

## PE1463/QQQ

Petitioner Letter of 23 February 2016

Dear Convener and members of the Committee

Please accept my sincere apologies for calling out during the last evidence session on 9th February and be assured of my continued gratitude for the very concerted efforts the committee make in examining this issue affecting many thousands of Scottish patients. It's a great pity that this hard work resulted in such a confusing and chaotic evidence session.

As per the briefing notes, I had expected to hear in depth the findings of the Listening Exercise and what lessons could be drawn from it. Instead I was dismayed to hear the Thyroid UK survey described **as** the Listening Exercise. Previous Scottish Government letters to the committee explained that the remit was much wider, to encompass patients **and** staff who were dealing with frustrated thyroid patients as well as patients from other disease groups (1) (2). My own meeting with the Scottish Government official tasked with implementing the exercise confirmed this.

At the evidence session there was barely any discussion on the findings from the survey and it seems absolutely nothing has come of it. What a waste of two years and of the efforts of Thyroid UK! What had the Scottish Government department actually been doing in those two years when the survey itself was completed within a few months of being commissioned?

And why was Minister Watt comparing the commissioned Hypothyroid Patient Experience Survey unfavourably with a clinical trial? It was intended to be the opposite of a clinical trial, to hear from patients and not from blood tests. The trustees of the charity championed by Graham Leese and Minister Watt, the British Thyroid Foundation, made the same, disparaging I feel, remark about the survey when refusing to share it on their website. Such a pity a charity claiming to be for Thyroid patients denied them a chance to be heard.

The confusion began early on in the session when Minister Watt inaccurately asserted that " the petitioner has been involved in seeing if the current guidelines and any future guidelines should be altered and **in fact**, as a result of discussions it was discovered that current SIGN guidelines are pretty good and that, if left to the petitioner, she would probably have come up with more or less what's out there now." I wonder who 'discovered' this because I most definitely am not happy, primarily because there are **no**

SIGN guidelines to be happy about, nor do I believe guidelines will help and outlined my reasons why in my evidence to the committee last December. I find it astonishing that Minister Watt can state such a thing in evidence and I object to such an unverified statement involving me as petitioner.

It seems this inaccuracy then led to further confusion when Graham Leese insisted the guidelines are out there and simply need to be advertised more. He is referring, not to SIGN or NICE guidelines but to his professional society, the British Thyroid Association's revised statement of 2015 which was published only after I highlighted via Ask For Evidence that it's previous statement was not backed by evidence(3). This is a position statement and still **not** a guideline, no matter how many times he calls it such. NICE and SIGN guidelines would be in existence by now if there was sufficient robust evidence to produce them and the fact that they do not exist speaks volumes. Whilst it's nice to hear from Graham Leese that doctors feel great sympathy for patients ill on Levothyroxine, sympathy does not replace hormone levels. Compassion doesn't replace them either.

Minister Watt further claims that this 'guidance' (I must assume that she refers to this BTA revised statement for want of any clarity again) does state that patients with remaining symptoms should be referred on to an Endocrinologist for further investigation. Except that it doesn't say this. Instead it says "It is acknowledged that a proportion of individuals on L-T4 are not satisfied with therapy and have persistent symptoms despite a normal serum TSH. Such symptoms should be given due consideration and patients should be thoroughly evaluated for other potentially modifiable conditions. In some cases, a retrospective review of the original diagnosis of hypothyroidism may be necessary. Symptom and lifestyle management support should be provided and further dose adjustments may be required." (4)

The reality is that GP's referrals are routinely refused by Endocrinologists because the patient's TSH is within range and nothing is ever done, save for the routine prescription of antidepressants and pain medication or a sticking plaster diagnosis of Fibromyalgia. If this 'perfect world' scenario of referrals to helpful Endocrinologists actually existed, this petition wouldn't exist and thousands of Scottish patients, including Elaine Smith MSP and myself would not be fighting for due care.

Again incorrectly, Minister Watt claimed that 'as a result of the Thyroid UK survey, we know what patients think of their care and as a result of that, specialists have taken forward SIGN guidelines'. This is entirely inaccurate and a brief glance through the petition letters would show that in fact the proposed SIGN Best Practice exercise (not guidelines) with the RCGP (not RCP as claimed) is a direct result of of the Petition

Committee inviting them to consider work in this area (5) It has nothing whatsoever to do with the Listening Exercise/Thyroid UK survey. I am seriously disheartened that this is the standard of evidence given by a Government official as it seems discourteous not to have done even basic research. It's a pity the shocking findings of the Thyroid UK survey were dismissed as being heavily weighted towards dissatisfied patients and not run along the lines of a clinical trial. The clue was in the name. This survey was to gather the views of the patients who live with this disease, in answers to questions signed off by the Scottish Government official at every turn. I do wonder where the remainder of the large Listening Exercise budget was spent because Thyroid UK's very competitive costs were a fraction of the available funds, at £1065.

Minister Watt undertook to write to the committee regarding what the parameters of the Listening Exercise were. Elizabeth Porterfield's letter of 19th February on the minister's behalf still fails to provide this (6). Is this really good enough?

When Graham Leese says that the evidence does not support the use of T3 or NDT according to trials, what he does not make clear is that these trials did not separate those patients who could not convert Levothyroxine! Patients were given Levothyroxine versus Levothyroxine and a small amount of T3. If a patient cannot convert Levothyroxine, just reducing the dose a small amount and adding in some T3 will of course not show any benefit. They will still not convert that reduced dose Levothyroxine and remain hypothyroid! If you ask the wrong question, you will get the wrong answer.

That these trials were conducted eight years ago somewhat gives lie to the claim that more trials will be done. Why are new trials not being conducted sorting the patients into those with D102 defects and unable to convert? I am all for evidence based medicine, so long as the quality of that evidence is high but when the evidence for the use of Thyroid Function Tests is based on generally poor quality, non validated evidence, I wonder how Dr Leese squares that with the need for sound evidence bases?

The situation with obtaining T3 on the NHS is another area where the repeated status quo helps no one. Yes we know there is only one UK manufacturer and that they occasionally have shortages, we have known this for over three years. What we now also know however is that the price for 28 tablets of 20 mcg liothyronine (T3) has increased from **£54** to **£152** in those three years. If that does not require some serious investigation into licensing procedures and procurement, I don't know what does.

The committee have tried very hard to get to the heart of the issues for thyroid patients and I applaud them for doing so. I realise this is a complicated area to take on. I believe the committee would gain greater clarity on the medical facts of this controversy if it

allowed evidence from Dr John Midgley who has confirmed he would be delighted to do so. I respectfully urge the committee to consider this.

Yours Sincerely

Lorraine Cleaver,  
Petitioner

## Links

- (1) [http://www.scottish.parliament.uk/S4\\_PublicPetitionsCommittee/General%20Documents/PE1463 II Scottish Government 05.02.14.pdf](http://www.scottish.parliament.uk/S4_PublicPetitionsCommittee/General%20Documents/PE1463%20II%20Scottish%20Government%2005.02.14.pdf)
- (2) [http://www.scottish.parliament.uk/S4\\_PublicPetitionsCommittee/General%20Documents/PE1463 YY Scottish Government 05.09.14.pdf](http://www.scottish.parliament.uk/S4_PublicPetitionsCommittee/General%20Documents/PE1463%20YY%20Scottish%20Government%2005.09.14.pdf)
- (3) Posted to the Ask for Evidence website on 6 November 2014.
- (4) [http://www.btf-thyroid.org/images/documents/BTA Hypothyroidism Statement.pdf](http://www.btf-thyroid.org/images/documents/BTA_Hypothyroidism_Statement.pdf)
- (5) <http://www.scottish.parliament.uk/parliamentarybusiness/report.aspx?r=9693&i=88087>
- (6) [http://www.scottish.parliament.uk/S4\\_PublicPetitionsCommittee/General%20Documents/20160219 PE1463 GGG Scottish Government.pdf](http://www.scottish.parliament.uk/S4_PublicPetitionsCommittee/General%20Documents/20160219_PE1463_GGG_Scottish_Government.pdf)