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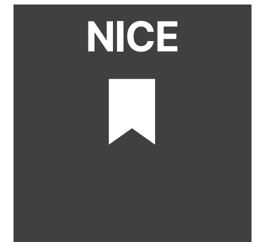


# 2018 surveillance of faecal incontinence (NICE guideline CG49)

Surveillance report

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# Contents

Surveillance decision ..... 3

Reasons for the decision to not update the guideline ..... 3

Overview of 2018 surveillance methods ..... 5

Evidence considered in surveillance ..... 5

Ongoing research ..... 6

Intelligence gathered during surveillance ..... 6

Overall decision ..... 10

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# Surveillance decision

We will not update the guideline on faecal incontinence.

## Reasons for the decision to not update the guideline

The recommendations in this guideline were largely based on consensus because of inadequate quantity and quality of evidence. The evidence base, and clinical practice, do not appear to have progressed enough to support an update of this guideline.

The evidence considered in this surveillance indicated that the following interventions may improve outcomes for people with faecal incontinence:

- rectal irrigation (Coggrave et al. 2014, Collins et al. 2013)
- anal plugs (Deutekom et al. 2015)
- sacral nerve stimulation (Thaha et al. 2015)
- injectable bulking agents (Maeda et al. 2013).

The guideline recommends rectal irrigation, anal plugs and sacral nerve stimulation, so no impact is expected for these interventions. Injectable bulking agents for faecal incontinence (NICE interventional procedures guidance 210) recommends this procedure under special arrangements. Although more evidence is available, it appears to be of a similar nature to that considered in developing the guidance (lower quality evidence, and no evidence of long-term effects). Therefore, no impact is expected on the guideline.

For the following interventions, the new evidence suggested no effect, or uncertainty in their effects:

- pelvic floor muscle training in antenatal and postnatal women (Woodley et al. 2017)
- biofeedback and electrical stimulation (Bartlett et al. 2015, Collins et al. 2016, Norton et al. 2012, Young et al. 2017)
- percutaneous tibial nerve stimulation (Knowles et al. 2015)

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- surgical interventions including levatorplasty and repair of sphincter or pelvic floor (Brown et al. 2013)
- surgery for complete rectal prolapse (Tou et al. 2015)
- drug treatment (Omar et al. 2013).

Pelvic floor muscle training, biofeedback and electrical stimulation were noted to have limited evidence for their use during guideline development, so the guideline committee used consensus to recommend these interventions only for people who had inadequate response to initial management. Therefore, the new evidence is unlikely to affect recommendations.

Recommendations on surgery were clear that discussions should take place between the patient and a specialist surgeon including: 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); and realistic expectations of the effectiveness of any surgical procedures under consideration.

Evidence on surgery considered when developing the guideline often found some evidence of short-term benefit but no long-term benefit, and adverse events were common. The new evidence suggests much the same, so no impact on the guideline is expected.

Drug treatments for diarrhoea are recommended to reduce faecal incontinence. Evidence for these drugs remains focused on the outcome of diarrhoea rather than incontinence, therefore, no impact on the guideline is expected.

A further study (Duelund-Jakobsen et al. 2015), suggested by a topic expert, suggested that people with faecal incontinence whose symptoms improved were satisfied with their continence status after nurse-led care, but those whose symptoms did not improve were dissatisfied. However, this study does not tell us whether nurse-led care affected patients' outcomes compared with usual care, so no impact is expected.

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# Overview of 2018 surveillance methods

NICE's surveillance team checked whether recommendations in faecal incontinence (NICE guideline CG49) remain up to date. The static list process was followed, consisting of:

- Feedback from topic experts via a questionnaire.
- A search for new or updated Cochrane reviews.
- A search for ongoing research.
- Examining related NICE guidance and quality standards.
- Examining the event tracker for relevant ongoing and published events.
- Consulting on the decision with stakeholders.

After consultation on the decision, we considered the comments received.

For further details about the process and the possible update decisions that are available, see ensuring that published guidelines are current and accurate in developing NICE guidelines: the manual.

# Evidence considered in surveillance

## Search and selection strategy

Previous surveillance in 2010 identified 49 studies that were considered to have no impact on recommendations.

Using the static list process, we searched for new Cochrane reviews related to the whole guideline. We found 9 relevant Cochrane reviews published between August 2010 and January 2018.

We also identified 1 NIHR signal on a relevant study.

We considered these studies in conjunction with 5 additional relevant studies from a total of 29 identified by topic experts. Many of the studies identified by topic experts were not

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eligible for consideration because they were general narrative reviews of a topic rather than systematic reviews, or were advice.

Two studies were identified in comments received during consultation on the 2018 surveillance decision.

From all sources, we considered 66 studies to be relevant to the guideline.

The recommendations in this guideline were largely based on consensus because of inadequate quantity and quality of evidence. The evidence base does not appear to have progressed enough to support an update of this guideline. Most of the new evidence was consistent with current recommendations.

# Ongoing research

We checked for relevant ongoing research: of the 6 ongoing studies identified, none were assessed as having the potential to change recommendations.

# Intelligence gathered during surveillance

## Views of topic experts

We considered the views of topic experts, including those who helped to develop the guideline.

Two topic experts indicated that uptake and implementation of the recommendations is low. However, there was no information to suggest that this was because of unclear or controversial recommendations.

## Views of stakeholders

Stakeholders are consulted on all surveillance decisions except if the whole guideline will be updated and replaced. Because this surveillance decision was to not update the guideline, we consulted on the decision.

Overall, 8 stakeholders commented; of these, 5 represented industry, 2 were patient organisations, and 1 response was received from a professional body.

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Six of the 8 stakeholders disagreed with the decision to not update the guideline.

One stakeholder suggested adding a section on managing incontinence associated dermatitis. Of the studies suggested by the stakeholder, only 2 were suitable for inclusion in surveillance (Park 2014, Heidegger et al. 2016). However, the evidence in these studies was deemed insufficient to inform new recommendations in this area.

Three stakeholders suggested that the guideline should be updated to refer to NICE's medical technologies guidance on the Peristeen transanal irrigation system for managing bowel dysfunction. The guideline recommends rectal irrigation as an option and the NICE Pathway includes the medical technologies guidance at the appropriate place. We therefore consider rectal irrigation to be adequately covered by existing NICE guidance.

One stakeholder suggested updating the guideline to include percutaneous tibial nerve stimulation. NICE's interventional procedures guidance on percutaneous tibial nerve stimulation for faecal incontinence recommends this intervention only with special arrangements for clinical governance, consent and audit or research. We will share the 8 studies identified by the stakeholder with the interventional procedures team for consideration.

One stakeholder suggested adding a specific brand of anal plug to the guideline. However, the guideline does not mention any anal plug brands. No evidence to support the use of one brand of anal plug over another was identified.

One stakeholder noted that the guideline may be poorly implemented. Again, there was no information to suggest that this was because of unclear or controversial recommendations.

We asked stakeholders whether they knew of new sources to refer people to for information about toilet access cards and RADAR keys. Several sources for both items were suggested, but there was no information to guide choosing a particular source over the others. Additionally, the variety of sources indicates that patients should be able to find this information in many places. Therefore, we decided to remove the out-of-date references about these items.

One stakeholder suggested an extension to the scope – this related to faecal incontinence caused by obstetric trauma. The stakeholder wished this topic to be covered by a separate guideline. However, it was unclear how the management of faecal incontinence

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due to obstetric injury differs from that due to other causes. Therefore, a separate guideline in this area is not justified.

This stakeholder also suggested that NHS England's guidance on conditions for which over the counter items should not routinely be prescribed in primary care would restrict prescription of anti-diarrhoeal drugs. NHS England's guidance refers specifically to acute diarrhoea, and so should not impact on prescription of appropriate drugs for people with chronic diarrhoea that may cause faecal incontinence.

See appendix A for full details of stakeholders' comments and our responses.

See ensuring that published guidelines are current and accurate in developing NICE guidelines: the manual for more details on our consultation processes.

## Equalities

One stakeholder suggested that specific groups of people with faecal incontinence, such as those with neurological causes, would be protected by the Equalities Act 2010, and should have specific guidelines for different populations.

Government guidance on defining disability suggests that faecal incontinence would be considered to be a disability covered by the Act irrespective of the cause. The guideline has recommendations aimed at specific groups, and we have found no evidence to inform new recommendations.

## Editorial amendments

During surveillance of the guideline, we identified the following points in the recommendations that should be amended.

### Footnote 6

Footnote 6 reads:

'See Section 3 of the Department of Health's 'Good practice in continence services' and 'National service framework for older people'.'

The hyperlink goes to the Department of Health homepage; however, direct links to each

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publication would be more helpful and in line with current style for hyperlinking.

The National service framework for older people is still hosted on the Department of Health's website, but Good practice in continence services appears to have been archived and the pdf is not accessible through the archive. This may mean that this document is not considered to be current, but no updated policy has been identified.

The footnote should therefore be amended to refer only to the National service framework for older people.

Suggested text: See the Department of Health's National service framework for older people.

### Footnote 7

Footnote 7 contains a link to an old version of the guideline on referral for suspected cancer (NICE guideline CG27). Because this guideline has been updated, this page simply contains text about the update with a link to the new guidance.

The hyperlink should be updated to take the reader directly to the updated guideline.

### Footnote 10

This footnote, about toilet access cards, reads:

'These are available from National Association for Colitis and Crohn's disease (NACC), Incontact or the Continence Foundation.'

NACC is now known as Crohn's and Colitis UK, and the website has changed (see the our history section of the Crohn's and Colitis UK website).

Incontact appears to have ceased. The website is no longer active and no useful results were obtained in web searches.

A topic expert noted that Continence Foundation no longer exists. Its website appears to be functioning. However, it is very basic and lacks useful resources. One website indicates that the Continence Foundation was dissolved in 2009. However, it is unclear how reliable the information is. Searches of Companies House and the Charity Commission show no

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entries for the Continence Foundation.

The purpose of the footnote is to direct users to information on toilet access cards. However, a suitable alternative resource is not clear because many organisations produce versions of these cards including Hartmann, Prostate Cancer UK, the IBS Network, and the Bladder and Bowel Community.

This footnote should be deleted.

### Footnote 11

Footnote 11, about RADAR keys, reads:

'These are available from RADAR.'

The hyperlink is broken, and the overarching website also appears to have gone.

The purpose of the footnote is to direct users to information on RADAR keys. There is no clear standard resource. Disability Rights UK sells RADAR keys but does not provide information about the scheme. Overall, no new source was thought to be suitable.

This footnote should be deleted.

### Footnote 12

This footnote reads:

'See advice from the National Patient Safety Agency (NPSA 2004).'

However, this organisation no longer exists, having been replaced by the NHS Commissioning Board Special Health Authority, which itself appears to have been incorporated into NHS England (redirects to NHS England's website).

This footnote should be deleted.

## Overall decision

After considering all evidence and other intelligence and its impact on current

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recommendations, we decided that no update is necessary.

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