

# Women's Health Consultation Response



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# Introduction

1 in 20 people in the UK have a thyroid condition and the trend is upwards. Women are up to 10 times more likely to be affected than men. Many women tell us that their experiences of thyroid disease are not being effectively addressed by the NHS in the UK and in many cases, due to debilitating symptoms which are not being optimally treated, women are having to give up work, becoming dependent on family members or the state, while still others are driven to the private sector or even informal channels, such as accessing prescription medicine on the internet, to access treatment that enables them to function and contribute to society.

The most common thyroid condition is hypothyroidism. The prevalence of treated hypothyroidism increased from 2.3% (1.4 million) to 3.5% (2.2 million) of the total British population between the years 2005 and 2014 and is projected to rise further to 4.2% (2.9 million) by 2025<sup>1</sup>.

The Thyroid Trust is a small patient-led charity for people affected by thyroid disease, including friends, family and interested professionals. We completed our registration with the charity commission in May 2019. As a group of patients, we have been providing information and support events and been involved in patient advocacy initiatives going back to 2010.

We strongly support this consultation on women's health and welcome this opportunity to share our story and present our evidence.

The NHS dispensed 33million items of levothyroxine sodium L-T4, for treating hypothyroidism, in 2019. It was the second most dispensed clinical substance across the entire health service.

The cost to the NHS of all thyroid and antithyroid drugs in 2019 was £98million.<sup>2</sup>

No-one is collecting data on the extent of disability, benefit claims, or co-morbidities amongst thyroid patients as a whole, or women with thyroid disease in particular. It is estimated that around 15% of patients are struggling - described in the literature as "dissatisfied with their treatment".<sup>3</sup>

Thyroid disorders are common, on the increase, can be highly debilitating and affect many more women than men, particularly older women, but they are often overlooked, with some women reporting appalling treatment from the NHS and a major scandal, as yet unresolved, regarding what ought to be a simple matter, fair access to a generic medicine that could help up to 300,000 women live a normal life,

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<sup>1</sup> Trends, Determinants, and Associations of Treated Hypothyroidism in the United Kingdom, 2005–2014, [Thyroid VOL. 29, NO. 2 | Original Studies Salman Razvi, Tim I.M. Korevaar, and Peter Taylor](#), Published Online: 26 Apr 2019 <https://doi.org/10.1089/thy.2018.0251>

<sup>2</sup>

<https://www.nhs.uk/statistical-collections/prescription-cost-analysis-england/prescription-cost-analysis-england-2019>

<sup>3</sup> <https://www.ncbi.nlm.nih.gov/pubmed/29620972>

which the government has failed to fully address, despite a major report from patient groups in 2018<sup>4</sup> and follow up reports in 2020<sup>5</sup> and 2021<sup>6</sup>.

Our experience and engagement with patients across the country reveals that untold numbers of women with thyroid disease are living a very poor quality of life and may be unnecessarily dependent on their families or the state, due to poor standards of care, low awareness, poor understanding and restrictions on access to treatment. It is time for that to change.

Thyroid treatment measures were removed from The Quality Outcome Framework (QOF), in 2014<sup>7</sup>. Until then the QOF was used to help monitor thyroid patients and prompt for regular testing. When thyroid patient groups have asked the NHS to start collecting data on thyroid patients they have been told there are no plans for this to happen. We believe this makes no sense given the high cost of the status quo.

## The thyroid gland and what it does

The thyroid is a butterfly shaped gland at the front of the neck. Thyroid hormones are important in regulating metabolism and play a crucial role in almost every biological process in the human body. A poorly functioning thyroid can have a huge impact on all those “woman’s health” issues at the heart of this proposed strategy: menstrual irregularities, infertility or sub-fertility, endometriosis, miscarriage, poor pregnancy outcomes and menopause.

Additionally, thyroid hormone dysfunction can cause significant physical disability, including obesity and mobility issues, muscle weakness, distressing facial disfigurement and / or hair loss, and a range of mental health challenges, ranging from anxiety or depression, to dementia-like symptoms and even, in rare cases, psychosis. The long-term consequences of both under and over active thyroid issues can be both musculoskeletal and cardiovascular issues.

Thyroid issues are complex and scientists are still discovering how precisely the body uses thyroid hormones. Put simply, when the thyroid is overactive it produces too much of the hormone thyroxine – this is called hyperthyroidism. When the thyroid is underactive, it doesn’t produce enough thyroxine – this is called hypothyroidism. Thyroid Cancer is on the increase for reasons which are not fully understood and some thyroid patients develop Thyroid Eye Disease which can be disfiguring and affect sight. Much more research is needed to understand what causes thyroid problems and how they can best be treated.

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<sup>4</sup> Report: Liothyronine – Case Details with Clear Evidence that NHS England Guidance on Prescription of Liothyronine is not Being Followed by CCGs [bit.ly/LiothyronineDossier2018](https://bit.ly/LiothyronineDossier2018)

<sup>5</sup> [T3 prescribing survey February 2020](#)

<sup>6</sup> [T3 prescribing status report 2021](#)

<sup>7</sup> [An electronic protocol replicating QOF thyroid alerts improves monitoring but does not help optimise levothyroxine replacement in hypothyroidism in primary care | SFEBES2017 | Society for Endocrinology BES 2017](#)

Thyroid symptoms are often non-specific (for example: lethargy/anxiety, temperature intolerance, weight gain/loss, muscle weakness, menstrual irregularities, low mood, impaired cognitive function, skin, hair and nail issues). Consequently, they are often overlooked, dismissed as “just part of ageing” or confused in the diagnosis of other issues e.g. menopause and depression. Patients with hypothyroidism can suffer from lethargy and thyroid patients may sometimes present as incoherent or particularly emotional, which can make it particularly difficult for them to access effective treatment, as they may not be able to ask for help and when they do they are often not taken seriously.

An overview of Thyroid disorders is available on the NICE website<sup>8</sup>.

A global view of the need for policy makers to start to address thyroid health more strategically has been published in Global Foresight magazine this in May 2021<sup>9</sup>.

The European Society for Endocrinology have published a White Paper for Hormones in Health Policy in Europe<sup>10</sup> which the UK government should also take notice of.

As a small under-resourced patient-led charity, due to capacity issues, we have chosen to focus the new evidence in our submission on one aspect of patient experiences which we have been working on since 2017 and requires an urgent intervention, the availability of liothyronine L-T3.

However we propose that this should be seen as a starting point for addressing issues faced by women with thyroid disease, which in essence boil down to a need for thyroid health and its effects on women’s health to be taken far more seriously and resources allocated for it to be effectively addressed, as part of the wider strategic framework for women’s health.

We would also flag up that since some men are also affected, it is important to remember their needs must also be addressed by the UK health service’s overall response to thyroid disease.

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<sup>8</sup> <https://www.nice.org.uk/guidance/ng145/chapter/Context>

<sup>9</sup> <https://foresightglobalhealth.com/the-thyroid-the-organ-below-the-radar/>

<sup>10</sup> <https://www.es-e-hormones.org/advocacy/eses-white-paper/>

# Women's voices

“I took levothyroxine [L-T4] for 20 years, never felt well but coped, then got progressively worse until bed bound for 80% of time. Heard about liothyronine [L-T3] and excitedly rushed to GP only to be told “there is only one treatment for thyroid - levothyroxine” and was **ordered out of the room**. Have since carried out my own research and self medicate with liothyronine bought on-line, **now feeling quite well!**”

The above quote is one of the responses to an ongoing survey on our website<sup>11</sup> where thyroid patients, mostly women, report on issues with accessing L-T3 in their local area. Sadly, this woman's experience is typical and echoes the common themes in the Liothyronine Dossier from 2018<sup>12</sup>.

See Appendix D for all survey responses received up to 28/5/2021, excluding personal data, including compelling personal statements.

The Thyroid Trust sees far too often that women with thyroid issues do not feel listened to and their concerns are not taken seriously. As a patient-led organisation which works closely with healthcare professionals and promotes evidence based medicine, we work hard to try to give people with Thyroid conditions a strong voice - and yet even with all our seeming expertise and support pledged from the highest level, following debates in both the House of Commons and the House of Lords<sup>13</sup>, women with thyroid disease, who are struggling with their conditions, continue to be ignored and left to languish, telling us they often find themselves derided by healthcare professionals and denied effective treatment.

There are a number of small thyroid patient organisations, but none have comparable resources to those that exist for similarly common health conditions. This in itself is a huge challenge and means that we struggle collectively to be heard, to provide effective support and to have the data collected and acted upon that would improve things for people affected by thyroid disease within the healthcare system.

We submit as further evidence, the common themes identified from the patient testimonies contained within the 2018 Liothyronine Dossier, which was prepared for the Department of Health to evidence that health authorities across the UK were not following national guidance and providing fair access to the specialist treatment for hypothyroidism, liothyronine, L-T3, a generic medicine.

The common themes, then and now, are:

- Patients who had been previously very unwell on L-T4 only, and then subsequently been stable on L-T3, either on its own or in combination with

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<sup>11</sup> <https://www.thyroidtrust.org/liothyronine-prescribing-reports.html>

<sup>12</sup> The Liothyronine Dossier 2018 <https://www.thyroidtrust.org/liothyronine-dossier-2018.html> - summarised with references in Appendix C of this document.

<sup>13</sup> Regret Debate: Hansard: Branded Health Service Medicines (Costs) Regulations 2018 <http://bit.ly/2vPBSqs>

L-T4, often for several years, have been told that the NHS in their area will no longer prescribe it for them.

- The justifications for withdrawing treatment have been either cost related or because of blood test results - patients' well-being is being overlooked.
- Patients are being told the only way to prove to their CCG that they require L-T3 is for them to stop taking it and become unwell - which is counter to BTA December 2016 guidance on L-T3<sup>3</sup> which states that if a patient is stable, disrupting their medication can cause serious problems and is likely to be costly to rectify.
- Many described their condition as being "unable to function" on L-T4.
- When treated with L-T3, many patients reported that they "got their lives back".
- When treated with L-T4 only, many patients report they were so unwell they had to give up working.
- Many reported once taking L-T3 they were able to return to work having previously been disabled. Several specifically stated they were able to return to high performing roles.
- Many described their improved condition by saying, "I can function again".
- Many reported that, when they were not taking L-T3, they were given multiple other tests and treatments which generally did not help them but will have been expensive for the NHS.
- Many reported they felt that if they were no longer prescribed L-T3, having been stable on it for some time, it was a life or death situation. Without this medicine, which had been proven to help them so profoundly, they did not feel that their lives would be worth living.
- Patients who are having their medication withheld are either now sourcing it privately, which many can ill afford and feel very uneasy about, or are finding their health deteriorating without it, in some cases dramatically.
- Several patients have been told explicitly, sometimes in writing, by NHS endocrinologists, GPs or health authorities, that the only way they can have L-T3, which is acknowledged to help them, is by sourcing it outside the NHS as the NHS will not pay for their medication.
- Several patients have been informed that they can have a private prescription from their NHS doctor, but that the NHS will not pay for their medication.

L-T3 is now the subject of a long running Competitions and Markets Authority<sup>14</sup> investigation where the original licence holder has been found provisionally guilty of abusing their dominant position and yet new licence holders are continuing to charge the NHS several times what any other country is paying for it and there are over 100

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<sup>14</sup> <https://www.gov.uk/cma-cases/pharmaceutical-sector-anti-competitive-conduct>

different policy documents in different local NHS areas across the country, at least 52% of which contradict national guidance<sup>15</sup>, which states L-T3 treatment should be available on the NHS for all who need it.

The majority of these “local policies” deny effective treatment to patients, mostly women, who require L-T3 to manage their hypothyroidism. Many of these women have told us that without it their lives are hardly worth living. Along with our partners, we heard from over 400 women for The Liothyronine Dossier, Case Details with Clear Evidence that NHS England Guidance on Prescription of Liothyronine is not Being Followed by CCGs, published in 2018. The experiences they reported were alarmingly consistent and while the improved prescribing guidance from the Regional Medicines Optimisation Committee, published in 2019, has helped in some areas, women in at least 52% of CCGs are still being denied NHS treatment.

This dossier makes tragic reading. Some women have been confined to wheelchairs, others have lost their jobs, others have had multiple miscarriages. Many women feel that they have been written off and put on antidepressants. Some have been sectioned.

We know that in many cases women have resorted to travelling to other countries to buy L-T3 over the counter, purchasing online from unknown sources, or paying through the nose for private prescriptions. Others are simply very unwell and struggling without the treatment they may need.

Women being treated for thyroid problems are apparently disproportionately well educated and affluent<sup>16</sup> - these women are sometimes stigmatised as overly demanding and perpetually dissatisfied.

Our concern, in addition to this very unfair stigmatisation, is that there are many more women who may have access to fewer resources to advocate for themselves and are therefore not being treated at all for thyroid conditions which may remain undiagnosed, severely curtailing their quality of life and their capacity to contribute to society and their families.

Thyroid disease often affects women’s appearance - weight gain, hair loss, facial swelling and eye distortions, as well as mental health effects and the fact that most patients are middle aged or older, a group particularly likely to be dismissed and ignored, all contribute to the stigmatisation and marginalisation of women with thyroid disease in a society which prizes attractiveness and youthfulness in women.

There is a wealth of anecdotal evidence of women with thyroid disease being told they are old, depressed, hormonal, the drug they are on is “like cocaine”, their symptoms are in their heads, or that they simply need to eat less, even when some are following near starvation diets in attempts to manage their weight.... etc

As the impact of a poorly functioning thyroid manifests itself in so many ways, patients often report that they are treated as hypochondriacs. “Which symptom do you want me to focus on” being a common response when women present at their

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<sup>15</sup> <https://www.sps.nhs.uk/articles/updated-rmoc-guidance-prescribing-of-liothyronine/>

<sup>16</sup> pete taylor and Ac bianco study cholesterol findings

GPs with multiple symptoms and this may be one reason so many women report that they were unwell for several years before being diagnosed and then sometimes continue to be unwell for years afterwards before getting effective treatment.

The NICE guideline for thyroid disease assessment and management<sup>17</sup> is clear that thyroid patients should be treated as individuals, levothyroxine doses can be adjusted to restore wellbeing and symptoms should be taken into consideration when interpreting blood tests and deciding on treatment. NICE also supports the Regional Medicines Optimisation Committee<sup>18</sup> prescribing guidance for liothyronine L-T3, and yet women with thyroid disease repeatedly tell us about GPs and specialists dismissing their experiences, withholding treatment, claiming that L-T3 is not available on the NHS “because it is too expensive” (this is an old generic medicine available over the counter in Greece for 5Euro a packet), levothyroxine doses cannot be adjusted, or that symptoms must be being imagined. The callous treatment some women tell us they receive is extraordinary to hear. See the testimonies in appendix D, as well as those in The Liothyronine Dossier, appendix C.

When the NICE guideline was being developed the equality impact assessment statement was that

“There were no equalities issues identified during the scoping process for this guideline.”

The Thyroid Trust commented that

“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.”

The response from NICE was disappointing:

“We have reviewed the recommendations in light of your comments. A new recommendation has been added about menopausal women: “1.2.5 Be aware that in menopausal women symptoms of thyroid dysfunction may be mistaken for menopause”.

We have checked the rest of the guideline and do not consider that any of the recommendations discriminate against women in any way.”

One patient reports telling her doctor she was falling asleep while driving her car (extreme fatigue and sleepiness can be a symptom of hypothyroidism), the doctor responded “you must be bored”. This patient is now paying £450 a quarter for the medicine she needs every day to be well and continue her career as a media

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<sup>17</sup> <https://www.nice.org.uk/guidance/ng145>

<sup>18</sup> <https://www.sps.nhs.uk/articles/updated-rmoc-guidance-prescribing-of-liothyronine/>

professional. She fears what will happen when she retires and may not be able to afford it any more.

One thyroid patient forum has over 118,000 members<sup>19</sup>. Forums like this one regularly receive posts from women declaring that they have become so disillusioned with the care available on the NHS that they avoid their GPs and in some cases have resorted to treating their conditions themselves, sometimes relying on books and websites from unofficial sources for advice and medication, with obvious and deeply concerning risks to their immediate and long term health.

## **Information and education on women's health**

Many of the issues associated with the poor diagnosis and treatment of thyroid issues could be improved with access to better high-quality information for women and also healthcare practitioners. There are opportunities in particular for more digital provision of information and discussion groups where patients can learn together and clinicians can gain more insight into common patient issues.

Women affected by thyroid disease are crying out for more information about their conditions and there is very little provided by GPs when they are initially diagnosed or longer term. There have been improvements with the advent of Patient Access and NHS websites, but these tend to be too simplistic for those who want to learn more about their conditions and are not available to the digitally excluded unless the GP hands out print outs.

The lack of quality information and the lack of support from the medical profession has led to many women joining online patients forums (e.g. Thyroid UK, Health Unlocked and various Facebook groups). Whilst many such peer support networks may be very good, we have concerns that some of the advice provided may not be backed up by scientific evidence. As the reality of the landscape now is that patients will gravitate to online forums with their peers the NHS needs to find ways to support peer support networks with reliable information and challenge potentially dangerous misinformation where it appears.

### **TTT Thyroid Patients Experiences Registry**

We have developed a patient registry with timeless, anonymised qualitative data on thyroid patient experiences covering all life stages and conditions. We need support to have this registry codified and propose that the information it contains could usefully help inform further research and policy development. Sample data from the registry is available on request. The questionnaire is hosted on our website.<sup>20</sup>

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<sup>19</sup> Thyroid UK Health Unlocked <https://healthunlocked.com/thyroiduk>

<sup>20</sup> <https://www.thyroidtrust.org/submit-your-story.html>

With additional funding we would like to undertake more formal patient surveys on different aspects and impacts of thyroid health issues.

## Women's health across the life course

- Thyroid disease in pregnancy can cause miscarriage
- Thyroid disease in babies and young girls can cause developmental issues, impaired IQ and poor performance at school - the UK is iodine deficient which may impact overall population intelligence <sup>21</sup>
- Thyroid disease in teenage girls can affect school performance, appearance, life chances and mental health
- Thyroid disease in young women can affect fertility and overall wellness and quality of life
- Thyroid disease in women of working age can affect work performance and even the ability to work at all
- Thyroid disease at any age can cause obesity or rapid weight loss, facial changes, muscle weakness, mental illnesses and cognitive impairment
- Thyroid disease in older women can cause osteoporosis and cardiovascular illness
- At all ages - women and girls with thyroid disease report that their concerns are not taken seriously and since symptoms can be wide ranging, short appointment times and the frequent exhortation from health professionals to focus on one symptom at a time can cause delays in diagnosis and a failure to treat thyroid conditions effectively.
- Data is not being collected at a national or local level

## Women's health in the workplace

The Thyroid Trust's anecdotal evidence and patient registry evidence reveals there are many thyroid patients who take time off work, reduce their hours of work or are medically retired early because of inadequate diagnosis, treatment and care. This impact on the quality of thyroid patients' lives of not being able to participate fully in the workplace is not at the heart of decision making on patient treatment guidelines.

Unfortunately, the NICE resource impact evaluation does not include any economic evaluation of the impact of lost working days in the assessment of treatment pathways.

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<sup>21</sup> <https://motherbabyiodine.org/about/>

With almost 2million women in England with a thyroid condition We are concerned at the inequitable impact on their livelihoods and careers and the cost to society of women who could be well and active members of society, if effectively treated, who are sadly simply left to languish as dependents with very poor quality of life.

No one is collecting data on how many women with a thyroid condition may not be economically active or whose earnings may have dropped substantially since having to give up full time work due to their conditions and what the overall impact could be if services and treatment options were delivered more fairly.

## **Research, evidence and data**

The NHS does not currently collect data on thyroid patients and women's experiences with thyroid disease have not been at the heart of research or guidance setting.

When the NICE guideline on thyroid disease assessment and management NG145 was developed, studies on patient experiences and patient reported outcomes were judged to be low grade evidence and were largely dismissed.

Patient charities and groups were notionally engaged but largely excluded from the patient pathways.

Women with thyroid disease need their experiences to be heard and taken note of when clinical trials evidence is scarce - as it is for both levothyroxine and liothyronine which are both old generic medicines which predate the current protocols new treatments have to undergo, yet there is a wealth of real world data

Healthcare professionals must be mindful that the decisions they make for patients have costs attached. However, costs may be direct or indirect, unidentified opportunity costs and unappreciated downstream consequences of withholding effective treatment for hypothyroidism have not been examined by the NHS.

Well produced national guidance brings inherent benefits in reducing national variation, as well as taking into consideration wider social and well-being / quality of life factors for patients.

## **Covid-19: The impact on women with thyroid disorders**

The risk of life threatening complications due to Covid-19 is significantly increased in women with active thyroid eye disease, due to the immune-suppressing medical treatment they must receive to treat their illness.

Women with thyroid disease undergo thyroid function tests regularly to check thyroid function and to ensure they receive the right medication and dosage. Routine tests and most thyroid conditions are not life-threatening, or urgent according to

government guidelines and so tests and appointments have sometimes been difficult to obtain during the pandemic. This has a potentially huge impact on quality of life for women with thyroid disease because if our thyroid hormones go out of kilter we can become extremely unwell, unable to function in some cases and this can happen at any time.

At times during the pandemic the government has postponed all non-urgent surgery and treatments and therefore those awaiting thyroid surgery and radioactive iodine therapy have sometimes not been able to proceed with their treatment. Whilst not life threatening in itself, this is understandably highly distressing for those awaiting surgery or other treatment that may provide relief from their symptoms.

Women with thyroid disorders are already vulnerable due to debilitating symptoms, including cognitive impairment and very inconsistent standards of care and access to treatment options across the country - the impact of Covid-19 on access to healthcare and on mental health could be devastating. Charities have done our best to be there for those that depend on our advice, support and advocacy now more than ever but the health service has to be the primary source of service provision. Charities for thyroid conditions do not have the resources required given the prevalence of thyroid disease. Of particular concern: the ongoing situation regarding access to liothyronine for those patients who need it, which was close to being resolved before the pandemic, is now becoming increasingly problematic since those responsible for NHS management are understandably focused on Covid19

During the Covid-19 pandemic it has been harder than ever for women with thyroid disease to access specialist care or treatment and in some cases also primary care.

Phone appointments have been a welcome innovation for some women thyroid patients but are not always effective.

Those patients driven to the private sector and informal channels for their thyroid medication, by the NHS failure to resolve its fragmented access to liothyronine, L-T3, have often experienced difficulties, including having to pay higher prices, as supply chains of liothyronine have been disrupted and some European manufacturers and pharmacies have said they will no longer supply to the UK due to Brexit.

NHS top level focus has been on Covid, understandably, however this has meant NHS England have not followed up on their promise<sup>22</sup> to write to CCGs to highlight their expectation that local health authorities follow the national guidance for liothyronine and many patients are still being refused treatment, having to go private, resorting to self- treating or simply being left unwell.

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<sup>22</sup> <https://questions-statements.parliament.uk/written-questions/detail/2020-02-12/HL1581>

# Actions required by government

1. Make funds available for more research into thyroid disease and effective treatments, particularly into understanding patient experiences and effective treatments
2. Make resources available to support women with thyroid disease with reliable information and social prescribing/ managed peer support networks
3. Improve training and ongoing professional development for GPs on thyroid issues. We understand that most GPs may only receive a 1 hour training on thyroid issues before they qualify to practice.
4. Consider providing and funding specialist thyroid clinics and in primary care and specialist thyroid nurses, to support patients.
5. Whilst charities like ourselves are plugging gaps and making high quality information available, we are doing so on a shoestring and ask that Government looks at how to provide financial support to those services.
6. Provide links to The Thyroid Trust informational resources from Ask My GP, NHS Choices and Patient Access.
7. All patient groups to input into the patient pathways when the NICE guideline for thyroid disease is revisited
8. National guidelines incorporate patient surveys to encourage the patient voice in the shaping of their care pathways and do not just rely on RCTs when robust RCT evidence does not exist
9. The NICE strong recommendation for L-T3 clinical trials is fully funded as a matter of priority
10. The Department of health and NHS should gather data on the health, quality of life, wellbeing and economic activity of thyroid patients.
11. National guidelines incorporate wider social economic impacts in the assessment of care pathways
12. Data is collected to measure thyroid patients economic activity
13. Measures are put in place to assist women with thyroid disease to be well, active and able to work - including ensuring access to treatment options that patients report are effective for them.
14. End the postcode lottery for liothyronine L-T3 and instruct all CCGs to ensure that patients who qualify for L-T3 under the RMOC prescribing guidance are prescribed it.
15. Consider fortification of salt with iodine to reduce the IQ impact of iodine deficiency on newborns

# Annex A, About The Thyroid Trust

The Thyroid Trust is an innovative new patient-led charity, representing around 5% of the UK population, who have a thyroid disorder, in particular, the circa 15% of patients who specialists acknowledge require improved standards of care and access to treatment options, in order to be well. The charity works collaboratively with all stakeholders, including leading medics and key organisations, to build understanding, raise awareness, increase the profile, and improve outcomes for people affected by thyroid disease.

The Thyroid Trust exists to work for the benefit of people in the UK who are affected by thyroid conditions and related conditions or diseases, in particular, but not exclusively, by providing empathetic peer support and reliable information from credible sources, holding regular meetings and raising awareness of thyroid health-related issues.

Our aims are to relieve unnecessary suffering and isolation in thyroid patients and their families, promote their well-being, increase the likelihood of early diagnosis and access to appropriate care and help them to be well informed, as well as create opportunities for healthcare professionals to build their understanding of patients' perspectives.

# Annex B, hypothyroidism and liothyronine access

Hypothyroidism is the most common thyroid disease, mostly caused by either an autoimmune condition or treatment for thyrotoxicosis, an overactive thyroid also called hyperthyroidism, or thyroid cancer. It is usually a lifelong condition requiring daily thyroid hormone replacement. The standard treatment is with a synthetic version of the thyroid hormone, thyroxine.

Thyroxine is normally converted into the active hormone, liothyronine, in the body, but some patients need to take synthetic liothyronine when that conversion process does not work properly.

Treatment with liothyronine, a different thyroid hormone replacement to levothyroxine, is often more effective in a minority of patients - either alone or in combination with levothyroxine - although the reasons for this are not yet fully understood. If levothyroxine does not resolve symptoms, then the addition of liothyronine is the only alternative.

Levothyroxine is the second most prescribed item by the NHS (2019).

Hypothyroidism is ten times more common in women than it is in men. In the UK, around 1-2 in 100 people have hypothyroidism. It most commonly develops in adult women and becomes more common with increasing age. However, it can occur at any age and can affect anyone.<sup>23</sup>

Studies indicate that 1 in 10 patients with hypothyroidism may only be returned to health by the use of liothyronine.<sup>24</sup>

## Liothyronine

When liothyronine was included in an NHS England consultation in 2017, as part of the medicines value programme work<sup>25</sup>, the consultation heard from a large number of patients and professionals about liothyronine and concluded with guidance that patients with hypothyroidism who require liothyronine, because it helps them and the standard treatment of levothyroxine has not worked, should continue to have it. Guidance from British Thyroid Association is included in the NHS guidance, stating clearly that patients deriving benefit from liothyronine should not have their treatment disrupted. Unfortunately many CCGs and the Regional Medicines Optimisation

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<sup>23</sup>

<https://patient.info/health/thyroid-and-parathyroid-glands/underactive-thyroid-gland-hypothyroidism>

<sup>24</sup> 2018 Study into patient satisfaction with treatments for hypothyroidism

<https://www.ncbi.nlm.nih.gov/pubmed/29620972>

<sup>25</sup>

<https://www.england.nhs.uk/wp-content/uploads/2017/11/items-which-should-not-be-routinely-prescribed-in-pc-cg-guidance.pdf>

Committee subsequently developed separate guidelines which either exclude or obscure the BTA guidance, causing patients to be denied treatment. The authors of The Liothyronine Dossier<sup>26</sup> in 2018 reviewed over 100 such separate NHS documents on this one medicine.

The Regional Medicines Optimisation Committee then helpfully clarified their guidance in 2019<sup>27</sup>, however a similar number of different local policy and guideline documents were still in existence in 2020 with 52% not in line with the national position<sup>28</sup>.

The NICE guideline for thyroid disease assessment and management NG145, published in 2019, does not make any recommendations for liothyronine, which is a specialist treatment, however the guideline is not intended to be comprehensive or to replace clinical judgement. NICE references the updated Regional Medicines Optimisation Prescribing Guidance published in June 2019, following the publication of the liothyronine dossier.

### **Cost**

CCGs have been seeking to limit prescribing of liothyronine since the cost increased by 6000% in the UK. Despite costing only a few euros in other European countries, the NHS is paying significantly more for reasons which are unclear<sup>29</sup> and the CMA investigation into the original sole licence holders is yet to reach it's conclusion despite finding them provisionally guilty of abusing their dominant market position.

### **Analysis of prescribing data**

An analysis of NHS prescribing data<sup>30</sup> by Dr Peter Taylor of Cardiff University's Institute of Molecular & Experimental Medicine demonstrates that UK prescribing of liothyronine has dropped dramatically in recent years, particularly in areas of the greatest deprivation.

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<sup>26</sup> Liothyronine – Case Details with Clear Evidence that NHS England Guidance on Prescription of Liothyronine is not Being Followed by CCGs [bit.ly/LiothyronineDossier2018](https://bit.ly/LiothyronineDossier2018)

<sup>27</sup> RMOC prescribing guidance

<sup>28</sup> T3 prescribing status report

<sup>29</sup> [6] 'Drug firm Concordia overcharged NHS with 6000% price rise, says watchdog,' The Guardian, 21 November 2017.

<https://www.theguardian.com/business/2017/nov/21/drug-firm-concordia-overcharged-nhs-with-6000-price-rise>

<sup>30</sup> Liothyronine cost and prescriptions in England Peter N Taylor, Salman Razvi, Ilaria Muller, John Wass, Colin M Dayan, Krishna Chatterjee, et al. The Lancet :January, 2019:[https://doi.org/10.1016/S2213-8587\(18\)30334-6](https://doi.org/10.1016/S2213-8587(18)30334-6)

# Annex C, Liothyronine Dossier

## Thyroid patients are being harmed by failures in prescribing of drug, liothyronine

A widespread failure of local NHS bodies to consistently follow national guidelines on the prescribing of a thyroid drug is causing harm to patients, says a significant report, published 26th November 2018. The report shows that liothyronine L-T3, a drug used in the treatment of underactive thyroid (hypothyroidism), is not being routinely provided across the country to the people who need it.

The evidence gathered shows that vulnerable people have ended up with depression, diabetes, heart problems, weight gain, high cholesterol and exhaustion from having this drug either taken away or not prescribed in the first place. The case studies also show people being unable to work and trying to find ways of funding the drug privately.

This is all despite NHS England approved guidance from last year stating that liothyronine should be provided to those who really need it.

The report, which was requested by the Department of Health, has been produced by a consortium of thyroid patient organisations, with guidance from the British Thyroid Association – the UK’s body for thyroid specialists.

The organisations received over 400 patients’ stories that showed how local NHS Clinical Commissioning Groups are not following the national NHS England approved guidance.

Patients who have had liothyronine withdrawn said,

“Like thousands of other UK patients, I cannot have a prescription for T3 from my GP or my endocrinologist. I am left in a frightening place.”

“Life without liothyronine for me is no life at all.”

“I feel completely abandoned by the National Health Service.”

The report – “Liothyronine – Case Details with Clear Evidence that NHS England Guidance on Prescription of Liothyronine is not Being Followed by CCGs”, follows the House of Lords debate led by Lord Hunt of Kings Heath, when Lord O’Shaughnessy, Parliamentary Under-Secretary of State for Health and Social Care, requested clear evidence that NHS England Guidance is not being followed by CCGs. The report was handed to NHS England who subsequently met with patient representatives and Healthwatch England agreed to revise prescribing guidance for liothyronine which has been adopted in some areas. However a review by The

Thyroid Trust in 2020 showed that at least 52% of CCGs are still preventing patients who require this treatment from being prescribed it.<sup>31</sup> .

Dr Krishna Chatterjee, Professor of Endocrinology and president of the British Thyroid Association stated in 2018, "The current uncertainty, with liothyronine-treated individuals either being denied ongoing prescriptions or needing to source the treatment themselves at their own cost, seems very much against patients' interests."

Lord Hunt of Kings Heath stated, "The evidence is clear that there are some NHS patients who need to have access to liothyronine. NHS England have accepted at a national level but the message just isn't getting through at a local level. It's not acceptable that vulnerable people are getting caught up in something that should have easily been avoided."

The authors have been calling for NHS England to exercise its formal powers to intervene on behalf of patients and ensure that those who need liothyronine have clear access to it through the NHS, regardless of which CCG they come under. To date this has not happened.

Liothyronine – Case Details with Clear Evidence that NHS England Guidance on Prescription of Liothyronine is not Being Followed by CCGs

[bit.ly/LiothyronineDossier2018](http://bit.ly/LiothyronineDossier2018)

NHS England guidance

<https://www.england.nhs.uk/wp-content/uploads/2017/11/items-which-should-not-be-routinely-prescribed-in-pc-ccg-guidance.pdf>

Also see British Thyroid Association guidance (linked to in the above)

<https://www.british-thyroid-association.org/current-bta-guidelines->

Regret Debate: Hansard: Branded Health Service Medicines (Costs) Regulations 2018 <http://bit.ly/2vPBSqs>

Hypothyroidism information and stats

<https://patient.info/health/thyroid-and-parathyroid-glands/underactive-thyroid-gland-hypothyroidism>

[5] 2018 Study into patient satisfaction with treatments for hypothyroidism

<https://www.ncbi.nlm.nih.gov/pubmed/29620972>

[6] 'Drug firm Concordia overcharged NHS with 6000% price rise, says watchdog,' The Guardian, 21 November 2017.

<https://www.theguardian.com/business/2017/nov/21/drug-firm-concordia-overch>

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<sup>31</sup> T3 prescribing status report

# Annex D, Example Scenario Data

## Thyroid Patients' L-T3 access issues reports

The below 87 anonymised patient reports have been submitted to The Thyroid Trust by people affected by thyroid disease via a form on the charity website, between January 2020 and May 2021, regarding experiences with L-T3 availability in their areas. 97% of respondents were women. The charity has not had the resource to further analyse or follow up with individual health authorities and NHS England have advised that due to the pandemic they are unable to even write to CCGs regarding the Regional Medicine Optimisation Committee's prescribing guidance, which is clear that liothyronine L-T3, should be prescribed on the NHS when it is recommended by an NHS endocrinologist. The likelihood is that many more women thyroid patients are being affected, forced out of the NHS to access the care they need, or simply left unwell if they don't have the resources to do this, some are resorting to treating themselves with medicine they are sourcing informally and all are being badly let down by our healthcare system which is taking no action to resolve matters.

The Area column is the first part of each respondents postcode

<b>Date</b>	<b>Have you been told by an endocrinologist that you need liothyronine, L-T3 for hypothyroidism ?</b>	<b>If No please specify why liothyronine availability is of interest to you</b>	<b>Area</b>	<b>What have you been told regarding liothyronine availability on the NHS in your local area?</b>	<b>How are you affected, if at all, by the situation regarding liothyronine in your local area?</b>	<b>If other please provide further information in the box below</b>
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01/16/ 2020 09:30 am	Yes	N/a	RM11	That it's not available in my area	Other	As I was prescribed before it was stopped I have seen a private Doctor who prescribed me T3
01/16/ 2020 12:06 pm	No	Levothyroxine is not changing any symptoms pre diagnosis 2 years ago despite dose changes. Full Thyroid panel testing won't be considered	G43	Too expensive will not get even if needed	Other	
01/18/ 2020 11:43 am	Yes		Gu21	That an increase in T3 is a private prescription. But my current dose which is not effective can only come from the Endocrinologist ccg	I am still being prescribed liothyronine but concerned about the future	

<p>01/25/2020 01:52 am</p>	<p>No</p>	<p>I suffer hypothyroidism even on high doses of T4. I have no thyroid due to thyca. I asked in Feb 2019 for a referral to see an endocrinologist and was refused. I asked for full blood tests including T3 and was refused. I saw my gp yesterday requesting a referral to see an endocrinologist and have been told I will be waiting a year. My hypo symptoms remain and some have worsened. I cannot work due to some of the symptoms including no</p>	<p>TN4</p>	<p>I suffer hypothyroidism even on high doses of T4. I have no thyroid due to thyca. I asked in Feb 2019 for a referral to see an endocrinologist and was refused. I asked for full blood tests including T3 and was refused. I saw my gp yesterday requesting a referral to see an endocrinologist and have been told I will be waiting a year. My hypo symptoms remain and some have worsened. I cannot work due to some of the symptoms including no energy, depression and anxiety. I have been suicidal. I am constantly run down and fighting viral infections every month.</p>	<p>Other</p>	<p>I suffer hypothyroidism even on high doses of T4. I have no thyroid due to thyca. I asked in Feb 2019 for a referral to see an endocrinologist and was refused. I asked for full blood tests including T3 and was refused. I saw my gp yesterday requesting a referral to see an endocrinologist and have been told I will be waiting a year. My hypo symptoms remain and some have worsened. I cannot work due to some of the symptoms including no energy, depression and anxiety. I have been suicidal. I am constantly run down and fighting viral infections every month.</p>
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		energy, depression and anxiety. I have been suicidal. I am constantly run down and fighting viral infections every month.				
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<p>01/29/2020 02:01 am</p>	<p>Yes</p>		<p>EH9</p>	<p>I received a prescription for Liothyronine with no problems at all yesterday ( 28/01/20). Last July (2019) I was living in England , postcode BH5 and also automatically received Liothyronine</p> <p>When my prescriptions were renewed - I had just moved there and fully expected the request to be rejected as had been the case when I was living at KT8 the previous 18 months where requests for Liothyronine had always been rejected.</p>	<p>Other</p>	<p>Recently returned to live in Edinburgh after a 2 years living in England. We moved to Edinburgh 2014 from Canada where I had been on prescribed dessicated thyroid for years. I saw a private GP in Edinburgh after being told I couldn't get Armour on NHS. About 3 years ago I saw endocrinologist Anthony Toft who understood my story and prescribed Liothyronine. However, I still could not get it on nhs and paid privately to have it. I found pharmacists who could import from Germany so cost was around £20 per month. Then moved down to Surrey where I was categorically told Liothyronine could not be prescribed. Moved again to Dorset and as I said, in July 2019 I automatically received it when I put in a request for a repeat prescription for all my meds. And, on returning to Edinburgh I was also able to get it automatically yesterday.</p>
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<p>01/30/ 2020 04:36 am</p>	<p>No</p>	<p>I am being tested for it (at my request after 11 years of asking) and finding out from privately funded testing that I actually am Hashimoto's thyroiditis and not just under active. Endocrinologist at Maidstone hospital said even if I needed T3 they would not prescribe</p>	<p>ME14</p>	<p>I have been told that even if my test shows that I need T3 they would not be able to prescribe due to cost and that it is not licensed in this country, and that I could get it myself on the internet or abroad but this is not regulated</p>	<p>Other</p>	<p>Awaiting test results for T3. Had to persevere to actually get test for T3 after synacthen test for adrenal fatigue came back negative. Also explained that most people under active are hashimotos and after explaining that I had been gluten free for 18 months the endocrine doctor at Maidstone hospital said not enough evidence to prove gluten free was effective which I wholly disagree with. All the research and information I have has been privately funded or sourced by myself or a naturopath. I have zero support or info from NHS GP</p>
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02/03/ 2020 12:59 pm	Yes		BS31	<p>In Bristol at the BRI they are refusing to accept referrals for hypothyroid patients, as they say they don't treat with liothyronine and the condition should be managed by a GP with levothyroxine.</p> <p>I am able to get liothyronine from Bath and NE Somerset CCG because of the intervention of Jacob Rees Mogg and a private endocrinologist. The battle was very tiring, especially for a sick person.</p>	I am still being prescribed liothyronine but concerned about the future	
02/03/ 2020 01:19 pm	Yes		HP11	Told by GP last week that Buckinghamshire CCG no longer funding Liothyronine as no evidence that it works. Am waiting to hear back from endocrinologist who	I am still being prescribed liothyronine but concerned about the future	

				prescribed (last appt was Nov 19) for clarification		
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02/03/2020 01:19 pm	Yes		SE10	<p>From last email from endocrinologist who treated me on NHS, but then they said they couldn't see me again, so I saw her privately instead.</p> <p>"The endocrine units of many NHS trusts (including King's College Hospital) do not have a dedicated budget to take on/over long term prescribing of liothyronine if a patient's GP was no longer prepared to prescribe it.</p> <p>If a patient's GP is prepared to continue prescribing liothyronine provided that there is documented support from the thyroid team, this is more straightforward</p>	I am still being prescribed liothyronine but concerned about the future	
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				<p>situation to manage and assist with. I can see you privately on Friday afternoon (August 9th) at 3pm if that would be helpful (?)</p> <p>After this second review, I was allowed to continue 20mcg liothyronine per day....</p>		
02/03/2020 01:32 pm	No	I'm not doing well on levothyroxine alone	Se6	That it is not available for me. And GP want my endocrinologist to prescribe and The endocrinologist want the GP to prescribe so nobody want to take responsibility while I'm suffering waiting for something to change	Other	Not been prescribed

02/04/ 2020 12:31 am	Yes		lp2	I've been prescribed it, but was very unwell, but because I demonstrated a 'clinical benefit' I get it. It has changed my life.	I am still being prescribed liothyronine but concerned about the future	I would not be able to work or be an economically active member of society without it. It may be expensive, but they can have someone claiming benefits at £317 a month, or they can provide me drugs at £200 (?) a month so I AM able to work. literally 75% of my health problems are improved with it.
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02/05/ 2020 12:56 am	No	I took levothyroxine for 20 years, never felt well but coped, then got progressively worse until bed bound for 80%of time. Heard about Liothyronine and excited rushed to GP only to be told there is only one treatment for thyroid-levothyroxine and was ordered out of the room. Have since carried out my own research and self medicate with Liothyronine bought on-line, now feeling quite well!	WR4	Not available. Have been told by others who have seen local endocrinologist that wouldn't even discuss it	Other	Never been able to even discuss treatment with Liothyronine with anyone, I buy Liothyronine on-line without a prescription
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02/05/ 2020 09:26 am	Yes		CA1	I have NDT prescribed through a NHS endo in Yorkshire	Other	I am prescribed NDT. I was initially prescribed in jail and never expected T3 my endo told me about all the letters going out not to prescribe T3 so was happy to prescribed NDT GP willing he said . Fortunately was a good GP and i'd doctor shopped at home prio for one willing to accept a specialists advice.. Prior to that i self medicated with NDT and have never had to try T3 alone but i also get side effects from T4 so that could never be an option
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<p>02/06/ 2020 03:09 pm</p>	<p>No</p>	<p>Working on behalf of someone else</p>	<p>WS3</p>	<p>Lorraine,  Tara has asked me to report that today I had a foi response from Betsi Cadwaladr Health Board which covers North Wales. I had asked if their 'red' status of liothyronine in 2015 had changed. Today they said that T3 is only being used in Thyroid cancer.  Linda,  ITT Campaign</p>	<p>Other</p>	<p>Hi, Lorraine,  I was helping an ITT member out by requesting information about liothyronine availability in North Wales.  Linda  ITT Campaign</p>
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<p>02/07/2020 08:16 am</p>	<p>Yes</p>		<p>TR27</p>	<p>My GP wrote me a letter on 6th January saying</p> <p>"T3 (liothyronine) is no longer available through the NHS. This is a local policy which applies to prescriptions from GPs and from NHS endocrinology clinics. It is supported by NationalNHS recommendations..... T3 therapy is much more expensive than levothyroxine...The decision is based on insufficient evidence of cost effectiveness of T3 treatment"</p>	<p>My prescription has been stopped and I don't know what to do</p>	<p>I was prescribed T3 over 20 years ago by an Endo because I was very ill on T4. I have been well on T3 until this decision that T3 will not be prescribed in the future. My GP doesn't seem to know anything about thyroid disorder. He prescribed thyroxine and said he will increase this and reduce T3 until I am no longer on T3. The thyroxine made me really unwell and I came off it due to liver pain, exhaustion, breathing problems, mood swings, chest pain, depression and feeling like I'm going to die. My T3 is running out and I will probably face a slow death because I am elderly and can't afford to pay privately.</p>
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<p>02/07/2020 10:37 am</p>	<p>No</p>	<p>My current T3 level is under the normal range and my daily life is highly effected by how I feel physically.</p>	<p>NR4</p>	<p>I asked a GP at my surgery about my T3 being under range and what could be done and was told there was no medication available to help with this available. I was also told that they only looked at the TSH result.</p>	<p>Other</p>	<p>I feel my results are not being considered properly due to the fact doctors are unable to prescribe medication to help patients. They know the medication exists but are not able to use it to help people. When people are able to buy this medication abroad for pennies it seems unbelievable the NHS are being held to ransom by pharmaceutical companies.</p> <p>I don't feel the condition of having this autoimmune disorder is being taken seriously enough and how unwell some patients can feel.</p>
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<p>02/08/2020 06:00 pm</p>	<p>No</p>	<p>I felt very unwell on Levothyroxine even after two years of being optimised on it. In desperation I started taking NDT after discovering Levothyroxine was not my only option - this information was never mentioned to me by the endocrinology department I attended who told me my blood tests were not quite normal and I would just have to accept I would never feel well again. Well I did start to feel well again almost immediately after starting NDT. In fact I became fully better again. I</p>	<p>CB4</p>	<p>I understand that Addenbrookes (my endo was Guys but I since moved to Cambridge) are totally against T 3 and NDT and have refused to treat anyone who self medicates on NDT - I presume they'd have been happier for me to have committed suicide on T4 than be proactive and regain my life on NDT. What right have they got to treat people like this who have worked hard all their lives paying NI contributions but once ill are denied any options (even with decades of asking if the health issues I had were thyroid related with a very compelling family history of the disorder and considerable ill health and premature death</p>	<p>Other</p>	<p>I simply will never be able to get a chance to be prescribed it, despite having a genetic reason to require it and blood test to back up my need for it. I am forced to continue to self medicate on NDT if I can get hold of it or I will have to go back to T4 monotherapy and be a disabled burden to society for the rest of my days. I was suicidal on t4 monotherapy I became utterly incompetent at work and lost my job I felt like a thing not a person I had no quality of life, in fact my life was not worth living in that condition and I wished that I had never been treated and had died if this was what I was left with. These are stressful things to have hanging over you all the time. I have gone through enough with my health. I don't need any more of it. I should not be victimised for choosing to be well, or denied support and correct treatment for my</p>
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		<p>have also discovered I have a poor converter status with my DIO2 gene and I have a gene for thyroid resistance. I should have been offered a trial of T3 but left to rot in levothyroxinr by theNHS which had already allowed my hypothyroidism to go undiagnosed for decades to the extent that I almost died of it. Now I am caught self medicating with zero support from the NHS with the added stress of unreliable supplies of NDT yet the NHS have more or less banned T3 prescribing since my diagnosis</p>		<p>relating to it yet being told they were not, and foolishly believing them to know what they were talking about and that is doctor after doctor who just blamed the menopause or saw each symptom in isolation never getting the bigger picture I have permanent problems as a result of being hypothyroid for so long before treatment commenced which were not of my making). It means there is no way I can even get a chance of being given a T3 trial I am forced to buy medication on the internet it is a darn disgrace I feel utterly cheated by a bunch of incompetents</p>		<p>condition on the NHS</p>
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		when I could have got it. I think I deserve a trial of T3/T4 after all what I went through and because I am unable to ever be well on levothyroxine alone. The NHS have really failed me big time with this disorder.				
02/09/2020 02:32 pm	Yes		SW19	That it's only available on private prescription	My NHS prescription has been stopped and I am now buying liothyronine from overseas or the internet without a prescription	

02/10/ 2020 05:58 am	No	I lived in Greece for 15 years - moved back last Sept. GP prescribed T3 due to consistently low levels. Then bought OTC for Euro 1.20 - 30 x 25mcg. Have been on T3 for many years.	EX39	We do not prescribe T3 - end of !	Other	Have recently registered with local GP and told NO T3. GP happy for me to self-medicate with T3 from abroad.
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02/10/ 2020 11:46 pm	Yes		BT	GP says it is unlicensed in the UK so cannot prescribe.	I am still being prescribed liothyronine but concerned about the future	I have to attend a private endocrinologist and obtain T3 from an on-line pharmacy. I did price with my local pharmacy and it would have been £200 per month. I did source T3 in Republic of Ireland initially but that was euro 100 for 100 tablets. I can't really afford to keep attending a private endocrinologist and paying for medication but don't seem to have any choice in the matter. I do feel so much better with 20mcg T3 added to 150mcg Levothyroxine.
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<p>02/11/2020 11:00 am</p>	<p>Yes</p>	<p>He said in light of chronic exhaustion and cognitive issues. Inability to maintain health to work.</p>	<p>YO32</p>	<p>Literally fobbed off 10 times since March 2019 by Specialist thyroid nurses, GPS and thyroid surgeon. Had thyroid removed 2017 due to 4cm thyroid cancer and had radiation. Health deteriorated March 2019 after being over medicated on T4 for many months. Was told T3 bloods were not necessary to test and they tell you nothing important about your thyroid levels. After educating myself I pushed eventually in May 2019 for a T3 test. I found I was low end T3 and even though I was over medicated on T4, and very symptomatic, I was refused T3 bloods again until November 2019, when I begged for a repeat</p>	<p>Other</p>	<p>Not been offered T3/liothyronine despite low levels of T3 and conversion issues despite high T4 levels over the last 10 months. Told T3 is nothing to be concerned about. That the NHS don't test T3 as it's not of any use, even if it's low. That it's TSH that matters. Refused access to Endocrinologist on the NHS. Refused access to thyroid ent consultant who did my thyroid removal even though I was very poorly. I was told I had to wait for my yearly review March 2020. Told my symptoms must be something else? I've been to a cardiologist and immunologist who say my thyroid medication is the concern. But no one will listen. I'm exhausted fighting this. I've raised an initial complaint with my CCG and I'm thinking of going to my MP. I would love to talk this over as I feel so isolated.</p>
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			<p>test, as I was chronically tired, suffering physically mentally and cognitively. T3 had reduced to 3.2, lowest number in normal range but T4 was 4 over top normal range, that is hyper, to me pointing to conversion issues. I was refused access to an Endocrinologist and to see thyroid surgeon numerous times. I was told something else must be causing my symptoms, even though my bloods showed otherwise. They told me to see a cardiologist who confirmed my fatigue and rapid heart beat, sweating was almost certainly thyroid related and he personally advocated a reduction in T4.</p>		<p>Thought getting the all clear was the end of the struggle but it was just the start of the lies, battling against nhs primary and secondary levels and even Macmillan nurses. I believe it's the costs of liothyronine and all the politics of that go along with that is preventing me accessing T3 and a chance to be well again</p>
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				<p>Concerned about possible regrowth of cancer and thyroid tissues due to hyper levels continuing even with 4 lowered T4 doses, between May to Dec 2019, no one offered a Thyroglobulin test so had to go back to Leeds nuclear team, who signed me off in 2018 in October 2019 in desperation to be told I should have been offered Thyroglobulin Test and access to an Endo due to weird hyper levels and low T3.</p> <p>Eventually feeling so poorly for months, after losing my business and having return to my family to be cared for. I went private to the Nuffield in York in Jan 2020 to see an Endo. He says my T3 is historically low and I</p>		
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				could be considered for combination therapy but put the proviso that I try HRT first, which I've tried before. Again on a second attempt on HRT in January 2020 I've reacted very badly to the progesterone element. I don't know if this is another delaying tactic tbh. I've reported my HRT issue to him and I'm getting more bloods this Friday. I feel like I'm fighting a battle.		
02/11/2020 09:06 pm	No	Because I still suffer symptoms after 3 years of levothyroxine treatment. My doctors do not do a t3 rest at all	SW1 4	Nothing	Other	My doctors won't even acknowledge that T3 is an issue...

<p>02/19/2020 01:27 am</p>	<p>Yes</p>		<p>BA11</p>	<p>ENDO CONFIRMED TO MY GP SHE WILL NOT BE PRESCRIBING FOR ANY NEW NHS PATIENTS DUE TO CCG ADVICE I BELIEVE.</p> <p>Myself : SOMERSET GP has been prescribing Sanofi Aventis cynomel since 2013 on advice of Royal United Hospital endo after problems with consistency of UK version. Sanofi not available from two pharmacies since Nov 2019, GP has issued two prescriptions each for one month only. The first was fulfilled with a mix of Morningside and Mercury. I am waiting for the second. GP</p>	<p>Other</p>	<p>See above: I believe my NHS scripts will end shortly and so have ordered Tiromel online as I cannot face being back in bed after years of struggling to get correct treatment protocol.</p> <p>I found correct treatment after extreme illness through self funding and establishing I was better with NO levothyroxine AT ALL as I do not convert or cells do not receive. I had self sourced Grossman cynomel for those trials.</p>
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				<p>says he will continue to prescribe until we have a "fix" but can't continue as Red listed. I gave him the RMOG guidelines and stated clinical need. Endo has offered to write private script to take to Germany or France and GP has done the same.</p>		
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02/29/ 2020 12:15 am	Yes		G82	<p>I live in Scotland - The NHS Greater Glasgow &amp; Clyde area. I eventually went private to Professor Toft. He agreed I need T3 &amp; advised my GP. I was given 5mg of T3 after less than 6 weeks my GP said it wasn't working &amp; would stop it. 5mg of T3 was not enough for me I now source NDT &amp; I am on 5 grains a day &amp; to be honest I think I could still up this amount to feel even better.</p> <p>I am now back at work &amp; starting (slowly) to lose some weight. I am never going back to T4.</p>	<p>My NHS prescription has been stopped and I am now buying liothyronine from overseas or the internet without a prescription</p>	
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03/14/ 2020 01:26 am	Yes		CR8	in 2017 CCG STOPPED my prescription (after 5 years of me receiving it from my GP on repeat) without my consent, against my NHS endocrinologist advice and forced my GP 'not' to prescribe. They 'forced me' to see a 'local' NHS endocrinologist (I have been under NHS endocrinologist care but not in my local CCG area as I am not a 'straightforward case'), once I broke under their unethical demands and I went to see a local endo, she prescribed for me for 18 months then she was forced by her hospital pharmacy to say that she can no longer prescribe....at present I seem to have convinced her to keep	Other	as above
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				<p>prescribing (as I was threatening to take 'legal action against the CCG), however the CCG is still stopping my GP from prescribing and I have to go to the hospital each time for a prescription which is impacting severely my life, they are not yet reinstating it as a repeat from my GP surgery! I am still seeking a lawyer to take this to court as I am planning on moving to another part of England but I live IN FEAR of having to battle again for my prescription if I chance CCGs, IT IS UNETHICAL and puts my life in danger each time that I move within the UK to have to fight for my life saving medication as I cannot</p>		
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				take T4 only T3.		
06/01/2020 05:26 am	Yes		SN3	An NHS endocrinologist at John Radcliffe recommended that I should take T3 in combination with levothyroxine. The cost of hello my GP initially prescribed it is now reluctant to continue it due to cost and said he cannot get involved in the management of the dosage which is really unhelpful. I am unable to take levothyroxine on its own due to emotional side effects I'm now contemplating getting in touch with nice as I understand that if I endocrinologist prescribes it the GP cannot stop it. Hps do not even give patients the option of this combination and is	I am still being prescribed liothyronine but concerned about the future	This is the only combination of medication that helped me in the past 16 years and I am really frightened that the GP has a power to stop this due to cost

				really unfair and I wonder how many other people in the UK are suffering		
06/25/2020 10:25 am	Yes		Br3	I have been told that it cannot be prescribed.	My NHS prescription has been stopped and I am waiting to see if levothyroxine only will agree with me	

07/02/ 2020 01:45 am	Yes		BS24	I was prescribed Liothyronine from 2014 to 29th May 2019 when my consultant told me that the CCG had withdrawn Liothyronine and he wasn't allowed to prescribe it any more with immediate effect. He said the reason was the cost of it. He agreed I still needed it but there was nothing he could do	My NHS prescription has been stopped and I am now buying liothyronine from overseas or the internet without a prescription	I complained about my treatment in June 2019 and am still waiting. The hospital say they have written to the CCG about my Liothyronine prescription but I haven't been allowed to see copies of what they wrote, nor have they had a reply. It's over a year since my medication was stopped abruptly. A shameful way to treat patients
07/21/ 2020 07:18 am	Yes		nw1	My endocrinologist at UCLH has suggested a trial of T3 but cannot prescribe it, nor can my GP. The endo suggested buying it myself	Other	I am trying to find an unofficial source of T3 to start a trial which the uclh will monitor.
07/21/ 2020 09:17 am	No	Yes	ME5	Nothing	I am still being prescribed liothyronine but concerned	

					about the future	
07/21/ 2020 11:15 am	No	Because I have not been told I could try it	Cb23	Nothing	Other	Never offered alternative
07/21/ 2020 11:33 am	Yes		Nw3	not available as not effective.	Other	I have never been prescribed it.

<p>07/25/ 2020 02:39 am</p>	<p>No</p>	<p>It's my doctor who has refused anything apart from levo. Not a good surgery in the first place, all about costs and not the patient. They even turned round and said, so you're refusing treatment, my TSH is 32 and I've been left with nothing, I'm house bound for 15 years with chronic pain before my thyroid packed in.</p>	<p>Pr2</p>	<p>I've just been told that nothing else is available, only levo!</p> <p>Which I can not tolerate after trying all brands, I couldn't move off the sofa I was that Poorly.</p> <p>My surgery hasn't even followed me up or checked anything to do with my health or thyroid since August last year.</p> <p>They just passed the buck saying so you are refusing treatment.</p> <p>Scared of arguing with them in case they strike me off.</p>	<p>Other</p>	<p>They refused anything else apart from levo</p>
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08/03/2020 01:53 am	Yes		TA4	Not available - by any means	Other	<p>Made thyroid-less by the NHS 42 years ago - at age 37. First daughter also thyroidectomy at age 37. Second daughter 'required' thyroidectomy at age 37. Saving the thyroid was paramount, so self-medicated 2nd daughter with NDT plus T3, with help from consultant (now deceased). She's doing well - swelling subsided - no pressure on trachea, but bloods would be useful.</p> <p>No help whatsoever from Somerset CCG or Coventry CCG - alternatives to T4 are banned by both.</p> <p>For the last 20 years I buy what we need from Germany and Mexico (following a fight for the private prescription required for Germany) and treat the cost as part of the food bill - it keeps us alive.</p> <p>I try to source all thyroid medication, and the girls fund</p>
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					<p>their own supplements; it is very expensive but I feel responsible they have inherited thyroid disease.</p> <p>I was around and researching long before the current Groups were formed. During that time we have lost our 2 best Consultants and things are getting much worse. We have neither monitoring nor support from 'our NHS'.</p> <p>Times when there are shortages and unavailability of either NDT or T3 are very stressful - continuity of supply would be a good start.</p>
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<p>08/05/2020 07:11 am</p>	<p>Yes</p>		<p>ST20</p>	<p>I asked for a referral from my home in Staffordshire to an NHS endocrinologist in Sheffield who had been recommended to me. This was because of continuing hypothyroid symptoms.</p> <p>The endocrinologist advised that I would benefit from T4/T3 combination therapy and recommended a trial but said that he was unable to prescribe T3 as it was blacklisted in his area. He wrote to my GP to ask if he could prescribe it. My GP contacted his CCG (Stafford and Surrounds) and they have refused it.</p>	<p>Other</p>	<p>My prescription has never started and so I am continuing on T4 monotherapy with hypothyroid symptoms. I will have to see the Sheffield endocrinologist privately if I wish to have a trial of T4/T3 - and then pay further if I wish to continue with T4/T3.</p>
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08/17/ 2020 05:08 pm	No	My NHS Endocrinologist has, after lots of testing,ruled out any other causes for my symptoms and has the suggested that it would be worth me trying T3 but that he could not prescribed it on the National Health. My GP has told me flatly that it can not be prescribed in East Sussex.. I have contacted a private endocrinologist since then to find out what my options are. He feels that I could benefit from starting with a very small dose..He was very thorough in his talk about	TN22	That it is not prescribed on the NHS in this area.	Other	I am having to consider going privately and possibly improving my life or staying as I am. I am 60 this year, unemployed, looking after my adult son who suffers from M.E.  Sometimes it is like 'the blind leading the blind'.
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		safety and side effects etc. The costs that he has told me would make this very expensive.. underlying				
08/19/2020 02:10 am	Yes		AL2	I have been told that I am clearly benefiting from taking T4/T3 combination therapy by my private endocrinologist. I have bought a 6 months supply of T3 medication initially as a trial and was told I will be referred to NHS endocrinologist /the same person my private endocrinologist/ who saw the benefits of combined therapy. He prescribed the T3 on the NHS , but it never went through and it was declined in the pharmacy. So I can't see the light in	My NHS prescription has been stopped and I am now buying liothyronine from overseas or the internet without a prescription	

				the end of the tunnel.		
09/02/ 2020 04:10 am	Yes		dy13	apparently gp can't prescribe, not sure if is cost or not allowed too. Pharmacy now able to source but had to drive all the way to hospital & gp reluctant to prescribe & only wants consultant too.	I am still being prescribed liothyronine but concerned about the future	
09/05/ 2020 09:49 am	Yes		GU4	That it is not available on the NHS. I have seen an endocrinologist and spoken to various GPs and no-one will prescribe it to me.	Other	I have been buying Natural Dessicated Thyroid from Thailand. But now that has stopped. They have also hiked the prices up from £35 for a 1000 to (and in some cases) £300 for 500.

09/06/ 2020 12:08 am	No	Because T4 hasn't worked for me since 2004	PO2	That it is not available on the NHS.	Other	Am only prescribed Levothyroxine and it has done nothing for symptoms,and just added more.  Just started LDN,waiting for my MP to investigate why i have been refused by arrogant Endospecialist and GP controlled by Portsmouth CCG.
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09/06/ 2020 08:19 am	Yes		CB24	My GP has told me that he is unable to prescribe Liothyronine as the CCG has told him that they will not fund it as my case is not exceptional enough.	Other	I have been sourcing Liothyronine myself since it was prescribed by a private endocrinologist in 2015. In 2019 my then NHS endocrinologist decided that I should be prescribed Liothyronine on the NHS as I am intolerant to Levothyroxine. I have tried all available brands of Levothyroxine including liquid Levothyroxine and it causes uncontrollable itching from head to toe and this is just unbearable as it is constant. Last year the endo wrote to my GP requesting that he prescribe Liothyronine for me on the NHS. The practice partner contacted Cambridge and Peterborough CCG asking that I be allowed a prescription as an exceptional case but they refused. My GP has since given me a private prescription for Liothyronine which I send abroad as it is so much cheaper there. I can
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						not afford to buy it in the U.K.
09/12/ 2020 02:06 pm	Yes		Ex14	My surgery will not prescribe it. - Devon CCG	Other	I saw a private endocrinologist who prescribed me T3 though when I asked my gp to prescribe it they refused.
09/17/ 2020 12:37 am	Yes		AL2	Even tho it was prescribed by NHS Endocrinologist ,hospital pharmacy declined the request and told me it wasn't approved.	My NHS prescription has been stopped and I am now buying liothyronine from overseas or the internet without a prescription	
09/28/ 2020 02:59 am	Yes		HU12	every month it is a problem getting my prescription, this month it has been 10 days since the pharmacy had my prescription	I am still being prescribed liothyronine but concerned about the future	

<p>10/05/2020 02:01 pm</p>	<p>Yes</p>		<p>TA10</p>	<p>I asked my endocrinologist today by email if he refer me for funding ( previously refused 2017/18) his reply The problem is in Somerset that the CCG won't pay for Liothyronine and thus if a GP decides to prescribe it, it creates a significant hole in their prescribing budget</p> <p>When I have done applications to the evidence based intervention committee, funding has been declined even if there is evidence of symptomatic benefit. This is different from Devon CCG for instance</p>	<p>Other</p>	<p>My doctor provides a private prescription for Cynomel but the chemist in France has said it can no longer prescribe prescriptions from non European countries so I now have 2 months of t3 outstanding and only a small amount to use</p>
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10/12/ 2020 03:50 am	No	I have had RAI treatment am now hypo and Iâ€™ve just been left My endocrinologist and gp wonâ€™t even test or discuss T3 with me at all !!!	SG12	Nothing. They won't even discuss it !!!	Other	Won't even discuss whether I need it or not. Won't even test for it
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<p>10/13/2020 10:47 am</p>	<p>Yes</p>		<p>TF11</p>	<p>My private endocrinologist advised in January 2020 that I would be a suitable candidate for referral for a therapeutic trial of T3. I heard nothing further from my GP and the letter sent to them was ignored!</p> <p>Giving them the benefit of the doubt due to Covid lockdown issues, I have recently started chasing my GP again for at least an acknowledgement of this request.</p> <p>Today, I received 2 letters in the post. The first confirming that I had finally been referred and that an</p>	<p>Other</p>	<p>I have never been prescribed T3 but have read extensively about the benefits it may provide when taken carefully alongside thyroxine.</p> <p>I underwent a full thyroidectomy 3.5yrs ago and have never felt myself since, suffering many of the usual symptoms and piling on weight, despite not changing usual habits.</p> <p>I find the whole GP experience surrounding anything to do with thyroid incredibly frustrating and so unfair!</p>
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				<p>appointment would soon follow, the second states the following..</p> <p>“...Referrals are not being accepted for initiation of T3, as per advice from the CCG as there is currently no agreed local pathway for its initiation.... “</p>		
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<p>10/19/2020 08:51 am</p>	<p>Yes</p>		<p>CV35</p>	<p>My GP has refused to prescribe T3 for me saying it must be prescribed by an endocrinologist. I have had it prescribed by an endocrinologist for some years now but the guidance says that the GP can continue to prescribe once the medication is initiated by an endocrinologist and this is not being adhered to. My endocrinologist has written to my GP asking them to take over prescribing for me but this has been ignored.</p>	<p>I am still being prescribed liothyronine but concerned about the future</p>	<p>I am obtaining a prescription from my endocrinologist but as the hospital will only dispense one brand of drug which doesn't suit me, I am forced to fill my NHS prescription privately from an online pharmacy in Germany. This costs me in the region of Â£200 per 3 months' supply.</p>
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10/19/ 2020 11:01 am	Yes		BS32	Not available from my GP even during lockdown and inability to see my Consultant Endo - suggested referring me to see NHS Endo and no idea how long that could take when I run out of medication.	Other	<p>I pay privately for it and have to buy it from Germany. I am worried what will happen with Brexit and whether I can continue to purchase it (I am fortunate enough to be able to pay for it and would happily pay the same in the UK) and what will happen to the cost.</p> <p>This deeply worries me as I feel like I have some sort of life taking combined T3 &amp; T4 because on T4 only I cannot and will be a burden on society and I worry how it will affect me.</p>
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10/26/ 2020 01:46 am	Yes		TA1	I have been advised by Boots the chemist that my regular prescription of 5mg by sigmapharm Greek letter e18 is no longer obtainable and as I had severe problems in the past this is the greatest worry	Other	My GP has stipulated the brand but Boots have been supplying Morningside which made me unwell to say the least
11/02/ 2020 01:21 pm	Yes		Mr20	Not available and to get it from Germany	Other	I've had to see a private doctor as been so I'll and progressively getting worse , private blood tests show I have hashimotos and recommended t3 along with levo I'm being prescribed on NHS . Unfortunately I'm having to buy from Germany which makes me feel very uneasy
11/05/ 2020 01:47 pm	Yes		Nn9	Too expensive and they can't prescribe	Other	Would not prescribe in the first place and told to but on the internet

11/14/ 2020 08:33 am	No	I have sinusitis, weight gain and swollen fingers on levothyroxine	bh24	Not available, resistance to having full set of thyroid blood tests and told not well tolerated and cardiotoxic	Other	Never been allowed to try it
11/30/ 2020 07:53 am	No	I have all the symptoms of underactive thyroid	B72	It is not available and IMO ky on the cusp but I e been on the cusp for years	Other	I plan to ask GP for private prescription
11/30/ 2020 11:15 am	No	My gp won't refer me to an endo because my tsh levels are fine	S10	It is not available. Referrals to an endocrinologist would have to be private. And no evidence to say t3 works.	Other	I am still getting hypo symptoms only on levothyroxine and blood levels of tsh normal

<p>12/04/2020 02:32 pm</p>	<p>No</p>	<p>Self source unable to tolerate synthetic T4</p>	<p>JE3</p>	<p>“We’re not allowed to prescribe Liothyronine here”</p> <p>Me: but NICE guidelines state 3 mth trial/not to remove ppl already doing well on t3, who are still symptomatic on T4 only..</p> <p>Reply: We don’t follow NICE guidelines. (Jersey)</p> <p>- oh but i think they do, go figure.</p>	<p>Other</p>	<p>Failed to tolerate T4 &amp; had reactions to all brands, it was assumed I was non compliant. Which I wasn’t, got fed up of not being helped so self sourced</p> <p>NDT &amp; T3 online. I’m now optimal &amp; need a high dose (6grain +20mcg T3 )so it wasn’t that I was not compliant, it just wasn’t high enough ... plus the issues T4 (synthetic) itself caused.</p> <p>I can no longer source this NDT, and can’t afford the dose of T3 I’d need if I switched to T3 only (150mcg) when it runs out who knows, I was on the verge of myxedema coma on T4 treatment with a TSH of 227.0 Ft4 0.4 Ft3 1.1 &amp; TPO 1110. So guess the option is to go back to that, get hospitalised &amp; given Lio in hospital ? Being the treatment for that stage of severe hypothyroidism.</p>
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<p>12/07/2020 07:07 am</p>	<p>No</p>	<p>I suffer from MECFS. I follow latest biomedical research very closely and there is strong evidence of hypometabolism. There is also evidence of suppressed T3 even in the absence of standard hypothyroidism diagnosis. Many patients significantly improve on T3. I received T4 on prescription but it wasn't enough. I now have to buy my own T3 abroad. It does help</p>	<p>BN11</p>	<p>Categorically not allowed to prescribe</p>	<p>Other</p>	<p>I have never been given a prescription. I had to purchase it myself because my life is so bad.</p> <p>I have very clear hypothyroid symptoms. My T4 and T3 were right at the bottom of the range with a normal TSH. My hair was falling out in clumps. I've gained weight. I tick so many of the symptoms for hypothyroidism. It is evident that my thyroid function is very low. The current system excludes patients like me and forces me to take things into my own hands.</p>
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12/08/ 2020 11:53 am	Yes		ka12	I was only started on it a year ago, after over 20 years of saying t4 didn't work. Due to Covid haven't seen endo or GP so nothing has been said.	I am still being prescribed liothyronine but concerned about the future	
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<p>12/21/2020 12:57 pm</p>	<p>Yes</p>		<p>PR9</p>	<p>Endocrinologist is refusing on cost grounds, but has asked the GP to prescribe, even though he recognises that I need this medication to function.</p> <p>GP is refusing because they don't have any one else on this medication and they don't know enough about it.</p> <p>Endo has written four times to the GP now and they are still refusing to prescribe.</p>	<p>Other</p>	<p>I continued to be symptomatic when taking levothyroxine, and had a private DIO2 gene test. I was positive for the defective gene which inhibits conversion of T4 to T3, after speaking to my endocrinologist I was encouraged to buy my own Liothyronine which I have been doing for 18 months but my financial circumstances have changed since the covid pandemic began and I also would like my medical needs to be acknowledged by the NHS.</p> <p>As I require this medication, which is completely supported by my endocrinologist, I feel that it should be available to me on the NHS.</p>
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01/07/ 2021 12:45 pm	Yes		NG4	My Endocrinologist is in Coventry, I am in Nottingham. My Endocrinologist agreed to a 3 month trial but said he wouldn't be able to prescribe any more regardless of any health improvements. He said he can't understand why NHS will not agree to treatment. My local CCG say Liothyronine is not available on NHS.	My prescription has been stopped and I don't know what to do	
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01/14/ 2021 08:47 am	Yes		La4	<p>I was told by my consultant about a year ago that he is now able to request of my GP liothyronine on prescription again. I have been buying it myself from a reputable pharmacy in Germany since it was taken off the nhs list a few years ago. I continued to source it myself as I felt it my moral obligation to do so as it only costs me Â£45 for three months and I can afford that but I still can't afford the cost of buying it privately in the uk.</p> <p>However I have just received my last packet of 100 tablets from Germany as they will no longer be able to use a private prescription from the uk as we are no longer</p>	Other	<p>As above I have received my last prescription via GP private prescription from Germany today. Now I will go back to the consultant.</p>
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				in the eu. So now I will ask the consultant to sort it out on the nhs or fight again...		
01/15/2021 12:24 pm	Yes		DE75	It cannot be prescribed	Other	I have been told even though it may be of help to me by my endocrinologist it is not allowed to be prescribed. He told me that people who have a prescription for it will be refused it in future
01/15/2021 12:24 pm	Yes		DE75	It cannot be prescribed	Other	I have been told even though it may be of help to me by my endocrinologist it is not allowed to be prescribed. He told me that people who have a prescription for it will be refused it in future

01/24/ 2021 12:03 am	Yes		BB7	That the local CCG will not allow GPs to prescribe it due to cost	My NHS prescription has been stopped and I am now buying liothyronine from overseas or the internet without a prescription	This is now prevented due to Brexit and my supply chain has ceased leaving me in crisis.
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02/06/ 2021 04:59 am	Yes		PO7	<p>I was really unwell on only Levothyroxine and GP wouldn't prescribe Lyothyronine. In fact, she suggested reducing my Levothyroxine. I made an appointment to see an endocrinologist privately and was prescribed (NHS) a combination of Levothyroxine and Lyothyronine two years ago. The Levothyroxine has since been increased and I feel well. However, the endocrinologist believes that unless I am reviewed on a six monthly basis, and the recommendation is I continue to be prescribed Lyothyronine, the GP is likely to stop the prescription due to cost.</p>	<p>I am still being prescribed liothyronine but concerned about the future</p>	
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02/12/ 2021 10:18 am	No	4yrs on T4 yet heavy symptoms persists.	Eh17	It's not Available in Edinburgh, no endocrinologist will issue it. T3 are not approved. Only route recommended via private GP.	Other	4yrs on T4 yet heavy symptoms persists. Was told it may take a few months to work, eventually sent to a CFS/ME therapy group For a few weeks on a management course. Absolutely lacking in energy to pursue matter in timely manner. The medication T4 doesn't work, I've never felt well. Would love to put on a trial of T3 to determine its effectiveness.
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<p>02/19/ 2021 04:56 am</p>	<p>Yes</p>		<p>L38</p>	<p>T3 has been prescribed by an Endocrine consultant ( private consultant with 25 years experience in NHS and Harley st as waiting list was so long on nhs) Been on T4 for years and for the last 2 years its not been working and been really unwell,despite dose being adjusted. Private tests show low T3 ( Gp wouldn't do test on NHS)GPsaid she cant prescribe T3 as its too expensive and they aren't allowed to prescribe it anymore !</p>	<p>Other</p>	<p>T3 has been prescribed by an Endocrine consultant ( private consultant with 25 years experience in NHS and Harley st as waiting list was so long on nhs) Been on T4 for years and for the last 2 years its not been working and been really unwell,despite dose being adjusted. Private tests show low T3 ( Gp wouldn't do test on NHS)GPsaid she cant prescribe T3 as its too expensive and they aren't allowed to prescribe it anymore !</p>
<p>02/24/ 2021 04:34 am</p>	<p>Yes</p>		<p>RH11</p>	<p>I have been told that it cannot be prescribed on NHS.</p>	<p>My NHS prescription has been stopped and I am now buying liothyronine</p>	

					from overseas or the internet without a prescription	
02/25/2021 04:07 am	Yes		BN2	<p>I was taken off it some years ago as my ccg told my doctor surgery not to prescribe it anymore.</p> <p>When I contacted them (ccg) they lied and said it had become unlicensed, despite making it very clear to them that was not true and only 5mcg is not 20mcg they said I still couldn't have it.</p> <p>There was no discussion or request to try levo only it was only when I tired to request my repeat I</p>	My NHS prescription has been stopped and I am now buying liothyronine from overseas or the internet without a prescription	

				wasn't allowed it anymore and had been on t3 after an nhs agreed to prescribe it, and my gp added it to my repeat prescriptions.		
03/01/2021 08:03 am	No	I'm not interested as my treatment is not working and hasn't for 7 years	SG12	I've been told nothing as no endocrinologist or general doctors in my area will either acknowledge or discuss the issue surround T3	Other	I've been on levothyroxine for 5 years and my levels have never settled. I struggle every day and symptoms are there constantly.

03/18/ 2021 04:20 pm	Yes		AB56	<p>I was initially on T3 when i was 1st diagnosed 24yrs ago with depression, misdiagnosed hypothyroid. I was told by endo 2017 nobody in Grampian region has ever been prescribed Liothyronine in over 20 years. They wouldn't consider prescribing it as it could cause heart attacks. It is severely frowned upon to use Liothyronine only. Should if ever only be used in combination wi levothyroxine, max 20mcg. Apparently my resolved symptoms while on T3 only are merely psychological.</p>	<p>My NHS prescription has been stopped and I am now buying liothyronine from overseas or the internet without a prescription</p>	
03/23/ 2021 06:06 am	No	Gp has recommended (ex consultant) due to wanting to get pregnant	LI11	<p>No chance of getting it on script in wales advised to go a private endo in England to get a private prescription</p>	Other	

04/18/ 2021 04:41 am	Yes		UB10	That GP won't prescribe it (they are based in Fulham ) and my endocrinologist Professor Kevin Shotliff at Chelsea and Westminster Hospital won't prescribe it on NHS either. I cant tolerate t4 levothyroxine in any form and am now so ill I am depressed and feeling suicidal.	Other	I've been without any thyroid medication for 5 years suffering and trying vitamins and supplements and herbs as well as low dose naltrexone. Things have been worse the past 18 months and I've been begging for t3 medication or armour to try to see if it makes me better- I'm also unemployed and on universal credit so can't afford any more private prescriptions
04/27/ 2021 08:43 am	Yes		SY1	My consultant requested that I have it but the CCG has refused the individual funding request four times now. This despite the faulty DIO2 gene which means I can't convert T4 to T3 and being really unwell.	Other	I have never been issued with it on the NHS but have had it on private prescription and now buy it myself from overseas

04/27/ 2021 01:44 pm	Yes		Hd3	So far my CCG still prescribe as I'm under the care of an endocrinologist.	I am still being prescribed liothyronine but concerned about the future	I want to move in the next few years, but am worried about being prescribed liothyronine in the future if I move out of my CCG.
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05/24/ 2021 12:43 pm	Yes		EX20	<p>I had no problems getting T3, I did get a call from the clinical pharmacist one who tried to tele how to take it and that my TSH was to low I asked her if she was qualified thyroid, she said she knew as much as a GP !so told her thats not a lot then :)I also asked her if. she had Been in contact with my Prof Endocrinologist to try to tell me how to take it, she said no, I then told her not to interfere with what the prof was doing as only seen him the week before and stick to talking to people who weren't complex and Thyroid was hout league as she hasn't got a clue,she has left me alone since then. She wrote on medical records I have done</p>	<p>I am still being prescribed liothyronine but concerned about the future</p>	
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				<p>all can on this one !</p> <p>.My GP was fine taking on prescribing T3 mono and Avery lucky when he left another was good about prescribing T3 , The GP told me Devon have a protocol of 10mgs but its not a mandate and she's allowed to prescribe if endo initiated it I am blessed really</p>		
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05/25/ 2021 06:51 am	Yes		Bs31	Originally told they didn't prescribe liothyronine but my MP intervned and I now get 20 mcg a day. After 2 doses of radioactive iodine for Graves my body was wrecked by this treatment from the Bristol royal infirmary and no amount of levothyroxine will work, itâ€™s a poison. It's bad enough having serious thyroid eye disease because of of the radioactive iodine and needing 2 operations to restore my sight, but to try and force this poisonous medication on me is the final insult. Anyone who tries to take my liothyronine away will face my lawyers.	I am still being prescribed liothyronine but concerned about the future	The consultant tried to stop it recently and this lead to considerable stress for me and my family.
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05/25/ 2021 08:54 pm	Yes		M29	I was told he could not prescribe it for me. Why I asked..... The powers that be will not allow me!!!	My NHS prescription has been stopped and I am now buying liothyronine from overseas or the internet without a prescription	
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<p>05/26/2021 05:52 am</p>	<p>No</p>	<p>I have low free T3 even when free T4 is mid range free T3 is below reference range. I am much better on ndt which I need to self source so saw an endo in the hope he would offer a T3/T3 trial.</p>	<p>PL26</p>	<p>My story covers more than liothyronine. I am writing in response to your Twitter request I tell you my experiences further to being told cost prevents prescribing liothyronine.</p> <p>I saw the Lead Endocrinologist, redacted at redacted Hospital on redacted date.</p> <p>He told me that he was unable to prescribe ndt which I had originally been prescribed for many years and had recently been self sourcing. He said he knew that people source their own supplies. He is perfectly happy for me do the same.</p> <p>He explained that there is no evidence that either ndt or</p>	<p>Other</p>	<p>I will continue to self source ndt as it's no harder to find than T3 and the costs seem to be about the same. It is very evident that the NHS is determined to leave me to continue suffering as I have for the last thirty years.</p>
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			<p>synthetic T3 have any benefit to patients with hypothyroidism. He said that some people seem to feel better taking them and it's their choice to obtain for themselves.</p> <p>T3 he advised cannot be prescribed due to cost.</p> <p>He went on to say that testing free T3 was not done because it gave no meaningful information. This is due to the short half life of T3. I did say I knew it to be 12 hours. No more was said about that.</p> <p>He pretty much dismissed the testing of free T4 as well and pointed out TSH was all he needed to know. If TSH is in range then everything is working perfectly. Unless a pituitary issue has</p>		
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			<p>been identified.</p> <p>He has agreed to test my pituitary (not for the fact I can have a suppressed TSH ( below reference range) and rock bottom FT4 and FT3. Not that he was happy I had used the NHS lab Monitor my Health for results. It is as I pointed out the only way to obtain these if I want a full picture. Also if self sourcing I can check the dose is suitable. ) He has agreed to test based on the fact that I was diagnosed with hypothyroidism in 1960. I have never had raised antibodies and I was told that the doctors believed my thyroid was damaged by radiation therapy I had for a birthmark in</p>		
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			<p>the early 1950s. So there is a possibility I have some pituitary damage.</p> <p>Generally I found him to be condescending at best and more to the point telling untruths.</p> <p>There were two young people in scrubs in the room. I assume they were students. No mention was made of them when I went in or at any time during the consultation.</p> <p>I asked about one particular set of tests which I had done in response to my GP refusing to prescribe levo at a time I could not get any ndt. ( This despite my having had the ok from a senior partner to self source. I had previously taken NHS</p>		
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			<p>prescription thyroid replacement for 58 years. Sadly the partner retired.) I had to wait months for a script from the GP and then promise faithfully to not take anything else. Levo dose is limited to 100mcg and no increase will be given. By the time that happened I had these results redacted</p> <p>The endo refused to consider these as I had paid for the testing. And of course there is no need ever to test free T3</p>		
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<p>05/26/ 2021 08:17 am</p>	<p>Yes</p>		<p>EX4</p>	<p>I have been told by the GP that in my case it is not due to cost but that my case is too complex for them to handle and that I will not be prescribed it in primary care. This is the third time of asking and several letters being sent to GP from my endocrinologist stating that I have clinical need.</p>	<p>Other</p>	<p>I have had to fund my own T3 as my surgery is unwilling to. I first saw my GP about this back in 2018 who asked if I had tried T3 only and agreed to refer me to an endocrinologist in Weston Super Mare as that was my choice, and I knew Exeter endocrinology would not prescribe any more than 10mcg which is Devon CCG policy. From the first day I saw the endocrinologist in Weston i was told by him that it was more than his job was worth to prescribe T3 on the NHS! Sent me straight over to his private secretary to get script of T3. He also does private and NHS and I've seen him in both. I am now retired so having to pay for my own meds and those of my son who is on NDT is costing me a lot of money which Im not sure how long I will be able to afford. Plus the fact that our private sources are becoming less and less.</p>
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					<p>Ive been turned down 3 times now. This whole situation with Devon is getting way out of hand and is very unfair, but I believe they are clamping down more than ever. No doubt they have heard through the grapevine that Devon patients are not happy. I dont blame them it seems that they would prefer to keep their patients ill and under-treated!</p> <p>I already sent the updated 2019 Guidance to both my doctor and endocrinologist, but it makes no difference. Im completely ignored regarding my son and my thyroid health. Its truly shocking and something needs to change sooner, rather than later with so many Devon (and other areas) patients being left to fend for themselves.</p>
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05/28/ 2021 12:24 pm	Yes		Ex16	<p>Endo at royal Devon &amp; Exeter prescribed 20mcg liothyronine 10 years ago but in March this year, before an appointment with the endo, I received a text message from my GP surgery telling me an endo at the hospital had halved my liothyronine prescription to 10mcg because of my suppressed TSH, which incidentally has been the case for many years without untoward effects. At the end of the virtual appointment he listened to me and I said I was very disappointed to receive the text message after 10 years with T3/T4 combination for my Hashimoto's thyroiditis but he then said he could only prescribe</p>	Other	<p>Still receiving liothyronine but the dose has been halved per CCG protocol</p>
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				<p>10mcg now. I said I knew what the CCG protocol says and he was following that instead of considering my health needs. I also said I had the DIO2 heterozygous genetic polymorphism discovered from a private test, and basically he said his hands were tied and that I would likely need less thyroid hormones as I was approaching 60. I had already told him I was a professional working full time in the pharmaceutical industry, a demanding industry and needed to be healthy with lots of energy and no brain fog. He wouldn't change his mind.</p>		
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