

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Interventional procedures

Patient Organisation Submission

Laparoscopic insertion of a magnetic titanium ring for gastro-oesophageal reflux disease IP973/3

Thank you for agreeing to give us your views on this procedure or operation and how it could be used in the NHS.

When we are developing interventional procedures guidance we are looking at how well a procedure or operation works and how safe it is for patients to have.

Patient and carer organisations can provide a unique perspective on conditions and their treatment that is not typically available from other sources. We are interested in hearing about:

- the experience of having the condition or caring for someone with the condition
- the experience of having the procedure or operation
- the outcomes of the procedure or operation that are important to patients or carers (which might differ from those measured in clinical studies, and including health-related quality of life)
- the impact of the procedure or operation on patients and carers. (What are the benefits to patients and their families, how does it affect quality of life, and what are the side effects after the procedure or operation.)
- the expectations about the risks and benefits of the procedure or operation.

To help you give your views, we have provided this template. You do not have to answer every question — they are there as prompts. The text boxes will expand as you type, the length of your response should not normally exceed 10 pages.

Please note, all submissions will be published on the NICE website alongside all evidence the committee reviewed. Identifiable information will be redacted.

About you	
1. Your name	██████████
2. Name of organisation	OPA
3. Job title or position	Operations Manager
4. Brief description of the organisation (e.g. who funds the organisation? How many members does the organisation have?)	Over 10,000 subscribers. Funded by Trusts and Foundations, and the local communities that we serve.
5. How did you gather the information about the experiences of patients and carers to help your submission? One to One discussion with patients when they call the OPA for help and advice. Especially following the GORD Awareness Week each year.	

Living with the condition

6. What is it like to live with the condition or what do carers experience when caring for someone with the condition?

It has a significant impact on the quality of life for patients. Some patients report that it impacts their ability to work and socialize with family and friends. Many patients report that the disease can affect their ability to sleep with some even reporting that they must sleep upright in a chair to help manage the symptoms in order to sleep. In summary, the disease has a huge impact on people's quality of life.

Advantages of the procedure or operation

7. What do patients (or carers) think the advantages of the procedure or operation are?

For many patients who are either non-responsive to PPI's or do not want to take PPIs as a treatment option, they are often put off by a fundoplication due to the side effect profile of the procedure. For these patients, LINX offers an alternative to consider as they perceive the side effects to be better. Patients are often attracted to LINX because it is removable, reversable and seen as less invasive which means they can go home the same day they have the surgery.

Disadvantages of the procedure or operation

8. What do patients (or carers) think the disadvantages of the procedure or operation are?

Hard to get access to it. Seems unfair that some NHS hospitals offer the procedure and others do not. Postcode lottery for access to the treatment when they feel everyone should have the option of getting it on the NHS if the procedure is right for them.

Patient population
<p>9. Are there any groups of patients who might benefit either more or less from the procedure or operation than others? If so, please describe them and explain why.</p> <p>It seems that many young patients prefer the option of LINX due to the option to have further surgery in the future and the fact the procedure is reversible/removable and less side effects.</p>
Equality
<p>10. Are there any potential equality issues that should be taken into account when considering this topic?</p> <p>Just that it seems unfair that many NHS hospitals in London offer the procedure, but very few outside of London.</p>
Other issues
<p>11. Are there any other issues that you would like the Committee to consider?</p> <p>No</p>
Key messages
<p>12. In no more than 5 bullet points, please summarise the key messages of your submission.</p> <ol style="list-style-type: none">1. Many Patients would like to have access to LINX as a treatment option on the NHS where the appropriate rather than having a postcode lottery2. It seems that for many patients who are not having Reflux resolved by PPIs, LINX seems to be a bridge between PPIs not working and having a fundoplication. It is perceived by patients as less invasive than a fundoplication and has better side effects.

Thank you for your time.

Please return your completed submission to ip@nice.org.uk