gov.uk](http://www.dh.gov.uk)).

<sup>33</sup> Bayon GC, Binks R., De L.E. et al. (2012) Prevalence, management and clinical challenges associated with acute faecal incontinence in the ICU and critical care settings: the FIRST cross-sectional descriptive survey. *Intensive & Critical Care Nursing* 28 (4): 242-250.

In the 2010 NACC, 60% of people requiring treatment for faecal incontinence had a treatment plan. Older people were generally less likely to have documented treatment plans than younger people, although a documented care plan was evident in almost all care home residents. In the 2012 pilot audit, 67% of NHS cases had a treatment plan recorded in the notes. In participating care homes, 11 out of 16 residents had a separate treatment plan and a treatment plan was included in the care plan in 15 out of 16 cases.

The RCP patient experience pilot of the NACC found that information about attendance at the continence service (includes bladder and bowel) was provided to the person's GP in 63% (62/99) of cases. A further third did not know whether this information had been shared or not<sup>34</sup>.

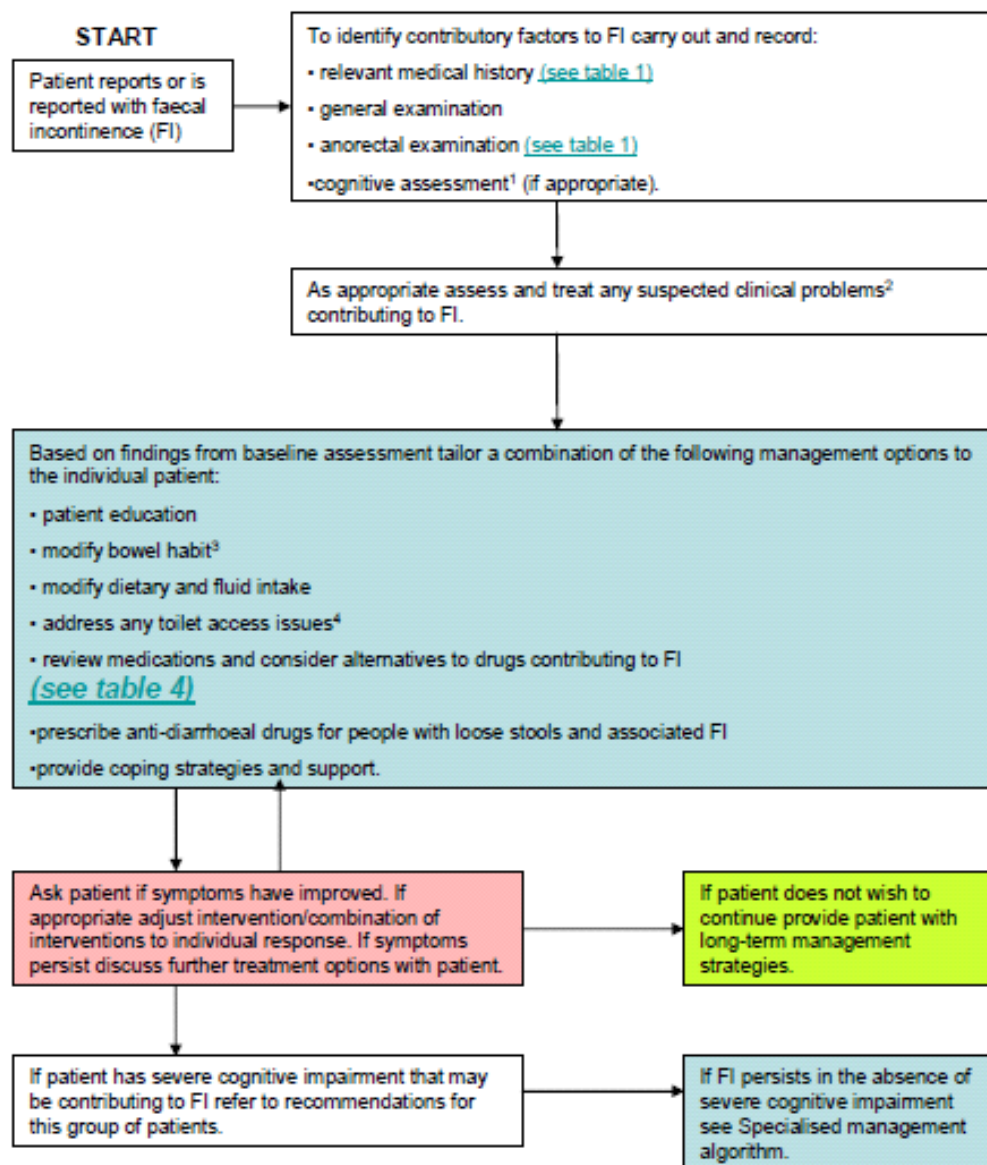
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<sup>34</sup> [National audit of continence care \(NACC\) Capturing patients' experience of NHS continence services](#) Pilot phase evaluation report. Royal College of Physicians (2012)

## Appendix 1 Additional information

The algorithms (CG49)

### Baseline assessment and initial management

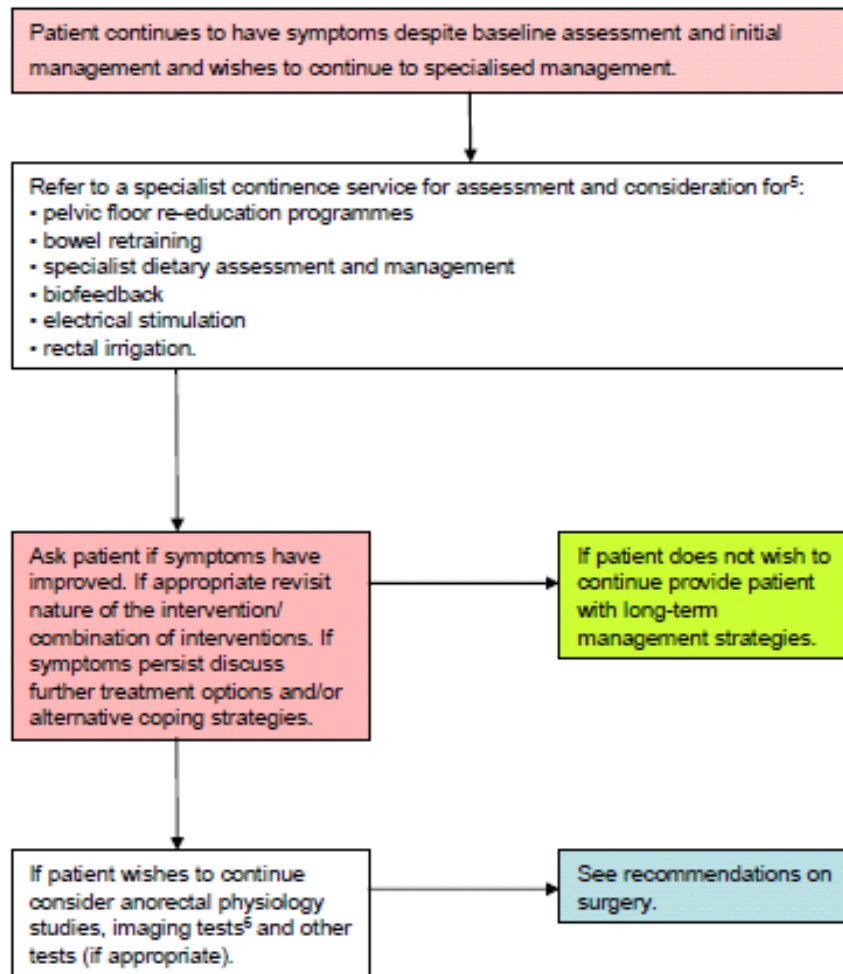


Footnotes:

1. Cognitive assessment: in patients with suspected cognitive impairment contributing to faecal incontinence it may be appropriate to conduct or refer for more formal cognitive testing.
2. For example, faecal loading, treatable causes of diarrhoea, warning signs for lower gastrointestinal cancer (see NICE clinical guideline on referral for suspected cancer, [www.nice.org.uk/CG027](http://www.nice.org.uk/CG027)), rectal prolapse, third-degree haemorrhoids, acute anal sphincter injury, acute disc prolapse.
3. Aim for ideal stool consistency, and satisfactory bowel emptying at a predictable time.
4. If appropriate refer to healthcare professional for assessment of home/mobility.

## Specialised management

START



Footnotes:

5. This referral may not be appropriate for patients who are unable to understand and/or comply with instruction, for example pelvic floor re-education programmes for those with neurological or spinal disease/injury resulting in faecal incontinence.
6. Endoanal ultrasound. If this is not available magnetic resonance imaging, endovaginal ultrasound and perineal ultrasound should be considered.

## Appendix 2 Key priorities for implementation recommendations (CG49)

Key priorities for implementation recommendations which have been referred to in the main body of this report are highlighted in grey.

### Good practice in managing faecal incontinence

- People who report or are reported to have faecal incontinence should be offered care to be managed by healthcare professionals who have the relevant skills, training and experience and who work within an integrated continence service<sup>35</sup>.
- Because faecal incontinence is a socially stigmatising condition, healthcare professionals should actively yet sensitively enquire about symptoms in high-risk groups:
  - frail older people
  - people with loose stools or diarrhoea from any cause
  - women following childbirth (especially following third- and fourth-degree obstetric injury)
  - people with neurological or spinal disease/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
- When assessing faecal incontinence healthcare professionals should:
  - be aware that faecal incontinence is a symptom, often with multiple contributory factors for an individual patient
  - avoid making simplistic assumptions that causation is related to a single primary diagnosis ('diagnostic overshadowing').

### Baseline assessment and initial management

- Healthcare professionals should carry out and record a focused baseline assessment for people with faecal incontinence to identify the contributory factors. This should comprise:
  - relevant medical history (see [table 1](#))
  - a general examination

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<sup>35</sup> See Section 3 of CG49, 'Good practice in continence services' and 'National service framework for older people' ([www.dh.gov.uk](http://www.dh.gov.uk)).



- an anorectal examination (see [table 1](#))
  - a cognitive assessment, if appropriate.
- People with the following conditions should have these addressed with condition-specific interventions before healthcare professionals progress to initial management of faecal incontinence:
    - faecal loading (see also section 1.7.3)
    - potentially treatable causes of diarrhoea (for example infective, inflammatory bowel disease and irritable bowel syndrome)
    - warning signs for lower gastrointestinal cancer<sup>36</sup>
    - rectal prolapse or third-degree haemorrhoids
    - acute anal sphincter injury including obstetric and other trauma
    - acute disc prolapse/cauda equina syndrome.
  - Healthcare professionals should address the individual's bowel habit, aiming for ideal stool consistency and satisfactory bowel emptying at a predictable time.

### Specialised management

- People who continue to have episodes of faecal incontinence after initial management should be considered for specialised management. This may involve referral to a specialist continence service, which may include:
  - pelvic floor muscle training
  - bowel retraining
  - specialist dietary assessment and management
  - biofeedback
  - electrical stimulation
  - rectal irrigation.

Some of these treatments might not be appropriate for people who are unable to understand and/or comply with instructions<sup>37</sup>.

### Long-term management

- Healthcare professionals should offer the following to symptomatic people who do not wish to continue with active treatment or who have intractable faecal incontinence:
  - advice relating to the preservation of dignity and, where possible, independence
  - psychological and emotional support, possibly including referral to counsellors or therapists if it seems likely that people's attitude towards their condition and their ability to manage and cope with faecal incontinence could improve with professional assistance
  - at least 6-monthly review of symptoms

<sup>36</sup> See the NICE clinical guideline on referral for suspected cancer ([www.nice.org.uk/CG027](http://www.nice.org.uk/CG027)).

<sup>37</sup> For example, pelvic floor re-education programmes might not be appropriate for those with neurological or spinal disease/injury resulting in faecal incontinence.

- discussion of any other management options (including specialist referral)
- contact details for relevant support groups
- advice on continence products and information about product choice, availability and use
- advice on skin care
- advice on how to talk to friends and family
- strategies such as planning routes for travel to facilitate access to public conveniences, carrying a toilet access card<sup>38</sup> or RADAR key<sup>39</sup> to allow access to 'disabled' toilets in the National Key Scheme.

## Specific groups

- Healthcare professionals should take a proactive approach to bowel management for specific groups of people:
  - people with faecal loading or constipation.
  - patients with limited mobility
  - hospitalised patients who are acutely unwell and who develop acute faecal loading and associated incontinence
  - people with cognitive or behavioural issues
  - people with neurological or spinal disease/injury resulting in faecal incontinence
  - people with learning disabilities
  - severely or terminally ill people
  - people with acquired brain injury.

## Surgery

- All people with faecal incontinence considering or being considered for surgery should be referred to a specialist surgeon to discuss:
  - the surgical and non-surgical options appropriate for their individual circumstances
  - the potential benefits and limitations of each option, with particular attention to long-term results
  - realistic expectations of the effectiveness of any surgical procedures under consideration.

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<sup>38</sup> These are available from National Association for Colitis and Crohn's disease (NACC) ([www.nacc.org.uk](http://www.nacc.org.uk)), Incontact ([www.incontact.org](http://www.incontact.org)) or the Continence Foundation ([www.continence-foundation.org.uk](http://www.continence-foundation.org.uk)).

<sup>39</sup> These are available from RADAR ([www.radar.org.uk/radarwebsite/tabid/41/default.aspx](http://www.radar.org.uk/radarwebsite/tabid/41/default.aspx)).

### Appendix 3 Suggestions from stakeholder engagement exercise

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
001	British Society Of Gastrointestinal and Abdominal Radiology (BSGAR)	Key area for quality improvement 1	The individual aspects of specialised care of faecal incontinence including the relevant diagnostic tests are well covered in CG49 and in the subsequent February 2012 NICE Pathway for the topic. However, the multifactorial aspect of the problem and the range of specialised input available means that multidisciplinary interaction/integration needs to be emphasised.	The diagnostic tools available – anorectal physiology, endoanal ultrasound, transperineal ultrasound , MRI and the clinical assessment require integration. Centres offering specialised care should work in a multidisciplinary manner with colorectal, gynaecological, urological, clinical scientist (physiology), radiological and physiotherapy input. MDT meetings review should be available to improve the quality and consistency of decision-making.	<a href="#">CG49</a>  <a href="#">Chatoor et al. Organising a clinical service for patients with pelvic floor disorders. Best Pract Res Clin Gastroenterol. 2009; 23:611-20.</a>
001	British Society Of Gastrointestinal and Abdominal Radiology (BSGAR)	Key area for quality improvement 2	Regarding ultrasound assessment; the NICE Pathway for faecal incontinence states “endoanal ultrasound; if this is not available, consider magnetic resonance imaging, endovaginal ultrasound and perineal ultrasound”. Currently 3D endoanal ultrasound is the gold standard for assessment of the sphincter complex.	Whilst other techniques may also be used as part of the imaging assessment, any centre offering specialised care for faecal incontinence should have an endoanal ultrasound service available locally with the appropriate hardware, 3-D software and skilled practitioners.	<a href="#">Abdool et al. Ultrasound assessment of the sphincter complex: a review. British Journal of Radiology. 2012; 85:865-75.</a>
002	Coloplast	Guidance on appropriate use of transanal irrigation	Many people with spinal injuries or neurological diseases suffer from neurogenic bowel dysfunction.  Transanal irrigation is a technique used to empty faeces from the bowel in a controlled manner and is an alternative to conventional bowel management	The 2007 NICE clinical guidance on faecal incontinence did include guidance on potential specialist management options for faecal incontinence.  However, products such as Peristeen, which was developed specifically for	Please see the following list of published evidence sources on transanal irrigation for the management of neurogenic bowel dysfunction.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			<p>strategies. Water is introduced into the rectum and colon via the anus, and subsequently evacuated into a toilet together with the content of the descending colon, sigmoid and rectum.</p> <p>Conducting transanal irrigation on a regular basis can be used to help prevent accidents in patients with faecal incontinence. Clinical studies have also shown a reduction in urinary tract infections compared to conservative bowel management strategies.</p> <p>In addition, regular evacuation of the recto-sigmoid area promotes transport through the entire colon, therefore helping to prevent blockages in patients with constipation.</p> <p>While transanal irrigation should always be started under medical supervision, after an initial period of training, many individuals can successfully take control of their own bowel management by conducting TAI, without the help of a carer, which helps increase independence and saves money.</p>	<p>transanal irrigation, were relatively new during the time in which the guidance was being developed, and there was little in the way of published evidence to provide guidance on the circumstances in which transanal irrigation would be appropriate or effective.</p> <p>Since then, several pieces of new evidence have been published on the efficacy of rectal irrigation, particularly those with specialist areas such as spinal cord injury and neurological condition.</p> <p>Although the 2007 guidance will form the primary basis for the new Quality Standard, we are keen to ensure that this new evidence is taken into account. This will help to ensure that transanal irrigation is offered to those who could benefit from it at the earliest possible stage.</p>	<p><a href="#">A randomized, controlled trial of transanal irrigation versus conservative bowel management in spinal cord-injured patients Christensen P, et al. Gastroenterology 2006;131:738–747</a></p> <p><a href="#">Treatment of neurogenic bowel dysfunction using transanal irrigation: a multicenter Italian study Del Popolo G, et al. Spinal Cord 2008;46:517–522</a></p> <p><a href="#">Cost-effectiveness of transanal irrigation versus conservative bowel management for spinal cord injury patients Christensen P, et al. Spinal Cord 2009;47:138–143</a></p> <p><a href="#">Long-term outcome and safety of transanal colonic irrigation for neurogenic bowel dysfunction Faaborg PM, et al. Spinal Cord 2009;47:545–549</a></p> <p><a href="#">Long-term outcome and safety of transanal irrigation for constipation and fecal incontinence Christensen P, et al. Dis Colon Rectum 2009;52:286–292</a></p> <p><a href="#">Transanal irrigation for the treatment of neuropathic bowel dysfunction López Pereira P, et al. J Pediatr Urol 2009;6:134–138</a></p> <p><a href="#">Long-term follow-up of retrograde</a></p>

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					<p><a href="#">colonic irrigation for defaecation disturbances Gosselink MP, et al. Colorectal Dis 2005;7:65–69</a></p> <p><a href="#">Neurogenic bowel dysfunction score Krogh K, et al. Spinal Cord 2006;44:625–631</a></p> <p><a href="#">Review of the efficacy and safety of transanal irrigation for neurogenic bowel dysfunction Emmanuel A. Spinal Cord 2010;48:664–673</a></p> <p><a href="#">Neurogenic bowel management after spinal cord injury: a systematic review of the evidence Krassioukov A, et al. Spinal Cord 2010;48:718–733</a></p> <p><a href="#">Transanal irrigation for disordered defecation: a systematic review Christensen P, Krogh K. Scand J Gastroenterol 2010;45:517–527</a></p>
002	Coloplast	Guidance on appropriate use of transanal irrigation	Often, it is not clear to clinicians when it would be appropriate to recommend that patients use transanal irrigation – a scoring system would help to provide a more objective assessment of bowel function and the impact on quality of life. This would encourage clinicians to consider whether transanal irrigation is an appropriate route to take.	<p>Coloplast has developed a symptom-based tool, the Neurogenic Bowel Dysfunction (NBD) score, to allow clinicians to assess the impact of NBD on a patient's quality of life.</p> <p>The NBD score uses a validated questionnaire to help clinicians identify which patients may benefit from using transanal irrigation.</p> <p>The tool provides 10 questions, giving a score of between 0 and 47 – with a</p>	<p>The NBD score was developed by Drs- <a href="#">Krogh, Christensen, Sabore, Laurberg.</a> <a href="#">Neurogenic Bowel Dysfunction score. Spinal Cord 2006; 44:625-631.</a></p> <p>Please see attached: <a href="#">Neurogenic Bowel Dysfunction questionnaire.</a></p> <p><a href="#">Guidelines for the Use of Trans-anal Irrigation for healthcare professionals</a></p>

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				<p>score of 10 or more indicating moderate to severe bowel dysfunction, which should prompt clinicians to consider the use of transanal irrigation. We would like to see this referenced in the NICE Quality Standard.</p> <p>Additionally, guidance, authored by Christine Norton and Maureen Coggrave, is now available for clinicians on when transanal irrigation would be appropriate and how it should be used.</p> <p>The Multidisciplinary Association of Spinal Cord Injured Professionals has also produced <i>Guidelines for Management of Neurogenic Bowel Dysfunction in Individuals with Central Neurological Conditions</i>, which provides further guidance on when and how it is appropriate to use trans-anal irrigation – including timing for changing bowel management treatment in Neurogenic patients.</p> <p>Given that much of this information was not available when the 2007 was written, it would be useful to see this reflected in the Quality Standard to ensure that up-to-date information is available.</p>	<p><a href="#">– Christine Norton and Maureen Coggrave.</a></p> <p><a href="#">Guidelines for Management of Neurogenic Bowel Dysfunction in Individuals with Central Neurological Conditions - Initiated by the Multidisciplinary Association of Spinal Cord Injured Professionals</a></p>
003	Royal College of Nursing	No comment			

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004	Royal College of Obstetricians and Gynaecologists	<p>Key area for quality improvement 1</p> <p>People with a full-length external anal sphincter defect that is 90o or greater (with or without an associated internal anal sphincter defect) and faecal incontinence that restricts quality of life should be considered for sphincter repair.</p>	<p>Obstetric anal sphincter trauma is not uncommon occurring in approximately 1% of vaginal deliveries.</p> <p>NICE guidance recommends that a patient with early onset incontinence after an obstetric or other injury to the external anal sphincter or with a combined IAS defect should be considered for repair. In later onset incontinence, where the defect may have been present for some time, caution should be exercised since the defect may not necessarily be the only cause of incontinence as it might have been expected to cause symptoms earlier if that were the case. It seems reasonable only to repair larger defects as smaller defects would be expected to have less influence on overall continence.</p>	<p>Even when adequately identified and repaired, 20 – 40% of women with obstetric anal sphincter trauma will describe incontinence of flatus or faecal urgency.</p> <p>RCOG Guidelines recommend that if a woman is experiencing incontinence or pain at follow-up, referral to a specialist gynaecologist or colorectal surgeon for endoanal ultrasonography and anorectal manometry should be considered. A small number of women may require referral to a colorectal surgeon for consideration of secondary sphincter repair.</p>	<p><a href="#">NICE CG49 Faecal Incontinence</a></p> <p><a href="#">RCOG Green-top Guideline 29 (The management of third and fourth degree perineal tears)</a></p>
004	Royal College of Obstetricians and Gynaecologists	<p>Key area for quality improvement 2</p> <p>Multidisciplinary team management of women with faecal incontinence in association with uterovaginal prolapse</p>	<p>Management of faecal incontinence does not fit comfortably within the remit of general gynaecologists who perform the majority of surgical repairs for uterovaginal prolapse. In the presence of faecal incontinence (which must be specifically enquired of) referral to a urogynaecological MDT is recommended in order to maximize the potential for surgical and non surgical management.</p>	<p>Faecal incontinence is underreported due to embarrassment and fear of stigmatisation but nevertheless has a major negative impact on QOL.</p>	
004	Royal College of Obstetricians and Gynaecologists	<p>Key area for quality improvement 3</p>	<p>Optimal management of women experiencing obstetric anal sphincter in</p>	<p>Endoanal ultrasound is a specialised investigation. A useful QS would be to</p>	

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	Gynaecologists		jury (OASIS) involves endoanal ultrasound; either during investigation of faecal incontinence or in advising women of risks of developing incontinence post OASIS (when contemplating mode of delivery in a subsequent pregnancy).	recommend readily available access to this investigation, which may require an investment in equipment and training.	
005	Royal College of Paediatrics and Child Health	We think the plan suggested is very good. We would like children to be added to the topic as well.	FI is a common problem in children and young people as well. We recently reviewed this situation and found there are several gaps in our knowledge on this area.	It has been clearly shown that children with FI have poor HRQoL.	Please see the following reference <a href="#">Rajindrajith S, Devanarayana NM, Benninga MA (Alimentary Pharmacology and Therapeutics 2013;37:37-48.</a>
006	Specialist committee member A	The single biggest opportunity to improve quality for patients with faecal incontinence is to address primary care case finding.	Most patients are not spontaneously forthcoming		
006	Specialist committee member A	Training to help the HCP tailor the approach to the patient: specifically, offering all patients assistance with first line measures (assessing bowel function, odour control, skin care, etc) and identifying the minority who need onward specialist referral. In	There is a mis-perception that little can be done to help these patients		



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		<p>other words, help educate re (1) the questions to ask of potential sufferers, (2) who those vulnerable patients are. Secondly to understand that conservative management is not just issuing pads and loperamide, but considering the factors in parentheses above.</p>			
006	Specialist committee member A	<p>It is worth considering whether standard documentation for continence care (used by district nurses, continence advisers, etc) could be developed.</p>	<p>This would help standardise practice, as well as help audit</p>		
006	Specialist committee member A	<p>In care homes and secondary care, there is need for standardised documentation of continence status in all vulnerable patients: this is a grossly overlooked area.</p>	<p>This would help standardise practice, as well as help audit.</p>		

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006	Specialist committee member A	Other outcomes - documentation of bowel function, consideration/performance of a rectal examination where appropriate, documentation of patient's personal goals for care outcome, loperamide prescription and advice about safe use, referrals for anorectal physiology and endoanal ultrasound testing.	Development of more valid outcome measures		
006	Specialist committee member A	Also, I am not sure in the NICE Pathway, under "Specialised Care" why the Specialised Assessment box comes <i>after</i> the Specialised Management box.			
007	Specialist committee member B	Key area for quality improvement 1 People with FI, their family and carers	People with FI are more likely to be able to live independently and participate in public and social life with dignity By meeting individual need with treatment and/or products lives can change	Too many people with FI do not receive regular support and care for what may be a life long condition . Many are given no choice over the products they receive. People with FI	<a href="#">Nice CG148</a> has this area as a key recommendation for people with neurological conditions with bladder dysfunction. Most people with Neurological conditions have

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		<p>receive training support and regular review about their chosen management option from healthcare professionals who are trained to provide support in FI and knowledgeable about the full range of treatments and products available,</p>	<p>from being housebound too afraid to leave in case of faecal leakage when out, to being able to cope with daily living in away others take for granted</p>	<p>due to a underlying bowel condition may end up being provided with pads that limit the ability to urinate normally even though suitable ones are available.</p> <p>People with neurological conditions are often not offered the chance to try out rectal irrigation because of no qualified person locally to teach them</p>	<p>concurrent bowel dysfunction resulting in FI if not managed The same basic principles should apply.</p> <p>There is recent evidence in people with MS of lives being transformed by the use of a rectal irrigation system on a regular basis(Peristeen) improving quality of live</p>
007	Specialist committee member B	<p>Key area for quality improvement 2</p> <p>People with FI should be assessed by clinicians trained in treatment and management of FI who do not make assumptions over the primary contributing factor</p>	<p>“Diagnostic over shadowing” can occur in people with long term conditions or disabilities such as neurological conditions or cognitive disorders. Often it is automatically assumed that the cause of their FI is due to their long term condition when there may be a wide range of contributing factors. Many woman with a neurological condition may have suffered damage to the pelvic floor during childbirth.</p> <p>People with a learning disability may have an underlying bowel or neurological condition.</p>	<p>False assumptions continue to be made and many people with FI are not being fully assessed by specialist clinicians. Few local continence services have all the necessary skills or resources.</p>	
007	Specialist committee member B	<p>Key area for quality improvement 3</p> <p>People with FI whether they wish to</p>	<p>Few local continence services have the necessary skills and resources or knowledge of all management options. Finding the best option for individual patients and their families may not be</p>	<p>Continence care tends to be poorly resourced and a Cinderella service.</p> <p>Many GPs are reluctant to refer people to secondary or tertiary care yet</p>	

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		pursue active treatment or long term management options should have the opportunity to be referred to specialist bowel centres.	straight forward, yet the right care will improve quality of life and transform lives often of both the person with FI and their family carer.	the right care will improve quality of life and transform lives often of both the person with FI and their family carer and reduce reliance on community services,.	
007	Specialist committee member B	Key area for quality improvement 4 People with FI such as those with a spinal cord injury or neurological condition should be able to continue to be supported with their normal method of bowel management to prevent FI when admitted to hospital	People with spinal cord injuries continue to report that nursing staff refuse to carry out manual evacuation when they are admitted to hospitals away from their spinal injury unit.	The number of people with SCI and neurological disorders is increasing with an aging population as people with SCI increased life expectancy, and military conflict. Apart from loss of dignity and control it is likely to lead to autonomic dysreflexia in those with high cord lesions.	
008	Specialist committee member C	It is very treatment specific. We know what treatments are available for FI but where I see a problem is how these treatments are delivered. There does not appear to be a national or			

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		<p>even local cohesive strategy for delivering a service for this group of patients. I have some ideas on this subject and would be happy to share them with you either before the meeting or on the day itself.</p>			
008	Specialist committee member C	<p>There is very little on the quality of life outcomes in the overview and I feel that this should be addressed.</p>			
008	Specialist committee member C	<p>A targeted and structured guidance based on the FI subtype will be helpful.</p>			
009	Urology User Group Coalition	<p>Patients with faecal incontinence currently experience a post code lottery in terms of assessment and treatment.</p>	<p>Patients throughout England should expect to receive the same high quality of assessment and treatment.</p>	<p>This should be a key area because there is no satisfactory reason why a patient in a more poorly served part of the country should receive a worse service than one in the best.</p>	<p>UUGC is aware of numerous examples of poor examples of assessment and treatment care. Additionally, the <a href="#">All Party Parliamentary Group for Continence Care</a> reported on the importance care and the needs for a quality integrated service.</p>

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009	Urology User Group Coalition	Inadequate postgraduate training / funding means that there is a dire shortage of clinicians (Consultants, Specialist Physiotherapists, Anorectal Physiologists and Specialist Nurses) and this directly affects the quality of care available.	A high quality cost-effective continence care service requires strong clinical leadership, specialist practitioners, medical and surgical specialists, and ongoing education and training of staff.	The UUGC is aware that it is not unusual for patients to wait 12 months for an appointment with a specialist nurse or physiotherapist. This delay causes significant disruption in the patient's life and unnecessary loss of dignity, and may also place increased burden on the NHS and other public services.	The APPG for Continence Care made a series of recommendations which are applicable to faecal incontinence including the planning and procurement of continence services.
009	Urology User Group Coalition	Treatment advances are not widely available despite research suggesting improved quality of life (from treatments such as percutaneous posterior tibial nerve stimulation, PTNS, and sacral nerve stimulation, SNS).	NICE guidelines (including IPG362) note that PTNS has success in reducing symptoms but it is not always readily available as a treatment. The same is true of SNS.	Adopting treatment advances more rapidly when there is evidence that it is efficacious will lead to improved outcomes for patients and consequentially is likely to decrease their discomfort, and loss of dignity. There may also be reduced costs for the NHS.	NICE IPG 362.
009	Urology User Group Coalition	Improving medicine management & care home staff understanding	Poor medicine management and a lack of understanding amongst care home staff can result in patients experiencing faecal overflow leakage – improved training within care homes is crucial.	This will lead to improved outcomes for patients, in particular for those in care home settings.	The UUGC is aware of many anecdotal cases of poor care. In addition, the APPG for Continence Care's review of the literature may be useful.

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010	Specialist committee member D	1. Proactive screening/asking in high risk groups (women after 3rd/4th degree tear and chronic diarrhoea such as IBD). Not happening at present. Up to 74% of people with IBD have FI.			<p><a href="https://doi.org/10.1016/j.crohns.2012.11.004">Norton C, Dibley L, Bassett P. 2012. Faecal incontinence in inflammatory bowel disease: associations and effect on quality of life. <i>Journal of Crohn's &amp; Colitis</i> ;doi.org/10.1016/j.crohns.2012.11.004.</a></p> <p>Dibley L, Norton C. 2012. Faecal incontinence in people with inflammatory bowel disease: self-reported experiences among a community sample in the UK. <i>Inflammatory Bowel Diseases</i>. Accepted, in press.</p>
010	Specialist committee member D	2. Screening for impaction or diarrhoea in Care Home populations.			
010	Specialist committee member D	3. Proactive bowel management in neurological bowel patients.			
010	Specialist committee member D	4. Referral for specialist services if simple community interventions are not helping.			