



Thyroid Support  
Group Norfolk



# T3 Prescribing Survey Report

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## Executive Summary

This survey was requested by Lord Hunt of Kings Heath, to ascertain the prescribing practices of Clinical Commissioning Groups (CCGs) in England since NHS England's Regional Medicines Optimisation Committee (RMOC) revised guidance, "Guidance – Prescribing of Liothyronine", was published, on the Specialist Prescribing Service website, in July 2019.

<https://www.sps.nhs.uk/wp-content/uploads/2019/07/RMOC-Liothyronine-guidance-V2.6-final-1.pdf>

The prescribing guidance states that liothyronine (T3) can be prescribed to hypothyroid patients who have unresolved symptoms on the standard medication, levothyroxine when initiated, or confirmed following review, by an NHS consultant endocrinologist. It also clearly states that a GP should not stop a liothyronine prescription without specialist guidance. The British Thyroid Association, the professional body for thyroid specialists, has produced separate guidance, which states clearly that a patient established and well on liothyronine should not have their treatment disrupted – because of the risk of them being made significantly unwell for a prolonged period by such disruption. [https://www.british-thyroid-association.org/sandbox/bta2016/information\\_for\\_endocrinologists.pdf](https://www.british-thyroid-association.org/sandbox/bta2016/information_for_endocrinologists.pdf)

This survey was conducted by the authors of The Liothyronine Dossier, which was published in November 2018 and led to the revision of the NHS England prescribing guidance. The dossier includes extensive patient experiences demonstrating how vital liothyronine is for those patients who require it. Common themes include patients experiencing years of crippling ill health, only resolved by liothyronine. - [bit.ly/LiothyronineDossier2018](http://bit.ly/LiothyronineDossier2018),

### Key findings:

403 respondents told us about prescriptions of liothyronine being denied or reduced, in 63 CCGs.

168 respondents told us they are now sourcing liothyronine outside the NHS:

- 29% via a private prescription
- 55% without a prescription, either from overseas or via the internet.

This matter is urgent. It is anticipated that this report will be reviewed and acted upon by NHS England and the Department of Health as well as the individual CCGs who have been found to be harming patients, by denying access to liothyronine, counter to national guidance and the NHS Constitution.

### Notes on additional patient reports

Patient organisations have been collecting anecdotal reports from patients, regarding CCGs where there are problems with liothyronine prescribing. This has resulted in a further list of comments from patients, identifying a further 26 CCGs and confirming issues in those identified in the survey, taking the total to 88 (see Appendix C).

## Further Conclusions

The sample size was relatively small, hence we cannot claim that the results are comprehensively representative of the country as a whole, however, the following conclusions can be drawn:

- a) Since the updated NHS England prescribing guidance was published by the RMOG in July 2019, only 5% of respondents told us that their CCG had reinstated a T3 prescription, which had previously been withdrawn. This shows that the updated guidance is having some positive effect on a limited number of CCGs, but seemingly very few – only 11 CCGs that we know of have restored liothyronine prescriptions.
- b) At least 63 (33%) of clinical commissioning groups are continuing to withdraw, refuse or reduce liothyronine prescriptions across England. Given the limitations of the survey's reach, it is likely they are not the only ones.
- c) 18 respondents told us about 14 (7%) CCGs who had reduced patients' doses of liothyronine. We did not ask about the impact of dosage reductions in this survey, but we know, anecdotally, that many patients are reporting to patient groups that they now feel unwell, having been prescribed lower doses than they were previously well on.
- d) There is still an unfair postcode lottery in respect of prescribing liothyronine, which must be addressed.
- e) Almost 10% of respondents told us that their GP or endocrinologist wanted to prescribe liothyronine to them, but that their CCG will not allow it and many doctors will not go against their local clinical commissioning group, despite the terms of the General Medical Services contract, which obliges physicians to prescribe any medicine in the Drug Tariff which they consider their patient requires.
- f) A significant number of patients are now obtaining liothyronine via a private prescription from their NHS GP or NHS endocrinologist, despite NHS guidance which says that private and NHS care should be kept separate.
- g) Many other patients are having to visit private clinicians to obtain liothyronine, in many cases incurring costs they can ill afford.
- h) If the survey is representative, it looks as though a majority of patients who require liothyronine may now be either purchasing it online or overseas, without a prescription, or are looking into one of these possibilities. Many are understandably afraid of purchasing it online, yet some feel they have no option, despite advice from patient groups that thyroid hormones should not be taken except under a doctor's supervision. It is genuinely shocking how many patients have been deprived NHS care and are going to such desperate lengths to try and keep themselves well.
- i) Those patients who are resorting to going outside of the UK to purchase it over the counter are finding it is available in some European countries very cheaply – the Drug Tariff price for this old generic medicine is far higher in the UK than in any other country.
- j) Many patients are finding that their GP will not refer them to an endocrinologist or that the endocrinologist is refusing a referral. This needs to be looked into further, to ascertain the reasons why. Many patients now believe that referrals are being refused due to pressure in the system caused by CCG imposed prescribing restrictions.

- k) While we have learned that some CCGs are now prescribing liothyronine for some patients, the procedures for obtaining T3 prescriptions are often very long and drawn out, causing a lot of anxiety.
- l) The same procedures are causing much higher workloads for both GPs and endocrinologists. We know that when patients are referred to a specialist, there are very long waiting lists. Something needs to be done to enable this whole process to become easier for clinicians and patients alike.

This survey clearly shows that NHS England must now intervene, on behalf of clinicians who want to prescribe T3 for their patients and those patients, whose quality of life has been affected, because levothyroxine alone does not resolve their symptoms.

T3 should not be withdrawn or refused on the grounds of cost and patients' experiences should be listened to more and taken more seriously.

The NHS Constitution states, "You have the right to receive care and treatment that is appropriate to you, meets your needs and reflects your preferences" and the new NICE guideline for assessment and management of thyroid disease emphasises the importance of shared decision making and acknowledges that levothyroxine does not work for everyone.

Thyroid patients have been lobbying the Department of Health and NHS England to stop restricting access to liothyronine, for those patients who require it, since at least 2015, but the situation appears to be worsening rather than improving.

The NHS continues to pay far more for this medicine than any other country. It is available over the counter in France for twenty Euros and in Greece for less than two Euros.

The Lancet has reported that the only reason prescriptions are being restricted is due to the price in the UK.

[https://www.thelancet.com/journals/landia/article/PIIS2213-8587\(18\)30334-6/fulltext](https://www.thelancet.com/journals/landia/article/PIIS2213-8587(18)30334-6/fulltext)

**An outline of the survey methodology, followed by the full results and the additional patient reports, can be found on the following pages.**

**Appendix A** shows an overview of CCGs' prescribing practices.

**Appendix B** shows the CCGs who are refusing to prescribe liothyronine even though the patient's endocrinologist has said that they need it, as well as those that are now allowing prescribing.

**Appendix C** shows the additional patient reports.

## Methodology

The survey was conducted, in the two week period, leading up to 28/11/19, on Survey Monkey, with respondents invited to take part via open invitations online, by each of the conducting organisations.

At the survey's close, there were 403 respondents. 14% (57) of respondents did not complete the survey, only answering some of the questions and then leaving.

23 of the respondents who did not complete the survey did not fit the criteria which was defined as follows:

This survey is **only** for people who live in **England** and who:

1. Have had their T3 prescription withdrawn since 16<sup>th</sup> July 2019, despite it previously resolving symptoms
2. Have had their T3 dosage reduced since 16<sup>th</sup> July 2019, despite previous dosage resolving symptoms
3. Have had their T3 prescription withdrawn **before** 16<sup>th</sup> July 2019 and then reinstated **after that date**
4. Have had their T3 prescription withdrawn and then reinstated **after** 16<sup>th</sup> July 2019
5. Have asked for T3 for the first time and been refused a prescription by their GP or endocrinologist since 16<sup>th</sup> July 2019
6. Have asked for T3 for the first time and been given a prescription either by their GP or endocrinologist since 16<sup>th</sup> July 2019

## The Results

We asked if people were being prescribed T3 (liothyronine) by the NHS or whether they had previously been prescribed it:

### Question 1: Are you being prescribed T3 (liothyronine) by the NHS or have you had it prescribed in the past?

Answer Options	Response Percent	Response Count
Yes, I'm prescribed T3 now but I had it withdrawn by my CCG for a while	4.96%	20
Yes, I am prescribed T3 but have had my dosage decreased	4.47%	18
Yes, I requested T3 and was prescribed it	10.67%	43
Yes, I've been prescribed T3 in the past but I'm not prescribed it now	12.41%	50
No, I have never asked for T3 (survey ends)	5.71%	23
No, when I requested T3 it was refused	61.79%	249
<b>Answered question</b>		<b>403</b>

Almost 5% (20) of the respondents who answered **Question 1** had had their T3 withdrawn for a while but now were prescribed it and we asked them which CCG had withdrawn it. 3 respondents did not know their CCG and 14 gave us the name of the CCG that had withdrawn their T3:

Name of CCG that had withdrawn T3	
1	Barnet CCG
2	Coastal West Sussex CCG
3	Croydon CCG
4	Enfield CCG
5	Hastings and Rother CCG
6	Herefordshire CCG
7	High Weald Lewis Havens CCG
8	Leicester City CCG
9	Milton Keynes CCG
10	Oldham CCG
11	Oxfordshire CCG
12	Southwark CCG
13	North East Essex CCG
14	Somerset CCG



6 respondents didn't know which CCG reinstated their T3 and 11 gave us the names of the CCG that had reinstated it:

	<b>Name of CCG that had reinstated T3</b>
<b>1</b>	Barnet CCG
<b>2</b>	Coastal West Sussex CCG
<b>3</b>	Croydon CCG
<b>4</b>	Enfield CCG
<b>5</b>	Hastings and Rother CCG
<b>6</b>	Herefordshire CCG
<b>7</b>	Leicester City CCG
<b>8</b>	Milton Keynes CCG
<b>9</b>	Oldham CCG
<b>10</b>	Oxfordshire CCG
<b>11</b>	West Kent CCG

4.47% (18) of the respondents that answered **Question 1** had had their T3 decreased. 4 respondents did not know their CCG and 14 told us which CCG area they lived in:

	<b>Name of CCG that had decreased their prescription</b>
1	Basildon & Brentwood CCG
2	Bath & North East Somerset CCG
3	Berkshire West CCG
4	Birmingham & Solihull CCG
5	Derbyshire CCG
6	Eastbourne, Hailsham And Seaford CCG
7	Greenwich CCG
8	Isle Of Wight CCG
9	Northamptonshire CCG
10	South Tyneside CCG
11	South Warwickshire CCG
12	Surrey Downs CCG
13	Waltham Forest CCG
14	West Essex CCG

Nearly 11% (43) of respondents that answered **Question 1** were prescribed T3 when they requested it. 11 respondents did not know which CCG had prescribed T3 and 28 gave us the name of their CCG:

	<b>Name of CCG that prescribed T3 when requested</b>
1	Berkshire CCG
2	Bristol CCG
3	Coventry and Rugby CCG
4	Darlington CCG
5	Derby and Derbyshire CCG
6	East Cheshire CCG
7	Haringey CCG
8	Harrogate CCG
9	Ipswich and East Suffolk CCG
10	Ipswich and East Suffolk CCG
11	Kingston CCG
12	Manchester CCG
13	New Devon CCG
14	North Lincolnshire CCG
15	Oxfordshire CCG
16	Oxfordshire CCG
17	Oxfordshire CCG
18	South Warwickshire CCG
19	Surrey Heath CCG
20	Swale CCG
21	Thanet CCG
22	Wakefield CCG
23	Wandsworth CCG
24	Warrington CCG
25	Warrington CCG
26	West Hampshire CCG
27	West Leicestershire CCG
28	West Sussex CCG

12.41% (50) of the respondents that answered **Question 1** had been prescribed T3 in the past but were not prescribed it now. 3 respondents told us that it didn't work for them and 47 said that they had had it withdrawn.

We then asked those that had had it withdrawn, which CCG had withdrawn it. 12 respondents did not know which CCG had withdrawn it and 33 gave us the name of their CCG:

	<b>Name of CCG that had withdrawn liothyronine</b>
1	Barnsley CCG
2	Berkshire CCG
3	Berkshire CCG
4	Bolton CCG
5	Bradford CCG
6	Brighton and Hove CCG
7	Brighton and Hove CCG
8	Cambridgeshire and Peterborough CCG
9	Cheshire CCG
10	City and Hackney CCG
11	Coventry and Rugby CCG
12	East Riding of Yorkshire CCG
13	Great Yarmouth and Waveney CCG
14	Greater Manchester CCG
15	Greenwich CCG
16	Hounslow CCG
17	Lambeth CCG
18	Leeds CCG
19	Leighton Hospital Crewe CCG
20	Nene CCG
21	New Devon CCG
22	Norwich CCG
23	Rotherham CCG
24	Somerset CCG
25	Somerset CCG
26	South Lincolnshire CCG
27	South Norfolk CCG
28	South Norfolk CCG
29	Southwark CCG
30	Suffolk CCG
31	Thanet CCG
32	West Essex CCG
33	West Kent CCG

5.71% (23) of the respondents that answered **Question 1** told us that they have never asked for T3. The survey then ended for these respondents as they did not fit the criteria.

61.79% (249) of the respondents that answered **Question 1** told us that when they had requested T3, their request had been refused. We then asked them why their request had been refused:

**Please tell us why your T3 prescription was refused**

Answer Options	Response Percent	Response Count
My GP would not refer me to an endocrinologist	15.16%	37
My endocrinologist would not accept a referral	2.46%	6
My GP told me that T3 is not available on the NHS	30.33%	74
My endocrinologist told me that T3 is not available on the NHS	20.90%	51
My GP wants to prescribe but the CCG have refused	2.87%	7
My endocrinologist wants to prescribe but the CCG have refused	7.39%	18
Other	20.90%	51
<b>Answered question</b>		<b>244</b>

Just over 15% (37) of the respondents who answered this question said that their GP would not refer them to an endocrinologist and almost 2.5% (6) said that their endocrinologist would not accept a referral.

Just over 30% (74) said that their GP told them that T3 was not available on the NHS and almost 21% (51) said that their endocrinologist had said the same.

Almost 3% (7) of the respondents said that their GP wanted to prescribe but the CCG had refused. We then asked them which CCG would not allow their GP to prescribe. 2 respondents did not know which CCG but 5 respondents gave us the name of their CCG:

	<b>Name of CCG that did not allow GP to prescribe</b>
1	East Cheshire CCG
2	Gloucestershire CCG
3	Mid Essex CCG
4	Somerset CCG
5	Southampton CCG

Almost 7.5% (18) of the respondents told us that although their endocrinologist wanted to prescribe T3 for them, their CCG did not allow this. We then asked which CCG did not allow their endocrinologist to prescribe. 7 respondents did not know which CCG but 9 gave us the name of their CCG:

	<b>Name of CCG that did not allow endocrinologist to prescribe</b>
1	Bolton CCG
2	Bristol, North Somerset and South Gloucestershire CCG
3	Calderdale CCG
4	Eastbourne CCG
5	Hastings & Rother CCG
6	Horsham And Mid Sussex CCG
7	Norwich CCG
8	Shropshire CCG
9	Somerset CCG

We gave the respondents an opportunity to give alternative explanations for their T3 prescription being refused in the “Other” section and the respondents responded by making the following comments. 1 respondent gave her case history:

	<b>Comments in response to “Other” (Please tell us why your T3 prescription was refused)</b>
1	Didn't believe T3 was relevant.
2	The endocrine surgeon told me they can't prescribe it.
3	My GP is also an Endo and said I didn't need it
4	My endocrinologist told me it would not help as I was not tolerating the Levothyroxine & it would make me feel too anxious, even paranoid.
5	Endo wanted me to go back on Levo first. I refused as I didn't want to go back to a life on the sofa.
6	Because of CCG restrictions endocrinologist currently procrastinating.
7	Waiting for gp and endo to decide between them who is responsible for writing the script.
8	Told as my T4 is within normal ranges I don't need further help.
9	My Gp told me that there was no evidence was any better than thyroxine.
10	My GP told me I had a T3 fixation & also wrote this comment on a hand written blood test request.
11	Was told that this and N.D.T. were untested and unsafe by endocrinologist.
12	My endo point blanked ignored T3 and decided to up my dose of levothyroxine to a dangerous level instead.
13	Although my Endocrinologist was happy to allow me to undertake a trial of Liothyronine, he told me that I would have to self-source Liothyronine as he was aware that my CCG had an effective ban on Liothyronine.
14	Liothyronine (tablets) prescribing is restricted by my Dorset CCG. The Dorset Formulary has placed a Black traffic light alert, (NOT RECOMMENDED) for new patients, against T3 prescribing throughout the county. The GP I saw at

	my West Dorset Medical Centre, printed me off a copy of the surgery's leaflet for pre-existing thyroid patients already prescribed T3. Surgery policy was clear. Those patients already prescribed T3 faced having their medication automatically withdrawn, based on the governing CCG's ban on Liothyronine prescribing due to inflated cost. The doctor thought I 'ought to know this' ahead of any request I might have for T3, because this was the Medical Centre's position.
15	I have been told that it does not exist.
16	Endo said there's no proof that it works.
17	Endo said there's no evidence that it works.
18	I was told it was dangerous to be prescribed T3! When I challenged this opinion. I was told he was certain it was dangerous!
19	Doctor told me we don't use that it causes heart attacks. So was flatly refused.
20	My endocrinologist said T3 was not safe and would not help.
21	My endocrinologist said T3 is not necessary.
22	My GP said cost too high.
23	GP said T3 was not important and the waiting list for an endocrinologist was too long to bother with!
24	GP said T3 is not recommended as hard to manage - despite 14 years compliance with other medication for Hashimotos.
25	He changed the subject and suggested we assessed my 'mood'.
26	Endo wrote to my GP to advise he felt I may benefit from T3 trial. GP refused due to cost.
27	GP and endocrinologist both refuse to prescribe and blame the CCG.
28	Endocrinologist refused stating T3 didn't work.
29	My endo is private. NHS waiting list too long. I'm off work on long term sick after a thyroidectomy for cancer.
30	Endocrinologist told me no one is ever prescribed T3 mono as it is dangerous.
31	Doctor refused to ask CCG.
32	To me it was very expensive and hard to monitor.
33	They dismiss the idea and despite them testing my t3 levels they do not disclose my t3 results. They find other reasons to blame symptoms on and appear to act dump on those aspects.
34	Dr said no evidence to prove it works.
35	My GP told me T3 it is not available at all in UK.
36	NHS endo will not prescribe.
37	I had a private blood test stating T3 under range. Go said ranges can be different between labs. Practically threw another TSH blood test form at me. won't be doing another test as pointless.
38	My endocrinologist told me that none of them will prescribe T3 in the local area.
39	I was told it's too expensive and they don't believe in it by the GP. And the endo told me their centre is not prescribing it and I should look in the forums to see if there are other centres prescribing it.
40	Was told no because it is controversial.
41	Endo said DIO2 heterozygous result, tho I am still symptomatic, was not enough to prescribe T3-that Colin Dayan said only proved to possibly help if patient has homozygous result.
42	Endo says i don't need it.
43	My endocrinologist requested my GP prescribe T3 but the CCG refused.
44	The endocrinologist said we don't have enough evidence that T3 is better . I challenged if it was a cost refusal & the response was let's try other tests first

	. I requested to trial a combination treatment & still refused . I said I've been on thyroxine for 30 years I want to trial T3 but again was refused.
45	My endo says T3 doesn't work though I have self medicated and my GP sees it working, would prescribe but the CCG says no.
46	My endocrinologist told me that T3 didn't work and I therefore wouldn't need it
47	Endo said he didn't believe in T3 and there is no evidence it is any better than T4 monotherapy, despite me being symptomatic.
48	Private endocrinologist said I did not need T3.
49	My endo was great the nurse wasn't and was denied treatment after becoming pregnant.
50	My endocrinologist was going to prescribe it then just suddenly changed his mind.
51	Was told thyroxine is the only treatment for thyroid problem.
52	<p>Liothyronine (tablets) prescribing is restricted by my Dorset CCG. The Dorset Formulary has placed a Black traffic light alert, (NOT RECOMMENDED) for new patients, against T3 prescribing throughout the county.</p> <p>When autoimmune Hashimoto's thyroiditis was confirmed in May 2018, I had already seen no improvement to hypothyroid symptoms, despite optimal treatment with Levothyroxine, since earlier, March 2017, hypothyroidism diagnosis. The GP I saw at my West Dorset Medical Centre, printed me off a copy of the surgery's leaflet for pre-existing thyroid patients already prescribed T3. Surgery policy was clear. Those patients already prescribed T3 faced having their medication automatically withdrawn, based on the governing CCG's ban on Liothyronine prescribing due to inflated cost.</p> <p>The doctor thought I 'ought to know this' ahead of any request I might have for T3, because this was the Medical Centre's position. They were actively pursuing withdrawing Liothyronine from pre-existing, medicated patients. New patients would be referred without guarantee of being prescribed a trial of T3.</p> <p>To date, I have been referred twice from Primary Care to NHS endocrinologists in Dorset and Devon. The first endocrinologist said there was not sufficient evidence on my incomplete, NHS, test results to convince him my symptoms were thyroid-related. He thought it may be 'something else'. Prior to February 2018 test results, my newly allocated GP confirmed the same, going further, he told me, 'The trouble is, you're fixated with thyroid. I will agree to refer you, for the satisfaction of you being told it's not thyroid.' I changed my GP.</p> <p>Follow-up blood test results reported Abnormal, above range, thyroid antibodies. The first endocrinologist did not understand why I had been tested for Thyroglobulin autoimmune antibodies in February 2018. Neither did he acknowledge the accompanying laboratory remark, 'Abnormal, but to be expected', test result: 3,000 &lt;115. However, I was referred for a Short Synacthen Test and Metanephrines Test, both tests showed normal levels/responses, which is now proving to be a helpful record. A second and last appointment with the same NHS endocrinologist lasted 90 minutes.</p> <p>As with the first appointment, my partner and I were bamboozled with misleading, inaccurate information. I was refused a trial of T3 on the basis: 'You might find my referral to the Dorset Chronic Fatigue Centre, where you'll meet and chat to like-minded people, more helpful and supportive.' I had not been</p>

examined. Thyroid Function Tests, vitamin B12, Vit D, Ferritin or Folic Acid tests were never ordered for diagnosis. The consultant confirmed he was removing me from his list and would confirm the same with my GP. I was advised to stop following social media. I rang and spoke to the Wimborne Chronic Fatigue Centre on receipt of their appointment, explaining the reasons behind my wish to pursue investigations into continuing thyroid symptoms. I received a sympathetic listening, they completely understood and the Chronic Fatigue appointment was cancelled.

At that time - the same applies now - it would have been impossible for me to drive and attend a clinic beyond my home town, due to current symptoms. My GP referred me to a second NHS Devon endocrinologist in December 2018. I was symptomatic, despite taking 150mcgms Levothyroxine daily. I had previously raised a poor T4 - T3 conversion suspicion in July 2018. Finding myself no further forward, I ordered a private Saliva genetic test. The test result confirmed: Genetic polymorphisms implicated in various pathways. Result: Deiodinase, iodothyronine, type II DIO2 (T92A) rs225014 Heterozygous variant genotype TA Interpretation: Consequences of the detected genotype: - decreased ability of the enzyme to generate the active T3 hormone.

The analysis report was validated by Prof. Dr. med. Bernard Weber. I was more prepared for the second NHS referral, though my GP warned me, she could not, would not, refer me a third time. She admits she knows nothing about thyroid. I presented further evidence, including NHS, Medicecks and Regenerus Laboratories Ltd test results. The genetic test result received an icy response. 'Where did you get this?' Its result was whipped away. The appointment did not go well at all. I had been referred beyond my local Dorset CCG to Devon. The head of this Endocrinology Centre did not appear pleased to see me. I wondered whether a negative exchange may have been shared between specialist 1 and 2, in my absence. Notes were turned over. I was not examined. Thyroid function blood tests were never mentioned. It transpired I was not being given a choice. The conversation about T3 prescribing was closed. After discussing two main issues, Diagnosis and the Devon CCG practice for prescription T3, a letter, dated 18 December 2018, from specialist 2, confirmed worst aspects of her appointment to my GP:

'1) diagnosis: although she has had thyroid antibodies that have been positive this is not uncommon in the background population and a TSH may normalise on repeat testing, therefore a one-off TSH of 5.1 might not indicate underlying hypothyroidism. However, she was started on Levothyroxine before having a repeat. Whilst you might add that this is of academic interest I think it raises the question of whether her initial symptoms were actually thyroid related at all. One way of confirming this diagnosis would be to reduce the Levothyroxine dose by 50 mcg every two weeks and doing a TSH monthly; if the TSH is above 5 mu/L this would be compatible with a diagnosis of hypothyroidism. I think this would be helpful, as it is difficult to correlate her symptoms with the level of thyroid dysfunction that she displays. The lack of improvement is also relevant, so getting this diagnosis would be really helpful and she can describe how her symptoms change in relation to TSH rising.

2) Treatment with T3. The local guidelines are in draft form and suggest that other autoimmune conditions are excluded; I can see that she has had coeliac



disease excluded but she has also been B12 and vitamin D deficient and it is likely this will have contributed to her symptoms (and were replaced at the same time as T4). She has a family history of rheumatoid arthritis and considering an ANA or other autoimmune conditions is certainly worth it. She asked what the other likely diagnoses would be given this symptomology; I did not examine her today or have time to explore these symptoms in a lot more detail and I know that she has previously had a referral to the chronic fatigue service which she did not wish to go to because she wanted to explore the thyroid diagnosis further.

Other common associated problems that can give very similar symptoms to hypothyroidism include things like anxiety and depression, Lyme disease, chronic fatigue as well as the other diseases that you have mentioned. In addition being overweight can contribute significantly to some of the symptoms described.'

During the initial interview, it had first been suggested I might stop taking Levothyroxine in order to assess elevation of TSH, which shocked me. I was later advised by a retired researcher, still publishing thyroid research papers, that what the specialist was proposing was dangerous, unprofessional and would do the patient harm.

One year on, still symptomatic, I am no further forward to being prescribed T3. In April 2019 I reluctantly began to reduce Levothyroxine by 25 mcgm every six weeks. The amount and duration was my suggestion. The endocrinologist suggestion, reduce 50mcgms every two weeks, seemed extreme, given doses are usually increased every six weeks, as the body adjusts. By July 2019 I had reduced to 100 mcgms, symptoms were worsening and I returned home early from holiday after becoming ill.

I stopped Levothyroxine reduction regime at that point and had a GP telephone consultation which was not helpful due to lack of understanding and thyroid knowledge.

A second symptom crisis occurred in October 2019 and coincided with no available Medical Centre GP appointments for two weeks, no available Endocrinologists available in the Devon Centre due to being away for half term.

I resorted to speaking to PALS, the Medical Centre a second time and one of the Specialist Endocrine Nurses in Devon. She listened and asked what tests I would like, reporting symptoms and test requests back to the endocrinologist (who was still in situ prior to going on holiday), before getting the ball rolling by emailing me with a GP letter authorising all the NHS tests I could/should have had a year ago - TSH, FT4, FT3, B12, Vitamin D, Ferritin, Folate, together with ANA, Lupus - other autoimmune test results having tested negative.

In summary, Hypothyroidism diagnosed February 2017; Hashimoto's autoimmune hypothyroidism confirmed May 2018; Medicecks 2018-2019 blood test results confirm autoimmune hypothyroidism, also suggesting poor conversion; GP, head of practice, confirms autoimmune hypothyroidism, October 2019; Endocrine Specialist Nurse, confirms autoimmune hypothyroidism, October 2019.

	<p>To date, first Endocrinologist refuses T3 trial, July 2018, based on lack of evidence, without conducting Thyroid Function Tests. December 2018 - November 2019 second Endocrinologist refuses to prescribe T3 based on original diagnosis lack of evidence and cost. Most recent NHS test results, October 2019, suggest poor conversion. Re-testing in six weeks. Request for Endocrine Centre appointment outstanding.</p> <p>Remain housebound with symptoms. In light of on-going symptoms, even if Devon confirms I am eligible for a T3 trial, will Dorset apply their black-list restriction. I have already been told by Devon endocrinologist, 'the NHS cannot help you. It's cost.'</p>
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We asked whether the respondents' endocrinologist had confirmed that they needed T3.

**Question 2: Has an endocrinologist confirmed you need T3?**

<i>Answer Options</i>	<i>Response Percent</i>	<i>Response Count</i>
Yes but it was refused by my CCG	25.70%	55
Yes, and I'm now being prescribed T3	21.96%	47
No	23.83%	51
Other	28.50%	61
<b>Answered question</b>		<b>214</b>

Over 25% (55) of the respondents who answered **Question 2** said yes, but it was refused by their CCG so we asked them which CCG had refused it. 15 respondents did not know the name of their CCG but 39 told us the name of their CCG:

	<b>Name of CCG that refused T3 even though the endocrinologist confirmed a need</b>
1	Barnsley/Wakefield CCG
2	Berkshire CCG
3	Berkshire CCG
4	Berkshire CCG
5	Bolton CCG
6	Bolton CCG
7	Brent CCG
8	Brighton & Hove CCG
9	Brighton and Hove CCG
10	Brighton CCG
11	Bristol, North Somerset and South Gloucestershire CCG
12	Calderdale CCG
13	Cambridgeshire & Peterborough CCG
14	Cheshire CCG
15	City and Hackney CCG
16	Croydon CCG
17	East Riding of Yorkshire CCG
18	Eastbourne Seaford CCG
19	Greater Manchester CCG
20	Greenwich CCG
21	Hastings and Rother CCG
22	Horsham And Mid Sussex CCG
23	Leeds CCG
24	Norwich CCG
25	Norwich CCG
26	Rotherham CCG
27	Shropshire CCG
28	Somerset CCG
29	Somerset CCG
30	Somerset CCG
31	Somerset CCG
32	Somerset CCG
33	South Cheshire CCG
34	South Norfolk CCG
35	South Norfolk CCG
36	Southwark CCG
37	Stoke on Trent CCG
38	Surrey Health CCG
39	Thanet CCG

Almost 22% (47) of respondents who answered **Question 2** said that their endocrinologist had said that they needed it and they were now being prescribed. We then we asked them which CCG was allowing the prescribing of T3. 13 respondents did not know the name of their CCG but 29 told us the name of their CCG:

	<b>Name of CCG that was allowing prescribing of T3 by endocrinologist</b>
1	Bath & North East Somerset CCG
2	Berkshire CCG
3	Berkshire West CCG
4	Coastal West Sussex CCG
5	Coventry and Rugby
6	Coventry and Rugby CCG
7	Derbyshire CCG
8	East Cheshire CCG
9	Enfield CCG
10	Greenwich CCG
11	Ipswich and East Suffolk CCG
12	Ipswich and East Suffolk CCG
13	Kingston CCG
14	Leicester City CCG
15	Milton Keynes CCG
16	North East Essex CCG
17	North Hampshire CCG
18	Oldham CCG
19	Oxfordshire CCG
20	South Tyneside CCG
21	Surrey Downs CCG
22	Swale CCG
23	Thanet CCG
24	Wakefield CCG
25	Wandsworth CCG
26	Warrington CCG
27	West Essex CCG
28	West Hampshire CCG
29	West Sussex CCG

Almost 24% (51) of respondents who answered **Question 2** told us that their endocrinologist had not said that they needed it.

We gave the respondents an opportunity to answer “Other” to this question and 28.5% (61) gave the following comments:

<b>Responses to “Other” – Has your endocrinologist confirmed you need T3</b>	
1	My NHS endocrinologist refused T3 although my bloods stated I needed it. My private Endocrinologist stepped in and contacted my NHS Endo. Suddenly my NHS Endo changed his mind and prescribed T3 to my delight.
2	Yes - but I have to pay for it.
3	Never seen one
4	My doctor won't refer me to endocrinology even after I requested he do so.
5	Not prescribed until seeing the third endocrinologist and then I had to fight for it. I had bought it online and it made me feel so much better that I had the strength to fight for it.
6	I was originally prescribed T3 by Dr Peatfield about 20 years ago. Then my doctor prescribed it for me until last year.
7	Not yet
8	My GP will not refer me to an endocrinologist because he says it is a waste of NHS money because I cannot be prescribed T3 as the NHS / Nice will not allow a Doctor to prescribe T3 in England.as it is not necessary T4 is an adequate treatment on its own!
9	After investigating Liothyronine myself and reading what it had done for others I did ask for a low dose which made a difference but it was refused after only taken for 1 year.
10	Was prescribed T3 by endo, GP was going to stop prescribing it, but Endo wrote 10 page letter telling them why they should keep prescribing
11	Still waiting for an appointment to discuss it.
12	I saw dr privately and gp agreed to prescribe T3 approx 10 years ago
13	private endocrinologist
14	Changed consultant he took me off it
15	Yes but it was withdrawn
16	Endocrinologist confirmed I needed it, but it was refused on the NHS so I got a private prescription.
17	No GP referral made
18	Yes but they reduced dosage
19	Endocrinologist refused to continue due to cost gave had to get it from private endocrinologist now
20	Prescribed for my Daughter by Hospital Endo but had to remind CCG that this was the case as they are always trying to stop my daughters drugs - my daughter has special needs.
21	Yes, but GP said it is not licensed!
22	Awaiting test results but said I would do better on T3 combination
23	I have never seen an endocrinologist and told I would have to pay privately to see one
24	Because i have been able to stock up on t3 from my home country, my levels appear perfect and my symptoms are gone. So bloodtests indicate no need. However, if I was to stop the medication, I would deteriorate quickly
25	Private Endocrinologist
26	My surgery told me they are dispensing it “as a favour”

27	Yes and never withdrawn
28	I am being prescribed t3 but only after a private trial costing me £1,000 (started trial in July this year)
29	My endocrinologists state I'm doing well but the CCG is not prescribing
30	Yes .I have private prescription
31	Prescribed on a 6-month trial at present
32	Don't know. Gp prescribed
33	He said it's not available
34	CCG agreed to a 3 month trial supported by Endo who agreed if it helped i could be permanently prescribed it, 3 month trial was amazing, GP refused to prescribe due to not being allowed. Different hospital wrote & tried to get it prescribed but again refused by GP, 2 years on im severely ill & trying to fight, CCG, hospital & Doctors
35	I am under endocrinologist who gave me 5mcg has now upped to 10 for next 7 months before retesting - I was on 20 originally
36	Yes I see a private endocrinologist and am prescribed T3 privately
37	Obtaining from Germany
38	I'm awaiting an appointment
39	A private consultant arranged for my lab test on T4 to T3 conversion. It confirmed that my body has a low conversion rate and therefore I benefit from taking T3
40	Yes but GP refused to prescribe
41	Was under Brighton but T3 withdrawn, had to fight to get it back a year without with Eastbourne hospital
42	An endo said to prescribe and it was when this problem started I was sent back to see another endo who told me she is not allowed to prescribe it, even though I had it prescribed and was better. She then discharged me.
43	Endocrinologist is currently trying to get funding from my gp /ccg
44	Yes but I'm having to source it privately
45	Initially refused by CCG but over turned on appeal
46	Was originally authorised by Thyroid cancer oncologist, gp refused as not authorised and then had to " prove " need to endocrinologist
47	On trial at Hospital
48	Yes but my GP won't prescribe it
49	My GP won't refer me as he says my levels are fine despite unresolved symptoms
50	Yes but doesn't want to prescribe it
51	Oncologist
52	I never get referred to endocrinologists
53	Dr wouldn't refer me said t3 not prescribed in uk
54	yes and prescribed for a trial only
55	Purchase it on private prescription from Germany
56	A locum Endocrinologist agreed I need T3 and I was happy on my dose combined with T4. He moved away - my current endocrinologist does not agree with ANYONE having T3 so tried to take me off it. I have argued my case and still have some T3/4 mix but lower levels and I am not so well.
57	No, can't get a referral. Have self medicated via internet purchases and feel much better
58	Never seen an Endo though I have Hasi
59	He said t3 isn't good for thyroid treatment I take ndt long term
60	A private endocrinologist said I need T3
61	Referral to endocrinologist was refused

We then asked the respondents if they were accessing T3 outside of the NHS. 346 respondents answered this question:

### Are you accessing T3 from outside of the NHS?

Answer Options	Response Percent	Response Count
Yes, I am sourcing T3 via a private clinician with a private prescription	5.20%	18
Yes, I am sourcing it online with a private prescription	5.78%	20
Yes, I am sourcing it online without a prescription	16.18%	56
Yes, I am sourcing it from abroad over the counter with a private prescription either by travelling myself or via friends/family	3.18%	11
Yes, I am sourcing it from abroad over the counter without a prescription either by travelling myself or via friends or family	10.40%	36
No	48.55%	168
Other	10.69%	37
	<b>Answered question</b>	<b>346</b>

Just over 5% (18) of respondents who answered this question said that they were sourcing T3 via a private clinician with a private prescription and almost 6% (20) told us that they were sourcing it online with a private prescription.

16.18% (56) told us that they were accessing it online **without** a prescription and 3.18% (11) told us that they were sourcing it from abroad over the counter with a private prescription either by travelling themselves or via friends/family.

Just over 10% (36) told us they were accessing it from abroad over the counter **without** a prescription.

Nearly 50% (168) told us that they weren't accessing it outside of the NHS. Many of the respondents wanted to explain more and they commented why in the "Other" option:

	<b>Responses to "Other" – Are you accessing T3 from outside of the UK</b>
1	I get my T3 from May 2019 on NHS prior I sourced it through a private Endocrinologist
2	Was buying t3 from abroad but can't get it anymore
3	I am sourcing it via an NHS Endo who has to get it as a "special" from abroad. This is because there is no other lactose free T3 in the UK. The Endo is going against the CCG's policy to prescribe and is constantly under review.
4	Bought it online but now at last got it on NHS
5	If I am refused by current endo despite assurances I will try to source privately. Refused on cost grounds originally.
6	I was buying it from Greece without a prescription and felt fantastic for the first times in years , can't get it now and Dr wasn't interested how better I felt on it
7	now sorcing Natural desicated thyriod myself after gp refused to prescribe
8	investigating the possibility of a private prescription for Germany

9	I have some but am scared to take it without blood work and heart supervision because I have had two ops in the past year.
10	I do not feel confident that the online sources of T3 will be safe, if I did I would order T3 online
11	I bought some in Greece as well as getting a prescription to help with NHS costs
12	In the process of trying to get a private prescription from a private GP
13	I was but am now getting it through NHS. Nhs mistakenly told me I couldn't have it costing me £1,000 (I assume I won't get this money back)
14	I initially sourced from abroad without a prescription however have since been prescribed t3 by my gp
15	Have sourced in France using NHS prescription but not always easy to obtain and cannot continue as prescription is too out of date
16	I have severe problems with ADRs and need 5mg Cytomel to add to my current medication. No one will provide me with a private prescription.add to my medication. I have ben trying since September 2013 to acquire Cytomel to no avail. No one will provide me with a private prescription
17	Working on getting vitamin levels up then will source T3 privately if required
18	Am considering as am desperate
19	Using ndt
20	I self source NDT. I was prescribed NDT by NHS and was well on Levothyroxine I was never well. My thyroid function was destroyed by radiation therapy in the 1950s when I was a baby / young child. When finally my tongue was so swollen I could not eat I begged for a referral but was refused as the GP I saw and another who I have never seen advised I had anxiety. No thyroid problem. I am now 68 and was diagnosed as a child. I advised I would self source if refused and so I did. I see another GP and she knows what I do. My T3 was only 10% into range and T4 about 35 % at best on both . On NDT T4 is about 60% and T3 at about 35%. Still room for improvement but I doubt I will ever get a referral. Comments were passed that my antibodies are fine so what do I think is wrong with me. Not having Hashimotos seems to be working against me. Had an ultrasound done a couple of years ago due to surface swelling around thyroid. At the appointment I was told I had arthritis but the smallest thyroid he had seen. The GO only said, no worry your thyroid isn't swollen. A seriously suppressed TSH of course means the GP scan tell me how well I am and suggest perhaps I need to stop thyroid replacement. I still long for the opportunity to be treated with T3 in the hope of feeling more human.
21	I am going to buy online without a prescription
22	Im having to source NDT privately due to not getting T3
23	Am still in process of researching options
24	I get mine from UK now I am prescribed but previous to that I have imported from Greece and Turkey
25	T3 stopped 2018 sourced online till reinstated
26	I have tried to source it but need prescription or letter from my endocrine consultant to buy from reputable source. If I get with out prescription I can't rely on that source or it's to costly to buy in uk. I can not afford private consultation to get private script
27	Tried online from overseas
28	Seriously considering sourcing extra elsewhere
29	Not yet



30	My NHS Gp was prepared to write a prescription for free which I then had dispensed by a German pharmacy
31	I am prescribed by the NHS but prepared to source from abroad due to cost being approximately a hundredth of the price
32	I am having to buy NDT from abroad.
33	I have had to access it online in past.
34	No I am financially unable to otherwise I would
35	I went private and my new endocrinologist has asked my gp to request funding for a three month trial from my CCG but we are still waiting for the reply
36	Ordering from abroad without prescription
37	No but I am researching into where to get it from

## APPENDIX A

### Overview of CCGs Prescribing Practices

Name of CCG	Withdrawn	Reinstated/ Prescribed	Decreased	Refused
Barnsley CCG	✓			
Barnet CCG	✓	✓		
Basildon & Brentwood CCG			✓	
Bath & North East Somerset CCG		✓	✓	
Berkshire West CCG	✓	✓	✓	✓
Birmingham & Solihull CCG			✓	
Bolton CCG	✓			✓
Bradford CCG	✓			
Brent CCG				✓
Brighton and Hove CCG	✓			✓
Bristol CCG		✓		
Bristol, North Somerset and South Gloucestershire CCG				✓
Calderdale CCG				✓
Cambridgeshire and Peterborough CCG	✓			✓
Cheshire CCG	✓			✓
City and Hackney CCG	✓			✓
Coastal West Sussex CCG	✓	✓		
Coventry and Rugby CCG	✓	✓		
Croydon CCG	✓			✓
Darlington CCG		✓		
Derbyshire CCG		✓		
East Cheshire CCG		✓		✓
East Riding CCG	✓			✓
Eastbourne, Hailsham and Seaford CCG			✓	✓
Enfield CCG	✓	✓		
Gloucestershire CCG				✓
Great Yarmouth and Waveney CCG	✓			
Greater Manchester CCG	✓			✓
Greenwich CCG	✓	✓	✓	✓
Haringey CCG		✓		
Harrogate CCG		✓		
Hastings and Rother CCG	✓			✓
Herefordshire CCG	✓			
High Weald Lewis Havens CCG	✓			
Horsham And Mid Sussex CCG				✓
Hounslow CCG	✓			

Name of CCG	Withdrawn	Reinstated/ Prescribed	Decreased	Refused
Ipswich and East Suffolk CCG		✓		
Isle Of Wight CCG			✓	
Kingston CCG		✓		
Lambeth CCG	✓			
Leeds CCG	✓			✓
Leicestershire CCG		✓		
Leicester City CCG	✓	✓		
Leighton Hospital Crewe CCG	✓			
Manchester CCG		✓		
Mid Essex CCG				✓
Milton Keynes CCG	✓	✓		
Nene CCG	✓			
New Devon CCG	✓	✓		
Northamptonshire CCG			✓	
North East Essex CCG	✓	✓		
North Hampshire CCG		✓		
Norwich CCG	✓			✓
North Lincolnshire CCG		✓		
Oldham CCG	✓	✓		
Oxfordshire CCG	✓	✓		
Rotherham CCG	✓			✓
Shropshire CCG				✓
Somerset CCG	✓			✓
South Cheshire CCG				✓
South Lincolnshire CCG	✓			
South Norfolk CCG	✓			✓
South Tyneside CCG		✓	✓	
South Warwickshire CCG		✓	✓	
Southampton CCG				✓
Southwark CCG	✓			✓
Stoke on Trent CCG				✓
Suffolk CCG	✓			
Surrey Downs CCG		✓	✓	
Surrey Heath CCG		✓		✓
Swale CCG		✓		
Thanet CCG	✓	✓		✓
Wakefield CCG		✓		
Waltham Forest CCG			✓	
Wandsworth CCG		✓		
Warrington CCG		✓		
West Essex CCG	✓	✓	✓	
West Hampshire CCG		✓		
West Kent CCG	✓			
West Sussex CCG		✓		

## APPENDIX B

### CCGs' Prescribing Practices – Endocrinologist Confirming Need for Patient

<b>Endo confirmed need/refused</b>	<b>Endo confirmed need/prescribed</b>
Barnsley/Wakefield CCG	Bath & North East Somerset CCG
Bolton CCG	Berkshire CCG
Brent CCG	Berkshire West CCG
Brighton & Hove CCG	Coastal West Sussex CCG
Bristol, North Somerset and South Gloucestershire CCG	Coventry and Rugby CCG
Calderdale CCG	Derbyshire CCG
Cambridgeshire & Peterborough CCG	East Cheshire CCG
Cheshire CCG	Enfield CCG
City and Hackney CCG	Greenwich CCG
Croydon CCG	Ipswich & East Suffolk CCG
Eastbourne, Hailsham and Seaford CCG	Ipswich and East Suffolk CCG
East Riding of Yorkshire CCG	Kingston CCG
Greater Manchester CCG	Leicester City CCG
Greenwich CCG	Milton Keynes CCG
Hastings and Rother CCG	North East Essex CCG
Horsham And Mid Sussex CCG	North Hampshire CCG
Leeds CCG	Oldham CCG
Norwich CCG	Oxfordshire CCG
Rotherham CCG	South Tyneside CCG
Shropshire CCG	Surrey Downs CCG
Somerset CCG	Swale CCG
Southwark CCG	Thanet CCG
South Cheshire CCG	Wakefield CCG
Surrey Heath CCG	Coventry and Rugby CCG
South Norfolk CCG	Wandsworth CCG
Stoke on Trent CCG	Warrington CCG
Thanet CCG	West Essex CCG
	West Hampshire CCG
	West Sussex CCG

## APPENDIX C

### Additional Patient Reports Gathered Separately to the Survey

In August 2019 the thyroid patient campaign group, Improve Thyroid Treatment Group (ITT), asked members of their Facebook group for up to date information on their CCGs following the new NHS England guidance on liothyronine prescribing. This was just a straw poll in a holiday week, but it resulted in 36 reports on CCGs refusing to prescribe liothyronine.

The campaigners observed that, “There may be a few improvements nationwide, but the situation is far from good.”

Subsequent to the straw poll, a further 12 CCGs, where there are issues, were reported by patients, via ITT and the other patient groups. This list is a snapshot of comments gathered in this way, between August 2019 and 19th January 2020.

Those CCGs marked with a star are in addition to those who have shown up in the T3 prescribing survey.

1	<b>Airedale CCG*</b> - endocrinologist has told my GP to prescribe T3 and he has. I don't know if it will last.
2	<b>Basildon CCG</b> - patient who has been well on 20mcg for some time, told she must reduce to 10mcg (ITT). Another patient who has completed a trial initiated by her endocrinologist is told by her GP that only the hospital can continue to prescribe as that is the CCG policy. Hospital say that the GP should prescribe, she has no idea if she will continue to get her prescription and is very anxious.
3	<b>Berkshire CCG</b> - I was given T3 once, but refused after that one GP left.
4	<p><b>Birmingham and Solihull CCG</b> - told a patient to ask any questions, regarding Liothyronine prescribing in B&amp;SCCG, directly to NHSE. The question is why this CCG is allowed to effectively ban T3 by quoting from the original July 2017 NHSE Items Which Should not be Routinely Prescribed Consultation document rather than the November 2017 recommendations from that consultation or the updated prescribing guidance published July 2019 . here is the Birmingham and Solihull Patient leaflet: <a href="https://www.birminghamandsolihullccg.nhs.uk/about-us/publications/your-health/items-which-should-not-be-routinely-prescribed-in-primary-care/1725-changes-to-liothyronine-prescribing/file">https://www.birminghamandsolihullccg.nhs.uk/about-us/publications/your-health/items-which-should-not-be-routinely-prescribed-in-primary-care/1725-changes-to-liothyronine-prescribing/file</a>. The patient has received the below reply from NHS England telling her to go back to the CCG for an answer - we suggest that this is unacceptable.</p> <p><i>Dear [name redacted],</i></p> <p><i>NHS England and NHS Improvement expect CCGs to take the guidance on items which should not be routinely prescribed in primary care into account in formulating local policies, and for prescribers to reflect local policies in their</i></p>

	<p><i>prescribing practice. CCGs need to take decisions on implementation locally, ensuring they take into account their legal duties to advance equality and have regard to reducing health inequalities. The guidance does not remove the clinical discretion of the prescriber in accordance with their professional duties.</i></p> <p><i>NHS England and NHS Improvement continue to work closely with CCGs to support them to implement the guidance. This includes monitoring unintended consequences and CCG prescribing data to see where variation exists, which is taken into account when working with CCGs to implement the guidance. As part of this monitoring process the clinical working group will take account of your feedback and concerns.</i></p> <p><i>If you have any specific questions on the position of your CCG, we would advise that you contact them directly.</i></p> <p><i>Best Wishes</i>  <i>Medicines Policy Team</i>  <i>NHS England &amp; NHS Improvement</i></p>
5	<p><b>Brighton and Hove CCG</b> - says it is waiting for the new NICE guidelines in November. Goodness knows why, because it has consistently failed to follow any previous national guidance since at least September 2016. A patient who has gone as far as ombudsman with complaint says: Brighton and Hove CCG has a zero limit, a policy of no prescriptions apart from two rare conditions, Myxoedema Coma and for patients in preparation for Radioiodine therapy. (Ombudsman initially has said that CCG is allowed to make their decision)</p> <p>Another patient reports being told that a maximum of 20mcg dose is possible on the NHS in Brighton and Hove.</p>
6	<p><b>Blackburn with Darwen CCG*</b> - the endocrinologist says there is not enough research evidence available for its benefits.</p>
7	<p><b>Bromley CCG*</b> - my repeat prescription was rejected, then accepted again for 2 months. But that may be a dead end as he has told my GP to stop it.</p>
8	<p><b>Calderdale CCG</b> - I am self-sourcing on the advice of my GP. I left the endocrinologist due to inadequate care.</p>
9	<p><b>Cornwall CCG*</b> - my GP practice refused me T3; I was told “they are avoiding causing me harm.” I said I would self-source an alternative to thyroxine and I now self-source NDT as I originally had that prescribed on the NHS.</p>
10	<p><b>Cambridgeshire and Peterborough CCG</b> - told by Professor Chatterjee at Addenbrookes Cambridge that I should continue Liothyronine and he requested that my GP prescribe it. My GP applied to the CCG and I just received a letter from the Cambridge and Peterborough CCG informing me that I was not an “exceptional case” and if I “still” need Liothyronine, then I should pay for it privately or it should be prescribed by secondary care.</p> <p>The Cambridge British Thyroid Foundation support group coordinator also reports receiving several calls from patients experiencing issues, in</p>

	Cambridgeshire, similar to the above - patients are being told the CCG will not permit T3 on the NHS.
11	<b>NEW Devon CCG</b> - My GP is trying to get me T3 via an endocrinologist, after I self-sourced T3. I once was prescribed Armour NDT, but then it was stopped.
12	<b>Devon CCG</b> - reducing patients' T3 doses. Patients report a maximum of 10mcg is permitted. Some are sourcing additional T3 independently. Some others report say they are simply taking the lower dose and becoming unwell.
13	<b>Dorset CCG*</b> - told by my endocrinologist it's not red-listed in Dorchester anymore & that my GP in Somerset can now prescribe it. But so far my GP has refused & my medication ran out yesterday.
14	<b>Eastbourne, Hailsham and Seaford CCG</b> - T3 is not allowed to be prescribed.
15	<b>East Hampshire CCG*</b> - patients are still refused T3.
16	<b>East Kent CCG</b> - In East Kent T3 testing is firmly refused so many people who would benefit from treatment are not identified unless they fund their own commercial testing.
17	<b>East Surrey CCG*</b> - will not prescribe T3.
18	<b>Framleigh (in Suffolk)*</b> - patient has been told to complete a thyroid symptom score for endocrinologist to review prescription. We have requested a copy. Concern raised regarding patients with doses of > 20mcg being told to reduce amount.
19	<b>Fylde &amp; Wyre CCG*</b> - I was initially put on T3 8 years ago by a dr who recognised the T4 alone just wasn't helping my underactive thyroid. Unfortunately he retired and every dr since just looks at the numbers on the bloods, they never ask how you are actually feeling. Dr withdrew it without warning or tapering, due to costs. I've been begging ever since for tests to prove I need it.
20	<b>Great Yarmouth &amp; Waveney CCG</b> - T3 was allowed previously for a patient via an IFR in Great Yarmouth and Waveney, and the patient is still under an IFR.
21	<b>Greater Preston CCG*</b> - liothyronine is still blacklisted for primary care and red-listed for hospital. No change or review of their guidance despite new NHSE clarification.
22	<b>Guildford and Waverley CCG*</b> - their stance has not changed in the last year. Still 'amber' for patients who have been on T3 and are stable, but not recommended for new patients. I was told it was the endocrinologists and GPs who wanted to stop it.
23	<b>Hambleton, Richmondshire and Harrogate CCG*</b> - will not issue T3.

24	<b>Harrogate and Rural District, CCG</b> - a private endocrinologist told me that it would take about a year before T3 would finally be available on the NHS and only if you meet certain criteria.
25	<b>Hillingdon Middlesex CCG*</b> - I'm still getting T3 via an endocrinologist, but I am allowed only 15 mcg a day and I need more. My GP will not prescribe it and is not in agreement that I should have it.
26	<b>Horsham and Mid Sussex CCG</b> - Refused T3. I have to self-source NDT. I am still not allowed T3 even after having serious heart issues caused by low T3.
27	<b>Ipswich and East Suffolk CCG</b> - one patient reports being allowed to continue with a T3 prescription. Another reports she was very well on 40mcg dose. Had a 'remote' review with endocrinologist (no appointment) GP said CCG then wanted to reduce amounts being prescribed. Endocrinologist suggested dropping to 30mcg. GP is supporting this patient staying on 40mcg, as he can see how well she is.
28	<b>Kirklees CCG*</b> - does not allow T3. I'm prescribed by endocrinologist in Salford (a different CCG). Have been on T3 now for 10 years.
29	<b>Lambeth CCG</b> - I was told as T4 is not working for me at all now I need to try T3, but only private Endocrinologist can prescribe it which cost a fortune. I can't afford it.
30	Medway, Kent CCG* - GP has told me T3 is no longer allowed to be prescribed on the NHS, but I can be given an alternative (thyroxine)
31	<b>Morecambe Bay CCG*</b> - I am told that thyroid patients do not need T3 and that it will not be prescribed by the trust - only if a patient was unconscious in intensive care would they be given T3.
32	<b>Norfolk CCGs*</b> - in theory they put T3 back on the formulary in 2018, but patients are still not allowed it. GP said recently that I could not have T3, and acknowledged that I have to pay for it privately (I had been given it before it was withdrawn)
33	<b>Norwich CCG</b> - my GP suggested I go private. He even said that primary care is not allowed to order a test for FT3.  <ul style="list-style-type: none"> <li>- endocrinologist appointment (22.10.19) - said he still couldn't prescribe the T3 he knows I need, saying that the CCG is dragging its heels and haven't sorted out who is paying for the first 3 months.</li> <li>- endocrinologist appointment (30.10.19) - said CCG had still not agreed how it would be funded by primary and secondary care, the protocol was not finalised, so he still could not prescribe it. I was sent away for yet another 6 months. But Norfolk CCGs agreed endocrinologists could prescribe T3 16 months ago.</li> </ul>
34	<b>North &amp; West Devon CCG*</b> - trying to remove my T3. Another patient stable on T3 for 8 years has had it removed.



35	<b>Rushcliffe CCG*</b> - they would not prescribe it before, and they still will not.
36	<b>Somerset CCG</b> - Somerset patient has been approved T3 by NHS endo who has now asked GP to prescribe. GP refused as CCG will not allow it.. Endo is now doing an IFR.
37	<b>Southampton CCG</b> - my NDT was withdrawn by my endocrinologist who had said to my face she would definitely not do that. I can't face the battle to have it reinstated at the moment so sourcing privately for now which I can't really afford. I was told that a T4 test gives no further information and doesn't change treatment.
38	<b>Southwark CCG</b> (January 2020) - a patient established and well on T3 for 9 years reports that the CCG has now withdrawn their prescription. This patient intends to go to the Health Ombudsman. A second patient reports "I live in Southwark CCG and the local GPs do not prescribe T3 - I checked on the prescribing data site for NHS. As a result I have not changed my GP from [another area in the north of England, where I used to live] and remain a patient there. To get medical attention I cross my fingers, travel north (round trip 6 hours) and see if I can do online/telephone. I cannot face the battle for T3 locally. I'm flat out with work which I need to be able to do to support myself."
39	<b>South Lincolnshire CCG</b> - I've been on T3 for 20 years and they have taken me off it due to costs and I am suffering in terms of immediate and quick weight gain, lethargy, etc. Not getting anywhere and having to buy tablets from Turkey.
40	<b>St Helens CCG*</b> - they refuse everything other than thyroxine. GP won't test other than TSH and Endocrinologist refused everything. Endocrinologist said previously he has given women a placebo and they report wondrous results.
41	<b>Staffordshire CCG*</b> - GP said that primary care will not pay for FT3 blood tests. So I hold even less hope of getting T3 prescribed.
42	<b>The Pan Mersey CCG (9 North West CCGs)*</b> - my endocrinologist still refuses me T3, despite letters from the consultant acknowledging I have the required exemption for it. She says there is no evidence to support its effectiveness
43	<b>The Pan Mersey Area Prescribing Committee</b> who direct 9 Clinical Commissioning Groups to adhere to their thyroid treatment recommendations state, "The NHS England document 'Items which should not be routinely prescribed in primary care' advises against the use of liothyronine (including Armour® Thyroid) except under exceptional circumstances when levothyroxine has failed and the consultation where the patient is deemed to require the drug must be undertaken by an NHS consultant in an NHS funded service." <a href="https://www.panmerseyapc.nhs.uk/media/1163/thyroid.pdf">https://www.panmerseyapc.nhs.uk/media/1163/thyroid.pdf</a> .  The Parliamentary and Health Service Ombudsman subsequently advises that: "The CCG have said that your treatment falls into its 'not routinely funded' category which under this policy states the CCG will only commission the treatment for an individual patient where an IFR demonstrates clinical exceptionality. This means that the patient has a different clinical picture from

	the general population of patients with that condition. Due to this, the patient is likely to have greater benefits than the general population with that condition". The patient asks how he is supposed to prove that he has a different clinical picture from the general population.
44	<b>Wandsworth CCG</b> - my NHS endocrinologist is trying to get my T3 through the CCG process and then to GP. Strict protocol, unknown outcome.
45	<b>West Essex CCG*</b> - CCG will not reinstate T3, and have stopped it being prescribed altogether. The CCG has told endocrinologists they are to find that nobody needs it, regardless. I have had to buy my own T3 for 18 years.
46	<b>West Kent CCG</b> - my endocrinologist can prescribe a 3-month trial, but after that the CCG will not allow it.
47	<b>West Midlands*</b> January 2020 - 83 year old patient who has been taking liothyronine and finding it helpful for 7 years, now told liothyronine is not licensed by the NHS, that if she continues to take it she will have to pay for it and may lose her right to any free NHS prescriptions.
48	<b>West Yorkshire and Harrogate CCG*</b> - endocrinologists can now prescribe T3, and a GP can do after a successful trial of between 3 and 6 months.



