

# National Institute for Health and Care Excellence

## 231/2 – Gastroelectrical stimulation for gastroparesis Consultation Comments table

IPAC date: Thursday 13<sup>th</sup> February 2014

Com . no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
1	Consultee 1 NHS Professional	1	By currently working in a specialised centre for gastroparesis I can agree that we follow all of these principles in practice and they have always been effective in the management of patients with gastroparesis.	Thank you for your comment.
2	Consultee 2 NHS Professional	1.3	The patient selection should occur in a true multidisciplinary environment	Thank you for your comment. 1.3 currently states that “Patient selection and follow-up should be done in specialist gastroenterology units with expertise in gastrointestinal motility disorders and the procedure should only be performed by surgeons working in these units”.
3	Consultee 3 Healthcare Other	1	Many thanks for the opportunity to comment. We support the recommendation of gastric electrical stimulation for gastroparesis to be upgraded to normal arrangements for clinical governance, consent and audit. We hope that this will enable patients in need, who currently are not receiving effective therapy for gastroparesis, to have access to this treatment without undue/unnecessary delay.	Thank you for your comment.

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4	Consultee 4 NHS Professional	1	I agree with most of the above. However this is a low volume procedure with only approximately 10 procedures per centre per annum in only a handful of centres. A centralised database would be enormously helpful and I shall be suggesting this through the upper GI clinical reference group even if not recommended in the NICE appraisal document	Thank you for your comment. NICE does not usually fund register development for procedures covered by normal arrangements guidance.
5	Consultee 5 Patient	1	More information is needed about procedures.	Thank you for your comment.
6	Consultee 6 Patient & founder of GastroParesis UK charity	1	A centralised database of statistical data on GES, submitted at regular intervals by the specialist clinicians, would be beneficial to both clinicians & patients in monitoring treatment options to those with gastroparesis	Thank you for your comment. Please see the response to comment 4
7	Consultee 7 NHS Professional	1,1.3, 1.4	Broadly agree with the recommendations.  1.3 - Also suggest that surgeons who performs these should also have some knowledge of gastrointestinal motility rather than simply acting as technicians.  1.4 - Our unit will be publishing long-term follow up data (13 years ) by the end of 2014	Thank you for your comments. 1.3 in the guidance covers this

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8	Consultee 8 Patient	<b>1</b>	I agree with the recommendations. These need to be made very clear to hospitals and clear information in place. I have gained funding for a GES through my private health insurance but even though I have an approved surgeon who has carried out the procedure before, it is proving very difficult to get approval from a hospital surgical committees for this to be performed. The request was refused at Queen Elizabeth Hospital Birmingham and is still to be decided by BMI Priory Hospital Birmingham. I have been trying to progress this for six months and am now in danger of losing my funding because there are no clear guidelines. Surgeon is Mr J Dmistrewski.	Thank you for your comment.
9	Consultee 1 NHS Professional	<b>2.2</b>	Although the majority of patients we see for consideration for insertion of gastroelectrical stimulation suffer with type 1 diabetes, we have found over the 13 years that the procedure has been carried out, it is also extremely effective for those suffering with idiopathic and post surgical gastroparesis. From our experience, it is most effective in improving nausea and vomiting, as well as general quality of life.	Thank you for your comment. Paragraph 2.2 has been amended.
10	Consultee 2 NHS Professional	<b>2.1</b>	Pain is not an indication for gastro electric stimulation the indications are nausea, vomiting and early satiety	Thank you for your comment. 2.1 reports more common and other symptoms of gastroparesis. 'pain' has been removed from 2.1.
11	Consultee 5 Patient	<b>2</b>	Long term feeding with a jejunostomy tube into my bowel and ges inserted 10 weeks ago.	Thank you for your comment.

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12	Consultee 7 NHS Professional	<b>2</b>	Broadly agree with the indications and current treatments.  2.2 - gastroparesis can also occur in type 2 diabetics and patients with Parkinson's disease. One of the important sub group not mentioned is the idiopathic (post-viral) gastroparesis. This group often consists of young women and can represent up to 40% of all patients with gastroparesis. With regard to treatment the results of gastrostomy tube and pyloroplasty have been not successful. The feeding jejunostomy will improve nutrition but will not improve patient's symptoms.	Thank you for your comment.  Paragraph 2.2 has been amended.
13	Consultee 8 Patient	<b>2</b>	Eligible patients with GP need to be offered every opportunity to find some kind of help. As a sufferer from Gastroparesis, I have constant sickness and even with anti-emetics I am unable to function. I have had to give up work and am not able to lead any kind of life. I understand that the GES does not cure Gastroparesis and the GES does not work for everyone. But if the GES reduced my symptoms by even 10% it would make a difference.	Thank you for your comment.
14	Consultee 1 NHS Professional	<b>3</b>	As a clinical nurse specialist, I have observed no problems with the procedure of insertion itself. most patients have a very short stay in hospital with few complications.	Thank you for your comment.
15	Consultee 5 Patient	<b>3</b>	Procedure went well for me, no problems.	Thank you for your comment.
16	Consultee 7 NHS Professional	<b>3</b>	Agree with the description of the procedure	Thank you for your comment.
17	Consultee 1 NHS Professional	<b>4</b>	In our experience, patients symptoms have been reduced, many have no longer needed the support of enteral or parenteral feeding and have had a significant reduction, and sometimes no further hospital admissions.	Thank you for your comment.

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18	Consultee 2 NHS Professional	4	My experience in adequately selected patients is the treatment changes lives. Patients are able to live normal lives, reduce their need for admission to hospital, reduce their dependence on enteral and parenteral nutrition and ultimately save the health authority money	Thank you for your comment.
19	Consultee 5 Patient	4	My gastroparesis is idiopathic and only had the ges for 10 weeks and happy to report that i have had no vomiting, holding down a bit of food and starting to wean myself of the feeding tube.	Thank you for your comment.
20	Consultee 7 NHS Professional	4	Agree with the description on efficacy. There are several studies now published showing that gastric electrical stimulation improves symptoms, quality of life and reduces the need for assisted feeding and hospital admissions. Our unit experience supports these findings.	Thank you for your comment.
21	Consultee 8 Patient	4	In the last 12 months I have had three hospital admissions and spent a total of 24 weeks in hospital. Anything that could help to minimise my hospital admissions would benefit both myself and the NHS.	Thank you for your comment.
22	Consultee 1 NHS Professional	5	In my experience, there have been no safety issues that I am aware of.	Thank you for your comment.
23	Consultee 2 NHS Professional	5	No issues with our 100 patients	Thank you for your comment.
24	Consultee 5 Patient	5	No major problems, do get the pins and needles sensation now and again	Thank you for your comment.
25	Consultee 6 Patient & founder of GastroParesis UK charity	5	I am an insulin diabetic and have been treated effectively with GES since 2003. The device was replaced in 2013 due to battery expiration, and continues to be an effective management tool for my gastroparesis symptoms	Thank you for your comment.

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26	Consultee 7 NHS Professional	<b>5</b>	<p>We have found the procedure to be safe with very little adverse events. We broadly agree with the description of safety.</p> <p>5.3 - Device removal appears to be somewhat high (11%). In our 13 year experience it is about 5%.</p> <p>5.4 - We have not had any battery failures in 90 patients. The Battery however has a life span of 7-10 years. It is not clear in the description, whether the battery failures were at the time of surgery or whether they were replacements after the he life span of the original battery.</p> <p>5.6 - It is also useful to acknowledge that the treatment success is about 74%</p>	<p>Thank you for your comment.</p> <p>Data reported in section 5 are on safety from peer reviewed publications.</p> <p>5.4 reports with respect to battery failures that 'timing is unclear'.</p>
27	Consultee 8 Patient	<b>5</b>	<p>More awareness of the GES should be made available, particularly as it can effect other surgeries and the type of equipment used!</p>	<p>Thank you for your comment.</p> <p>NICE will provide 'information for patients' for this procedure that explains the guidance produced.</p>
28	Consultee 1 NHS Professional	<b>6</b>	<p>Our quality data from the last 13 years shows a significant improvement in quality of life after insertion of gastroelectrical stimulator.</p>	<p>Thank you for your comment.</p>

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29	Consultee 5 Patient	6	<p>Please keep in mind this is the last resort for patients. I was refused funding several times and felt very upset and unfair as it wasn't my fault I had gastroparesis. A charity paid for my ges treatment and felt they were giving me a chance and the nhs wouldn't. I'm very relieved it's working and feel that without the charities help, I wouldn't know this and would be stuck on a feeding tube forever. Please understand there is no cure and anything that can relieve symptoms is a godsend. This illness is life changing and is not our fault!!!!!!</p> <p>gastroparesis patients, I was well aware of the complications and the chance it won't work, but still went ahead with it as I felt it was my last option. I have to say I was refused funding several times which I found very upsetting and unfair, as it wasn't my fault I had gastropatesis. A charity paid for my treatment and I was grateful to them for giving me the chance to have it done, where the nhs didn't. I'm very relieved it's working</p>	Thank you for your comment.
30	Consultee 7 NHS Professional	6	<p>We broadly agree with the comments. As the committee suggested it is very difficult to design a randomised study due to the 'carry over' period after the device is turned off. Our long-term experience suggests that patients continue to do well up to 13 years after the procedure which makes placebo effect less likely. This data has been presented in peer reviewed meeting and will be published by end of 2014. The quality of life scores also suggests significant improvements for patients with a debilitating condition. I hope that NICE would consider the patients outcomes as an important end point when considering the efficacy of this procedure, which would be the standard for any other surgical procedures such as oesophagectomy for oesophageal cancer.</p>	<p>Thank you for your comment.</p> <p>Quality of life outcomes were added to section 4 of the guidance.</p>

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31	Consultee 8 Patient	<b>6</b>	There is no cure for Gastroparesis, the drug therapies on offer are limited and patients like me are suffering everyday. Gastraparesis needs much more research and also greater awareness of the condition needs to be made especially within the medical profession. Doctors and surgeons do not understand not only how debilitating and life limiting can be but also how painful. A life of not been able to eat, tube feeding and diet of morphine and laxatives is untenable. Any procedure or help that can be given should be made available. More research around the GES needs to be done. The committee have dismissed the device based on a small research projects. There needs to be greater research before dismissing the GES out of hand.	Thank you for your comment. In 1.4 the Committee recommends that 'further publications providing data about the effects of the procedure on symptoms in the long term and on device durability would be useful'.
32	Consultee 2 NHS Professional	<b>NOTE</b>	I work in a gastro paresis clinic within the nhs treating patients with symptoms of gastroparesis	Thank you for your comment.
33	Consultee 6 Patient & founder of GastroParesis UK charity	<b>NOTE</b>	A centralised database of statistical data on GES, submitted at regular intervals by the specialist clinicians, would be beneficial to both clinicians & patients in monitoring treatment options to those with gastroparesis	Thank you for your comment. Please see the response to comment 4
34	Consultee 7 NHS Professional	<b>NOTE</b>	Our unit has one of the largest series of patients who have undergone gastric electrical stimulation for gastroparesis	Thank you for your comment.
35	Consultee 10 Consultation & committee services manager Professional Affairs Royal College of Physicians	<b>1</b>	The RCP is grateful for the opportunity to comment on the above consultation. In general, we supportive of the NICE guidance as further evidence on long-term efficacy is needed and this group of patients can be extremely debilitated.	Thank you for your comment.



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36	Consultee 10 Consultation & committee services manager Professional Affairs Royal College of Physicians		Unfortunately, the published data on GES are of low methodological quality, largely consisting of non-comparative case series reports which include a mixture of prospective and retrospective data collection. However, there are two randomised controlled crossover studies that have been reported in patients with diabetic and idiopathic gastroparesis.	Thank you for your comment. The RCT by Abell T et al 2003 is part of the 2 systematic reviews (O Gardy 2009, Chu 2012) included in the IP overview. The RCT by McCallum 2013 found in the update search will be included in the IP overview.
37	Consultee 10 Consultation & committee services manager Professional Affairs Royal College of Physicians		Abell T et al (Gastric electrical stimulation for medically refractory gastroparesis. Gastroenterology 2003; 125:421) suggested that there was significant benefit with treatment on versus off in a combined group of idiopathic and diabetic gastroparesis with the predominant benefit in those with diabetes. But, the other controlled study (McCallum RW et al. Gastric electrical stimulation with Enterra therapy improves symptoms from diabetic gastroparesis in a prospective study. Clin Gastroenterol Hepatol 2010; 8:947) showed no difference between on and off treatment periods after an initial six weeks unblinded on treatment phase. However, following the on and off treatment periods all patients had their stimulators turned on and all had improvements in subjective and objective parameters with chronic stimulation after 12 months of gastric electrical stimulation, compared with baseline.	Thank you for your comment. Abell T et al 2003 is included in the systematic reviews by O Gardy 2009, Chu 2012. McCallum RW et al 2010 is included in the IP overview.
38	Consultee 10 Consultation & committee services manager Professional Affairs Royal College of Physicians		In the United States, the Enterra Therapy system (Medtronic) has been approved as a humanitarian exemption device only for diabetic and idiopathic gastroparesis.	Thank you for your comment.

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39	Consultee 10 Consultation & committee services manager Professional Affairs Royal College of Physicians		There are potential reductions in healthcare costs such as recurrent hospital admissions, enteral and parenteral nutrition, and drug use.	Thank you for your comment. It is outside the remit of IP programme to assess the cost effectiveness of this procedure.
40	Consultee 10 Consultation & committee services manager Professional Affairs Royal College of Physicians		Some patients are severely debilitated by diabetic gastroparesis and GES may be proposed as an alternative to gastrointestinal surgery for patients with severe symptoms of gastroparesis and refractory to conventional medical management. However, it has to be acknowledged that some patients report no benefit.	Thank you for your comment. 1.2 of the guidance states that 'During the consent process clinicians should inform patients considering gastric electrical stimulation for gastroparesis that some patients do not get any benefit from it'.
41	Consultee 10 Consultation & committee services manager Professional Affairs Royal College of Physicians		In 2010, it was estimated that between 80 and 100 UK patients had received an Enterra™ implant (? - how many for diabetic gastroparesis). It would be useful to find out the outcome in these patients and there should be an aim to get updated up to December 2013.	Thank you for your comment.

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42	Consultee 9 Carer		<p>My 17 year old son suffers with this condition and just over 5 weeks again was fitted with a Gastric Pacemaker. I want to share his story with you in the hope you will update your guidelines to include this treatment on humanitarian grounds for anyone else who suffers from this horrendous and debilitating condition.</p> <p>At the beginning of November 2012, [REDACTED] began to feel constantly nauseous, this was made significantly worse when he travelled to college, and even walking anywhere became an issue. Eating would also make him feel ill and his stomach always felt full and bloated. We saw the GP who thought he may have Vertigo, and he was given anti sickness medication. This had little effect, so after a few weeks, we were back and unable to pin point the problem, blood tests were arranged. Based on these results, we were referred to a Paediatrician at our local hospital.</p> <p>Over the Christmas period, eating became more of an issue, he could drink nothing other than water, he was completely exhausted, yet unable to sleep very much, the nausea got worse and he began to lose weight. After Christmas, he was too ill to leave the house to continue to attend college, but he tried to keep up with his coursework from home.</p> <p>We were seen quickly in early January 2013, as they were worried about his blood sugar levels. Following his examination, we were asked to give urine and faeces samples and a CT scan was arranged, to check his inner ears. However the consultant did say it may all be Psychosomatic. I found this very hard to believe, as [REDACTED] was normally fit and healthy and I couldn't understand or see a reason for the dramatic change in him.</p> <p>The CT scan and other tests were all returned as normal and he was discharged from the hospital, but his symptoms were getting worse and we still had no explanation as to why. I returned to the doctor and as [REDACTED] was covered under his dad's private medical insurance, asked for a referral to another pediatric consultant. We were referred to [REDACTED] as Gastric specialist. We first saw him in February 2013. By this stage, [REDACTED] has lost close to 2.5 stone and was eating very little, not because he</p>	<p>Please respond to all comments</p> <p>Thank you for your comment.</p> <p>The Committee noted in it's committee comments that gastroparesis is a debilitating condition with very few treatment options. Section 6.1 and 6.2 were split up and the Committee noted that the patient commentaries received described improvements in quality of life when using gastroelectrical stimulation for gastroparesis.</p>

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			<p>wasn't hungry, but because eating made he feel so sick. After his initial examination, he said he wanted [REDACTED] to have an endoscopy and a colonoscopy, to see if anything obvious was going on. These both proved clear and at our next appointment said that [REDACTED] may have a condition called Idiopathic Gastroparesis. He prescribed some medication that may have helped the symptoms and arranged for [REDACTED] to have a delayed gastric emptying test. This took a few weeks to arrange, but the test confirmed that [REDACTED] suffered with Gastroparesis at the age of 16.</p> <p>We will never really know the cause, but blood tests show that [REDACTED] has had glandular fever at some point and that is the likely cause. The medication gave him a little relief for a few days, but after that seemed of no benefit. The medication was changed, but again, he saw no real benefit. He was able to eat less and less and continued to lose weight.</p> <p>In June 2013 we saw [REDACTED] again. None of the medication was having any effect on the symptoms for [REDACTED] and he was shocked that [REDACTED] had now lost 4 stone and prescribed him Fortijuice drinks. He also prescribed the last drug that may have helped [REDACTED] and referred us to [REDACTED] to discuss the possibility of fitting a gastric pacemaker. He also arranged for [REDACTED] to have an MRI, to make sure that the structure of the small bowel and intestine were also clear of any abnormality.</p> <p>[REDACTED] quality of life was very poor. He only left the house to stay with his dad on occasional weekends and to attend hospital appointments. At home he spent most of his time in his bedroom, lying down was often the only place he could cope with the symptoms and being around food or even just the smell of cooking was very difficult for him. He was clearly depressed, so was also referred for some counselling. He was completely emaciated, his muscles had all wasted away and he had no energy. The simplest of tasks, such as going to the bathroom, left him exhausted.</p>	

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			<p>We travelled to Chelmsford and saw ██████████ in July 2013. He chatted to ██████ and after listening to what he had to say, said he felt that ██████ may benefit from the pacemaker and explained everything to us. He told us the pros and cons and made it very clear that this may not work, but discussed the outcomes of previous procedures which made us very optimistic. The only other test he wanted ██████ to have was a feeding tube. Although an MRI showed that everything below the stomach was structurally correct, he needed to know that it functioned correctly, or the pacemaker would not benefit Tom.</p> <p>On the 19<sup>th</sup> August, when most 17 year olds have their first driving lesson, ██████ had a Naso Jejunal feeding tube fitted. Initially this was only going to be for a period of a week or so, to make sure he could tolerate the feed, but after the first week, it became evident that although he didn't lose the symptoms of the condition, he was able to benefit from the nutrition, so as much as he hated the thing, the decision was taken to keep it until the pacemaker could be fitted.</p> <p>This came with its own issues though. We had blockages and ended up at A &amp; E, ██████ was tied up to the pump around 12 hours a day order to get enough calories in him, but it did stop him losing much more weight.</p> <p>By this time ██████ had absolutely no quality of life left, he was unable to continue with his education, had withdrawn from most of his friends and his mood was extremely low. Life at home was becoming very difficult, most times he and his brother would he come together was to eat, and that hadn't happened in a long time because of his condition and it was becoming increasingly difficult to cook for us and not distress ██████ with cooking smells.</p> <p>Once it was confirmed that the tube feeding worked for ██████, the surgeon was happy to fit the pacemaker, then began the next battle, funding!</p>	

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			<p>Prior to knowing that the pacemaker was required, [REDACTED] was covered by Aviva, under his dad's insurance policy through work. Once the request was made for a gastric pacemaker to be fitted, they said [REDACTED] would no longer be covered for the condition and a pacemaker would not be authorised as it was policy exclusion. This was escalated through his employer, but to no avail, in fact I was horrified that they didn't seem interested in [REDACTED] as a person or taking his particular situation into account, there was no discussion, it was just not covered.</p> <p>I was able to add [REDACTED] to my companies' policy, as we have the opportunity to make changes in September every year and luckily, they cover pre-existing conditions.</p> <p>I entered into discussions with AXA PPP 5<sup>th</sup> September, even though [REDACTED] would not be covered until 1 October, but they said that wouldn't be an issue. I told them over the phone what the procedure was and sent the surgeon's referral letter. They called me a few days later saying it would not be covered, the reason, the guidelines on your website from December 2004.</p> <p>I then began a battle with them over [REDACTED] quality of life. The FDA, who I understand are the US equivalent of NICE, approved the use of this device on humanitarian grounds on 31 March 2000. If everything else has been tried, and all tests have been carried out to ensure you are a suitable candidate and the pacemaker may help you, the operation should be carried out in these cases. I pursued on this basis and under the exceptional circumstances, was finally given authorisation and [REDACTED] had his pacemaker fitted on Wednesday 27 November.</p> <p>[REDACTED] had his surgery at 8.30am on 27 November and by 6.00pm on Friday 29 November, I was taking him home. He was understandably sore from the operation, but left hospital taking only paracetamol and only needed to continue taking that for a week. His recovery has been excellent and the change in him immense.</p>	

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			<p>█████ is now 5 weeks post his operation, and the change in him has been unbelievable. He was eating small amounts the day after his operation and from there has gone from strength to strength and is now eating more or less normally and is gaining weight. His mood has lifted and completely changed, he's more sociable and starting to get out of the house. I had forgotten what it sounded like to hear him laugh or see him smile and he's looking forward to getting back to his education. It's like having my son back, instead of the shell he had become.</p> <p>We visited ██████████ on 19 December and the pacemaker was adjusted slightly, now that his body is recovering from the surgery and the pacemaker is settling. Again, he felt his symptoms improve a little more and hopefully this will continue as further adjustments are made to the settings over the coming months.</p> <p>I do however feel very aggrieved. It was an incredibly difficult and stressful time for me getting ██████ to the point of getting a diagnosis and having the surgery he needed, and because of this, ██████ suffered far more and for longer than he needed to. In researching the condition, I have found others who have suffered; they have all had similar battles in getting their operation in the UK, most under 20 years of age.</p> <p>I'm very glad that it was eventually covered by insurance, but would not have hesitated in pursuing the NHS if this had not been the case, as others have had to do. However, I don't believe it is right that it should be such a battle to give someone the opportunity to lead a normal life and be a productive member of society. Without this surgery, ██████ long term outlook would be to have spent the rest of his life being fed through a tube, not complete his education, unlikely to ever leave home and live an independent life, would not be able to work and would therefore have to claim benefits. To find at the age of 17, that this is how your life would be through no fault of your own, is just unbearable.</p>	

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			<p>I urge you to please review your guidelines to allow this operation to be carried out on humanitarian grounds, if indications are that someone is a suitable candidate and end their suffering. I understand there is not much in the way of statistical information in the UK for this procedure, but as the condition is rare and it's such a battle to have the operation, will there ever be? The operation has been completely life giving to [REDACTED]. I will be eternally grateful to [REDACTED] and his team for giving my son the opportunity to lead a normal life again.</p> <p>[REDACTED] will only be covered for this condition until March by my insurance company. After that, all of his care will need to come under the NHS, but hopefully, this will be fairly minimal.</p> <p>People with this condition should not be condemned to a life of misery. [REDACTED] outcome following his surgery can only show that this operation is completely worthwhile, along with [REDACTED] other past cases.</p> <p>I look forward to receiving your comments.</p>	

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