

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Interventional procedures

Patient Organisation Submission Ultrasound-guided Percutaneous Microwave Ablation for Benign Thyroid Nodules IP1868

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	British Thyroid Foundation (BTF)
3. Job title or position	CEO Development
4. Brief description of the organisation (e.g. who funds the organisation? How many members does the organisation have?)	<p>The BTF works with patients and medical professionals to provide reliable information by people who are living with thyroid disorders and their families and carers. www.btf-thyroid.org</p> <p>It is a membership organisation (we currently have approximately 3,500 members) and the majority of the charity's income comes from subscriptions. Other income comes from fundraising donations and grants from trusts and foundations.</p>
<p>5. How did you gather the information about the experiences of patients and carers to help your submission? (For example, information may have been gathered from one to one discussions with colleagues, patients or carers, telephone helplines, focus groups, online forums, published or unpublished research or user-perspective literature.)</p> <p>Through the services we provide (e.g. patient information events, a telephone helpline, local support groups and medical query service) we receive regular feedback about the experiences and concerns of patients across the UK.</p> <p>We have also requested specific responses to prepare for this submission through our communications to our members and supporters (via our e-bulletin, our website, and our social media channels).</p> <p>We understand this is a new procedure and is only currently available in one centre. We have not heard directly from any patients who have had this procedure, however, last year we ran two focus groups with patients who were interested in finding about alternatives to thyroid surgery for benign thyroid nodules. We believe their responses they shared with us are also relevant for the purposes of this submission.</p>	

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?

Even though the majority of thyroid nodules are harmless, many patients tell us that living with a benign thyroid nodule can be very stressful. The physical symptoms, often swallowing and breathing difficulties, have an adverse impact on people's quality of life and many people feel unhappy and uncomfortable with cosmetic changes that nodules bring.

Psychologically some people find that just knowing there is something growing in their neck causes enormous anxiety and they want it to be removed.

Advantages of the procedure or operation

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

Patients have told us *'I really don't want to lose my thyroid'* and *'The thought of being on medication for life is very frightening.'*

If successful this procedure means that a patient will not lose their thyroid and will avoid going on lifelong thyroid hormone replacement (levothyroxine). Around 10-15% of patients do not feel well on levothyroxine so if this procedure is successful for them they will avoid the risk of a poor quality of life with an underactive thyroid.

'This treatment would be much less invasive – at the very least I would like to have the option to try it.'

There are a number of significant risks of having surgery, including laryngeal nerve damage, permanent low calcium levels and post operative bleeding. In addition to these risks, preparing for surgery and managing the recovery process creates a lot of stress for people and puts an increased burden on their families and loved ones who have to support them. Knowing there is an alternative treatment pathway, or at least having the option to try it, would remove a big source of anxiety for some patients.

'It could just be like going to the dentist: you go in, you have it done, you go home!'

Thyroid surgery scars are often very discreet but some patients will end up with more visible scars that can be itchy and painful for a long time post-surgery. Patients who successfully have this procedure will avoid the risk of scarring.

Disadvantages of the procedure or operation

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

If this procedure was unsuccessful patients may of course be disappointed with the outcome and end up having to have the surgery they had wished to avoid. However, by selecting patients carefully and giving them balanced information, i.e. explaining it was not guaranteed to solve the problem and the about any possible risks of the microwave ablation, these disadvantages should be managed.

Waiting times for thyroid surgery are currently very long in many parts of the country, more so since the pandemic, so treating appropriate patients with an alternative to surgery would benefit patients and alleviate precious NHS resources.

Patient population

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.

One group of patients who may benefit from this procedure are people who are living with the increased burden of mental health problems, and are particularly anxious about staying in hospital and having a general anaesthetic and surgery.

One patient we spoke to was very happy to have the opportunity to have a non-invasive procedure which had been successful for him. He said '*The fact I could return home on the same day was brilliant.*' He said that having constant communication with the team looking after him throughout the procedure was very reassuring and made a huge difference to the overall experience.

Equality

10. Are there any potential [equality issues](#) that should be taken into account when considering this topic?

Women are far more likely to be diagnosed with thyroid nodules than men. They are therefore more likely to suffer complications from surgery and be among the group who, once they become hypothyroid, do not feel well on levothyroxine.

Currently this treatment is only available in one hospital in London. This enforces the health disadvantages that patients living in other parts of the UK experience. If this is a genuine option for patients it must be available for and accessible to people throughout the UK. If it is not available at all large centres, it is fair and equitable that there should be clear referral pathways so that patients who are deemed eligible for the procedure should be informed of the option and considered for it.

Other issues

11. Are there any other issues that you would like the Committee to consider?

Patient choice is essential. Surgery is expensive and there is a real risk of long term complications, particularly when surgery is performed by surgeons who do not perform a high volume thyroidectomies. The emergence of alternative treatments for some types of thyroid nodules is very encouraging. We are very supportive of this consultation which will provide more evidence as to whether this procedure should be a realistic alternative to surgery for some patients and improve their health outcomes.

Key messages

12. In no more than 5 bullet points, please summarise the key messages of your submission.

- 1.
- 2.
- 3.
- 4.
- 5.

Thank you for your time.

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