

NICE consultation response: Persiteen anal irrigation system for managing bowel dysfunction

1. This response has been drafted on behalf of the PCF, an independent national campaigning group, which was set up in 2003 to improve awareness amongst policymakers of the needs of children and young people with continence problems and to improve NHS services in this often-neglected area of child health. The PCF has formal representation from expert clinicians, the charities ERIC and Bladder and Bowel UK, as well as the Royal College of Nursing, the Royal College of Paediatrics and Child Health, the Community Practitioners' and Health Visitors' Association and the School and Public Health Nurses' Association.
2. The PCF also has five company members that support our work. One of these is Coloplast Ltd, the producer of the Peristeen anal irrigation system. The PCF would like to emphasise that while Coloplast has had sight of this response after its completion, it has not had any input into or opportunity to comment on the content prior to its submission. This response was produced by the PCF's clinical members who have experience of using Peristeen, with no involvement from our company members.
3. The PCF agrees with the document's assertion that evidence around the use and effectiveness of Peristeen in children is varied, but believes that this should not prevent transanal irrigation, whether with Peristeen or other irrigation systems from being used in children. The PCF made similar assertions in a previous response to the consultation on the proposal for 'no update' to the NICE guideline on constipation in children and young people, submitted in April 2017.
4. Chronic idiopathic (functional) constipation can usually be successfully treated with appropriate laxatives, as per the NICE Guidance (CG99). However, a small number of children with idiopathic constipation continue to soil and CG99 recommends progression along a pathway to ACE procedure. Although a decision has been taken to have a further review on whether to include transanal irrigation when there is more evidence on its use, clinical experience confirms a role for irrigation in children who are not responding to treatment, prior to consideration of a surgical option (ACE procedure).

For children with constipation secondary to anorectal malformation, Hirschsprung's disease or neurogenic bowel, transanal irrigation is a long-established treatment, having been documented thirty years ago, as follows: Shandling B, Gilmour RF. 1987 The enema Continence catheter in spina bifida: successful bowel management. *Journal of pediatric surgery*. 22: 271-3. According to Google this work is cited in 144 related articles. The Shandling enema was the forerunner of Persiteen and other modern transanal irrigation systems. While its primary use was in children with spina bifida, particularly those with a negative anocutaneous reflex and therefore no anal sphincter tone, it was also useful for children with high congenital anorectal anomalies, resulting in an ineffective anal sphincter.

5. The experience of some of the PCF's clinical supporters is that some CCGs are blacklisting all transanal irrigation (including Peristeen) in spite of its benefits for adults and children with intractable faecal soiling. The inclusion of guidance on the use of Peristeen in children in these recommendations would highlight to clinicians that transanal irrigation should be an option available to children and young people with soiling secondary to constipation and/or congenital or acquired bowel dysfunction, as part of a pathway of bowel management.

6. To avoid bias the PCF believes that NICE should acknowledge the existence of other transanal irrigation systems and consider evidence for their use in children with faecal incontinence, for whom other treatments have been ineffective. Evidence not reviewed by NICE includes: Koppen I et al (2017) Transanal Irrigation in the Treatment of Children With Intractable Functional Constipation. Journal of pediatric gastroenterology and nutrition; Feb 2017; vol. 64 (no. 2); p. 225-229, and Jorgensen C et al (2017) Transanal irrigation is effective in functional fecal incontinence. European Journal of Pediatrics; Jun 2017; vol. 176 (no. 6); p. 731-736.
7. We believe that transanal irrigation should be considered prior to formation of a stoma (colostomy or ileostomy) or an ACE procedure as it negates the need for general anaesthetic and formation of a catheterisable channel, with the associated financial costs, potential problems including infection and stenosis, the need for surgical reversal and impact of altered body image. Children do not appear to have the same high drop-out rate shortly after starting as has been reported in adults. As transanal irrigation is commenced at a young age in many children with neurogenic bowel and is often only needed for a period of months in children with intractable functional constipation, it must represent significant cost savings as compared to surgical alternatives.
8. Point 4.6 of this consultation document highlights that children who had used Peristeen “were able to maintain bowel control that allowed them to attend school.” As well as the impact on education, soiling is associated with a great deal of social stigma, with children experiencing bullying and avoiding social situations. As the consultation document has recognized the benefits of Peristeen for some children in enabling them to go to school regularly and socialise with their peers, the PCF believes that this provides grounds for transanal irrigation to be utilised for children where other treatment methods have been unsuccessful, whilst further high-quality research is undertaken. Furthermore, the PCF would be happy to contribute to a group for expert opinion and experience while that research is awaited.

Submitted on behalf of the Paediatric Continence Forum (PCF), 27th September 2017.