Thyroid disease: assessment and management

NICE National Institute for Health and Care Excellence

Consultation on draft guideline – deadline for comments 5pm on 17 July 2019 email: ThyroidDisease@nice.org.uk

	Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly. We would like to hear your views on the draft recommendations presented in the guideline, and any comments you may have on the rationale and impact sections in the guideline and the evidence presented in the evidence reviews documents. We would also welcome views on the Equality Impact Assessment. In addition to your comments below on our guideline documents, we would like to hear your views on these questions: 1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why. 2. Would implementation of any of the draft recommendations have significant cost implications? 3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.) See section 3.9 of Developing NICE guidance: how to get involved for suggestions of general points to think about when commenting.
Organisation name – Stakeholder or respondent (if you are responding as an individual rather than a registered stakeholder please leave blank):	The Thyroid Trust

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Disclosure Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.	Nothing to disclose.
Name of commentator person completing form:	Lorraine Williams
Type	[office use only]

Comment number	Document [guideline, evidence review A, B, C etc., methods or other (please specify which)]	Page number Or **'general'** for comments on whole document	Line number Or **'general'** for comments on whole document	Comments Insert each comment in a new row. Do not paste other tables into this table, because your comments could get lost – type directly into this table.
1	Guideline	General	General	Thyroid disease has many aetiologies and presentations. This guideline should emphasise the need for a choice of treatment options that best suit individual patients.
2	Guideline	General	General	We note that observational data has been discounted on the whole but that the committee's own observations are used extensively, in the absence of robust evidence from large clinical trials. This would seem to be somewhat biased. We feel that for these guidelines to be successful it will be vital to incorporate the experiences and practical insight from patients and other clinicians

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3	Guideline	General	General	The Guideline needs to reference NICE Guidance on Medicines Optimisation (NG5), and Medicines Adherence (CG76), which stresses the importance of patient involvement in the decision on a medicine.
4	Guideline	General	General	The Guideline needs to cross reference the NICE Guideline on Multi-morbidity (NG56), as this is common and may affect the treatment decision.
5	Guideline	General	General	We believe the guidelines should also reference the latest RMOC guidance on prescribing liothyronine (published 15th July 2019, replacing the November 2018 version) and the BTA 2016 guidance for GPs and endocrinologists, on liothyronine switching and prescribing.
6	Evidence Review E	16	26	This guideline misses some key points related to patients' experiences. The NICE methodology, focusing only on RCTs and academic evidence, combined with the way in which the guidelines are 'designed by a committee' will in our view, be limiting if it is rigidly adhered to.
7	Evidence Review E	16	26	Some other NICE Guidelines may cover older medicines that are known to be effective but have little or less research than the thyroid hormone treatments used to treat hypothyroidism. We don't know of specific examples, but we would ask that NICE considers this issue and how it may be addressed in other Guidelines. We acknowledge the difficulty is that there's limited incentive (funding) to do research on older medicines, such as liothyronine and thyroxine, which have gone off patent, as there's less money to be made in producing them. If the NICE methodology will only look at academic research RCTs etc (much of which is industry funded), using committee members' experience, to plug the gaps, is not a sufficiently robust process. The experience of the wider clinical community, where a relatively small number of specialists can be classed as thyroid experts, as well as patient experiences, such as those detailed in The Liothyronine Dossier, must be added to the committee's experiences, or the Guideline will be too narrow. The NICE methodology risks misses important evidence on drugs that are off patent.
8	Guideline	General	General	While we appreciate that pregnant and postpartum women are out of scope for this Guideline, we believe that the link with successful pregnancy and thyroid disorders is too important to not be mentioned at all in the NICE Guidelines. We would suggest that the new guidance, currently being developed, by the Royal College of Obstetricians & Gynaecologists, should be referenced prominently somewhere in the NICE Guideline: as it is in the Scope document.

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9	Guideline	General	General	As Thyroid Eye Disease is mentioned several times in the Guideline we would suggest that there should be some mention of the need for a specialist referral in the case of suspected thyroid eye disease and perhaps a link to a resource where signs and symptoms are detailed, since so many Thyroid Eye Disease patients currently wait a long time to be diagnosed and properly treated. http://www.clinmed.rcpjournal.org/content/15/2/173.abstract
10	Guideline	29	3	It is not known how many people may suffer from secondary hypothyroidism but we know that often patients wait years for a diagnosis because doctors are not aware it is a possibility. In our opinion, something more needs to be said about diagnosis and treatment of secondary hypothyroidism in the NICE Guideline.
11	Guideline	General	general	Mental health impacts can be severe when a thyroid disorder is not well managed and this should be made very clear in the Guideline, this aspect appears to be entirely missing from the draft. The risk is that clinicians treating thyroid patients with mental health symptoms may not make the connection. It has been said previously that anyone with any mental health symptoms should have their thyroid checked. http://www.thyromind.info/ This appeared to be a sensible statement and worth repeating.
12	Guideline	25	16	We would suggest that more research needs to be done into the mental health aspects of thyroid disease. Thyroid patients report experiences ranging from depression and anxiety to psychosis and dementia like symptoms.
13	Guideline	8	6	We would suggest that a section should be added detailing tests that should be done for other possible causes of symptoms, that may be similar to symptoms of a thyroid condition – particularly where treatment for a thyroid condition has not resolved symptoms – Vitamin D, Vitamin B12, etc.
14	Guideline	8	6	We are pleased to see a clear recommendation to test FT3 when TSH is below the reference range however in the subsequent section on managing hypothyroidism, page 9, from line 2, there needs to also be guidance on when to consider using T3 treatment otherwise “hard to treat” hypothyroid patients will continue to be ignored or end up seeking alternative practitioners or self-treating options which may be unsafe.
15	Guideline	9	2	We would strongly suggest that the guideline needs to include advise to consider using careful levothyroxine dose titration for “hard to treat” hypothyroid patients. We know that even small adjustments can be transformational for those patients whose conditions are finely tuned.
16	Guideline	9	2	We recommend including a mention that some patients may be intolerant to changing manufacturer of levothyroxine and may need to be prescribed specific formulations including in some cases liquid thyroxine, for those intolerant, or allergic, to fillers.

17	Guideline	8	23	We would suggest that clinicians consider genetic testing for patients who may show signs of being unable to convert T4 to T3.
18	Guideline	25	16	Further to our comment 16, we would also suggest adding to Research Recommendations, that the NHS collates and analyses any such genetic test data, to help build understanding of the genetic aspects of thyroid disease.
19	Guideline	9	14	We are concerned that the draft Guideline does not acknowledge the profound difference to quality of life that treatment with liothyronine makes for some patients, who are unable to live normally without it. The following quote is typical of patients we hear from very regularly and those who submitted their stories for The Liothyronine Dossier. While the genetic link is unproven and unlikely to be the only reason some patients may need this treatment, there is no denying that for some patients, liothyronine is necessary and life changing: "The addition of 15mcg of T3 a year ago to my existing prescription of 100mcg of T4 for autoimmune underactive thyroid has been life changing. I have a heterozygous DIO2 gene impairment resulting in a decreased ability to convert synthetic Levothyroxine to active T3 and I would like the incredible improvement in the following symptoms after adding in T3 recognised by NICE: fatigue, anxiety, depression, brain fog, general aches and pains, wellbeing. My quality of life has improved immeasurably after the addition of T3 and I have returned to work full time having had to stop work due to immense brain fog. I think it is extremely worrying that NICE do not recognise the beneficial impact that T3 can have."
20	Guideline	General	General	There are several references to using the TSH reference range as a diagnostic range or a therapeutic target. There is no evidence base for these statements. Many patients who have a TSH within the reference interval are hypothyroid. Some patients require a low TSH to resolve signs and symptoms of hypothyroidism. Some patients have a very narrow therapeutic range within the TSH reference interval. There is no evidence that biochemistry reflects clinical presentation in all cases. The guidance should assert the superiority of clinical response over biochemistry. Serum is the intermediate space; it does not consistently reflect intracellular hormone status.
21	Guideline	24	11	We recommend adding the following Research Recommendations: • Understanding Quality of Life issues and impacts for thyroid patients • Gut function and autoimmunity • Gluten intolerances and thyroxine absorption

				• How many patients are taking liothyronine or NDT for hypothyroidism and are satisfied with it, having previously suffered, and how else should they be treated?
22	Guideline	General	General	Approximately 3% of UK population are prescribed Levothyroxine If a patient remains unwell on levothyroxine, once dose has been increased high enough to bring TSH under 1 and all four vitamins optimal (and gluten free if applicable) then they should be entitled to an NHS referral to a thyroid specialist endocrinologist and option of a trial of T3, yet across many areas of the UK this is not happening https://www.british-thyroid-association.org/sandbox/bta2016/bta_response_to_the_nhs_england_consultation_for_website.pdf For patients with hypothyroidism who are not on liothyronine but wish to trial it, the principles guiding decision-making should follow those outlined in the BTA statement [1]. Combination treatment with Levothyroxine and Liothyronine should only be initiated and supervised by accredited endocrinologists [1]. Patients experiencing symptomatic benefit on a combination Levothyroxine and Liothyronine regimen should be able to continue such therapy prescribed from primary care. There are numerous reports from patients of seeing endocrinologist and being advised that despite clinical need they are unable to be prescribed T3 on NHS for variety of reasons, such as: 1)Initial 3 month prescription via hospital, but the refusal of GP to cover ongoing prescribing, care and cost 2) Endocrinologist applies for individual funding request on patients behalf, but this is refused 3) Endocrinologist can't prescribe at all 4) Endocrinologist would monitor patient if the patient sources T3 from abroad 5) Endocrinologist advises patient to buy T3 from abroad, but no ongoing monitoring 6) A private prescription written in a way that enables the patient to access to cheap T3 from EU 7) A private prescription that is deliberately only written to access UK T3 and therefore financially beyond most patients All of these reasons are unacceptable. The Department of Health and Social Care must take decisive action on the price, then doctors can do their jobs and not have to waste time filling in individual funding requests and being forced to deny thyroid patients access to the treatment they need.

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23	Guideline	9	11	We suggest it would be useful for NHS research to test all patients who are well and stable on T4/T3 combination (and also consider testing patients who are currently on NDT.) We note that some NHS thyroid specialists endocrinologists already offer DIO2 testing on NHS and NHS prescription of T3 if a patient tests positive and also investigate gut and gluten issues. A negative result should not exclude a T3 trial.
24	Guideline	4	8	The use of the word 'manage' here is ambiguous. We are concerned that the goal of treatment not positioned as being to resolve symptoms, we would prefer the clear wording used in the British Thyroid Association 2015 hypothyroidism guidance - "to restore wellbeing".
25	Guideline	4	14	We would suggest revised emphasis here, so that GPs and patients are alert to the possibilities of titrating dose, for potentially profound differences to patient wellbeing - this is key for many patients we hear from.
26	Guideline	5	11	What are the interactions – we would suggest listing these here, or link to? Also include interactions with supplements, particularly iron and calcium
27	Guideline	5	11	Brands of thyroid hormones are not interchangeable for some patients. Some people may feel less well with different formulations of levothyroxine. The reason for this is not clear but might relate to differences in fillers and bulking agents between the various manufacturers' tablets. We would suggest that the Guidelines should mention this and patients should be advised, where possible to stay on the same manufacturer's formulation of thyroid hormones. https://academic.oup.com/jcem/article/98/2/511/2833067 Until better data become available, we would suggest the 2013 AACE/ATA/TES recommendations on LT4 treatment are included in the Guideline. These state that physicians should: alert patients that preparations may be switched at the pharmacy; encourage patients to ask to remain on the same preparation at every pharmacy refill; and make sure patients understand the need to have their TSH retested and the potential for dosing readjusted every time their LT4 preparation is switched The new Teva, lactose free formulation of Levothyroxine, with mannitol, for example, is known to upset some patients.

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28	Guideline	5	9	We would strongly suggest also providing information on: causes of hypothyroidism including autoimmunity and include an explanation of “Hashimotos” benefits and risks of treatment- and treatment options. Patients tell us these are the questions they most need answers to.
29	Guideline	5	14	We would strongly suggest including ‘hyperthyroidism’ in this heading as people often do not realise the three terms mean the same thing.
30	Guideline	6	2	Add that hypothyroidism can sometimes be hard to manage and have severe affect on QoL. TTT have seen many anecdotal reports of patients who say they may not have had treatment had they known how hellish hypothyroidism could be for them and that they were unprepared by their doctors.
31	Guideline	6	1	In table 1, we consider that the risk of hypoparathyroidism following surgery is understated and recommend expanding this to explain that this may require life-long monitoring and treatment with vitamin D and calcium tablets.
32	Guideline	5	8-13	Given the rationale for the guideline - that it is important for people to understand the disease etc...- we think it is important patients with hypothyroidism should told that T3 and NDT and levothyroxine dose titration are possible treatment options for hypothyroidism. All of these are very important to those patients who need them Many patients and their carers are unaware of treatment options and greater awareness amongst health professionals is badly needed.
33	Guideline	7	12	Why no mention of the specific symptoms which could indicate a need for testing, or = a clinical suspicion that thyroid disease may be present? GPs and patients should be aware of common symptoms and they should be detailed here.
34	Guideline	7	21	Instead of referring simply to anxiety or depression, we would suggest that ‘anyone presenting with any mental health symptoms’ should have their thyroid checked, as per British Thyroid Association 2015 guidance. Mental health impacts of thyroid hormone imbalance can include psychosis and dementia like symptoms.
35	Guideline	8	12 and 19	We are pleased to see the recommendation to test Ft3 in hypothyroidism if TSH is below the reference range – this indicates to us that T3 should always now be checked if patient is symptomatic but TSH appears suppressed, which makes sense, there is no point testing T3 when everything else is out of kilter as it will always be out of kilter too, if everything else seems fine, that is the time to test T3 and consider possible T3 treatment.
36	Guideline	8	7	TSH only gives part of the picture, why not routinely measure TSH and FT4?

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37	Guideline	8	7-20	The tests listed are 'surrogate markers' (a measure of effect of a specific treatment that may correlate with a real clinical endpoint but does not necessarily have a guaranteed relationship). For patients it's the signs and symptoms (how they feel) that matter most. These should be listed in the guideline in our view. (See overall point 1.1 above).
38	Guideline	9	2	As the guideline only considers primary hypothyroidism. It should be made clear that there are multiple causes of hypothyroidism e.g. primary, central, resistance to thyroid hormone, endocrine disruption, subnormal TSH secretion (down-regulated axis) etc. It should be stated the guidelines do not apply to any condition other than uncomplicated primary hypothyroidism and that more complex cases may require a specialist referral.
39	Guideline	9	5	We are concerned that there is no mention here of testing Thyroglobulin antibodies. It is most common with autoimmune thyroid disease to have high TPO Abs or high TPO Abs and high TGAbs. Some patients with hypothyroidism report to patient organisations that they ONLY have high Thyroglobulin antibodies and they therefore have often struggled to get diagnosed. It's less common, but we believe that it may not be rare to only have high TG antibodies: Reference: https://www.healthline.com/health/antithyroglobulin-antibody#results *If you have high levels of antithyroglobulin antibodies in your blood, it may be a sign of serious autoimmune disorder, such as Graves' disease or Hashimoto thyroiditis*
40	Guideline	9	12	We are aware of increasing numbers of patients being issued short prescriptions and in some cases being forced to ring or drive around many pharmacies every 1 or 2 months in search of whichever formulation of Levothyroxine or Liothyronine they require, which is inconvenient and an inefficient use of the health service resources as well as patient time. May we suggest that the Guideline explicitly states that once a patient is established on a stable dose they should be issued with prescriptions for 3 months at a time. Some patients have reported that their surgery will only issue 1 months supply at a time, saying they are incentivised by their CCGs not to prescribe for longer.
41	Guideline	9	14	why is FT3 testing recommendation not followed up with recommendation for when a trial of liothyronine may be appropriate or what other treatment may be recommended for patients with low T3 when TSH and FT4 blood tests are "optimal" but symptoms remain. Given the patient stories in Thyroid Trust registry and liothyronine dossier, showing many patients reporting losing years of their lives till liothyronine treatment restored QoL, the guidelines should say more about when T3 treatment may be considered.
42	Guideline	9/10	11 (p10) to 14 (p11)	Why no mention of any other treatment option for patients who do not respond to initial treatment?

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43	Guideline	9	14	Given the patient stories in Thyroid Trust directory and liothyronine dossier showing many patients reporting losing years of their lives till liothyronine treatment restored QoL, the guidelines should say more about when T3 treatment may be considered.
44	Guideline	10	2	This sounds like a very positive recommendation. We believe there are thousands of patients currently left on 25mcg, 50mcg or 75mcg levothyroxine, becoming increasingly unwell and GP's refusing to increase the dose despite ongoing hypothyroid symptoms. It would be good to see this dose by weight message highlighted in communications when the Guideline is published.
45	Guideline	10	10	Based on clinical experience and patient reported outcomes, on Levothyroxine, we would suggest that the usual reference range is too wide for many patients To alleviate all hypothyroid symptoms we know that many patients on Levothyroxine need their TSH to be under 2, or indeed less than 1. Frequently patients need TSH under 1 and many find TSH becomes suppressed on almost any dose of Levothyroxine. http://www.pathology.leedsth.nhs.uk/pathology/ClinicalInfo/Biochemistry/EndocrinologyampDiabetes/ThyroidFunctionTests.aspx *See Box - Thyroxine Replacement Therapy in Primary Hypothyroidism* ***TSH 0.2-2.0 - sufficiently replaced. Over 2.0 likely under replacement*** If TSH becomes suppressed when patients are on less than recommended dose of 1.6mcg per kilo, we would suggest that FT4 and FT3 and vitamin levels should be tested. Annual monitoring of FT4 and FT3 and vitamin levels should continue with patients whose TSH is under 0.2. If FT4 and FT3 are within range and patient is well, low TSH does NOT appear to indicate they are over treated
46	Guideline	10	17	We would suggest revising this to add "and symptoms have resolved" after "until the level has stabilised within the reference range", otherwise the monitoring criteria is meaningless.
47	Guideline	11	11	We would suggest, based on patient and clinician experiences, that only testing TSH and FT4 may be inadequate if symptoms remain. Frequently key nutrient levels become very deficient as direct result of hypothyroidism and conversion of FT4 to FT3 can be poor. TSH will often be extremely low and FT4 near top of range in such cases. Full testing of TSH, FT4 and FT3 plus vitamin D, folate, ferritin and B12 should be arranged by GP. If symptoms remain after vitamin levels are improved patient should be referred to endocrinologist for further evaluation. Recommending test tests

				at primary care level will reduce the need for expensive secondary care referrals and lengthy delays in resolving symptoms.
48	Guideline	11/12	15 (p11) to 9 (p12)	Why no mention of any other treatment option for patients who do not respond to initial treatment?
49	Guideline	11	14	Frequently we hear of patients who are diagnosed as subclinical with very debilitating symptoms who are only prescribed a very low dose of Levothyroxine, (25mcg or 50mcg) and left with high, but just within range, TSH results and FT4 or FT3 not tested. When symptoms remain in these cases, we would strongly recommend the dose of levothyroxine should be increased and bloods retested after 6-8 weeks. If symptoms remain when TSH is low in range, under 1, then FULL thyroid and vitamin testing should occur. Low vitamin D, folate, B12 and Ferritin are all extremely common and very often need to be supplemented. A high percentage of auto immune patients are either coeliac(5%) or gluten intolerant (over 70%) yet the NHS rarely tests for coeliac or discusses possible link to gluten intolerance with patients. See our research recommendations. Any thyroid patients, with raised antibodies and ongoing symptoms should be tested for coeliac. If coeliac test is negative GP should discuss that patient might wish to try a gluten free diet, for three to six months, to see if there's noticeable benefit.
50	Guideline	30	20	The American Thyroid Association surveyed 12,500 patients with hypothyroidism in 2018 and found that that 15% of patients report impaired quality of life on levothyroxine treatment alone. PMID:2962097. Given these findings, from a large sample size, it is not reasonable for treatment options, other than standard levothyroxine, to be withheld from patients who need them.
51	Evidence Reviews	General	General	We are unclear as to whether the committee have discussed the Common Themes in the Liothyronine Dossier patient stories? We strongly recommend that they do so and consider the patient experiences before finalising this Guideline. We can also offer access to The Thyroid Trust Registry which is available for researchers and has over 60 detailed stories in database form, including year of birth and age at diagnosis.
52	Evidence Reviews	General	General	The research into combined levothyroxine / liothyronine therapy is inconclusive. Half the studies substitute L-T3 for L-T4 in a 1:4 or 1:5 ratio based on their relative serum potency. Basic pharmacokinetics indicate the ratio patients swallow

				will most likely not be reflected in the blood, due to different absorption rates and elimination half-lives. All the studies fail to select appropriate cohorts – patients who fail to do well on levothyroxine. None of the studies attempted to determine the L-T3 dose patients required. The researchers decree that the patients must suffer from primary hypothyroidism (and no other form of hypothyroidism) and this must be corrected by small amounts of L-T3, contrary to clinical experience. Demanding patients respond according to unproven theory is not good science.
53	Guideline	10	10	It is important that this is amended, to include "and restore wellbeing" and to highlight the potential importance of dose titration for patient wellbeing when patient feels unwell within the reference range
54	Guideline	11	11	Why the use of the word "consider" here – surely it is important to measure FT4 in this instance and direction should also be given on when to measure FT3 and when it may be appropriate to consider treatment with liothyronine
55	Guideline	31	9 onwards	There is no mention here of resolving symptoms, it is vital that doctors do not have the impression that symptoms do not matter and that they can treat hypothyroidism purely by paying attention to numerical blood test results. Long clinical experience of specialists in the field, as well as patient reported outcomes, indicate that, for many patients, if symptoms are not resolved once TSH is in the range, they may be resolved with a titrated dose and lower TSH. It is vital this is flagged up in the NICE guidelines.
56	Guideline	11	18	Add reference to 'presence of clinical symptoms which may suggest underlying thyroid disease'
57	Guideline	12	6-9	Strongly suggest adding recommendation to titrate dose until T4 is at upper end of the range and TSH less than 1 before concluding that thyroxine may not be a useful treatment. Also strongly recommend adding testing T3 if TSH goes below 1 and symptoms persist, to see if the issue is non conversion. We make these recommendations based on experienced clinicians' advice and patient reported outcomes. We are concerned if these recommendations are not made then patients will be left with unresolved symptoms, which can be crippling.
58	Guideline	12	19	greater awareness of signs and symptoms needed, we would suggest they ought to be listed here and wherever symptoms are referred to in the Guideline, alternatively they need to be detailed and signposted very clearly elsewhere under a specific heading.
59	Guideline	13	7	As above, we believe it is important to include a mention of symptoms, which can be a sign of underlying thyroid disease.

60	Guideline	13	7	There is no recommendation as to treatment here, just measuring TSH & FT4. Clinicians tell us they would find this frustrating. Is the guideline saying just stop treatment and monitor even though symptoms may be present?
61	Guideline	15	10	We recommend that patients are enabled to make an informed choice between RAI and surgery A minority of patients report life-changing consequences of RAI although the reasons for this are not yet understood. We note the recommendation for research, number 4, 'Long-term effectiveness and safety of radioactive iodine therapy' demonstrating the need for greater understanding of the risks and benefits of this treatment option. We note that 20% of patients after complete thyroidectomy or RAI may need addition of small dose of T3 to regain full health. There is evidence that T3 blood serum levels do not return to pre surgery levels with levothyroxine alone.
62	Guideline	32	15	See The Thyroid Trust Registry for possible evidence? Patient reported experiences indicate subclinical hypothyroidism can include low T3 and/or fine tuning of levothyroxine dose plus other interventions such as Vit D and gluten free can make a profound difference
63	Guideline	14	24	The meaning of "supportive treatment" for hyperthyroidism is not clear, the wording appears to assume a degree of understanding which may not be there (as with previous references to signs of underlying thyroid disease).
64	Guideline	19	9	Add "and are not showing symptoms of hypothyroidism" as criteria, if TSH is in range but patient feels unwell they should not simply have TSH monitored further action is required to restore wellbeing, such as levothyroxine dose titration and/or possible testing of T3.
65	Guideline	19	26	We would strongly suggest that further tests are required if patient is symptomatic.
66	Guideline	20	4	After the word "range", add: "and patient feels well". It is not sufficient to imply that TSH in range is the sole goal of treatment, indeed extensive patient reported experiences tell us that this stance, when taken by clinicians, can be harmful to patient outcomes.
67	Guideline	10	16	For cases where patients are hard to treat, might we suggest including testing SHBG sex hormone binding globulin for tissue health which we understand used to be used routinely to check for hypo or hyperthyroidism. If this test result is fine, we believe it may show good tissue health and may give clinicians peace of mind, regarding monitoring patients who report they only feel well with a suppressed TSH.

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68	Guideline	General	General	In relation to the guidelines for hypothyroidism, one of our commenters observed:, the proposed guidelines are consolidating practices that have been discredited over the past two decades. They fail to address large-scale patient dissatisfaction with hypothyroidism therapy and restrict the options available to patient and physician.
69	Guideline	General	General	In response to the question: 'Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why'. The treatment of those patients with hypothyroidism who do not respond well to levothyroxine monotherapy is the area of current practice which needs to change most. The NHS is currently paying far more for liothyronine than other markets but as the cost is being brought down, this should not be a barrier for treatment for those who cannot thrive on levothyroxine alone. It's widely accepted in medical circles that approximately 10-15% of patients do not recover full health on Levothyroxine mono- therapy https://www.sciencedaily.com/releases/2016/10/161012132038.htm and https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4980994/ "….authors have questioned the efficacy of l-thyroxine monotherapy because about 10% to 15% of patients are dissatisfied as a result of residual symptoms of hypothyroidism" 10% -15% remaining unwell on Levothyroxine is approximately 200,000-300,000 patients in the UK. UK Thyroid support groups are inundated with dissatisfied patients, most of whom are only prescribed Levothyroxine and many of whom are on very low doses with seemingly no regard given to resolving their symptoms. Thousands of UK patients on Levothyroxine remain unwell, often with severely curtailed life, frequently unable to work or contribute to society...these patients' situations cannot be overlooked by the Guideline.
70	Guideline	General	General	In response to the question ' Would implementation of any of the draft recommendations have significant cost implications?' The cost implications of prescribing liothyronine, where it is required, will be mitigated considerably by more effective procurement of this generic medicine by the Department of Health, to bring the price into line with other countries and in line with overall NHS procurement whereby this country generally pays a lower price than most other markets for most medicines.

				This work is underway and we are advised that the price is coming down rapidly but liothyronine is still perceived as being prohibitively expensive by many local health authorities. It should be borne in mind that patients who require liothyronine and do not have it prescribed are likely to cost the health service and society dearly, since without treatment they often describe themselves as "unable to function" and are likely to visit their doctors much more often, with many other tests and treatments being given, often for many years. See The Liothyronine Dossier and The Thyroid Trust Registry for case examples.
71	Guideline	General	General	In response to the question: What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.) We would suggest that where patients' symptoms are unresolved, clinicians are directed to seek guidance from the British Thyroid Association and/or centres of excellence in thyroid care, where there are clinicians who are skilled at resolving symptoms in thyroid patients (as per recent new NICE parathyroid guidelines).
72	Guideline	24	11	Further to point 71 - to address the scant evidence base, retrospective research, into patient experiences and responses to different treatments, should be conducted through large scale patient surveys with thyroid patients who are well and less well, to gauge relative success of treatment options and lifestyle choices.
73	Guideline	9	14	We note that many doctors are currently being told by their CCGs that NHS England does not permit liothyronine to be prescribed, which is incorrect – where there is a medical need, NHS England and The Department of Health and Social Care have confirmed, this treatment should be available.
74	Equality Impact Assessment	1	2.1	Women's health issues are recognised by the WHO to be under addressed, this needs to be acknowledged. In our view, the Equality Impact Assessment is glib and wrongly slanted and must be revised, to acknowledge that gender health inequality is a factor in thyroid disease. We know that conditions which affect mostly women are poorly studied and that, because thyroid disorders affect more women than men, they can tend to be taken less seriously than they should be.
75	Guideline	General	General	Are there any considerations related to ethnicity and treatments of thyroid disorders? Even if there aren't, we believe this should be noted in the guideline and in the Equality Impact Assessment.

Insert extra rows as needed

Checklist for submitting comments

- Use this comment form and submit it as a **Word document (not a PDF).**

Please return to: ThyroidDisease@nice.org.uk

Thyroid disease: assessment and management

NICE National Institute for Health and Care Excellence

Consultation on draft guideline – deadline for comments 5pm on 17 July 2019 email: ThyroidDisease@nice.org.uk

- Complete the disclosure about links with, or funding from, the tobacco industry.
- Include **page and line number (not section number)** of the text each comment is about.
- Combine all comments from your organisation into 1 response. **We cannot accept more than 1 response from each organisation**.
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You can see any guidance that we have produced on topics related to this guideline by checking NICE Pathways.

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