The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

PUBLIC PETITIONS COMMITTEE

Tuesday 1 October 2013

Session 4

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PUBLIC PETITIONS COMMITTEE
16th Meeting 2013, Session 4

CONVENER

*David Stewart (Highlands and Islands) (Lab)

DEPUTY CONVENER

*Chic Brodie (South Scotland) (SNP)

COMMITTEE MEMBERS

*Jackson Carlaw (West Scotland) (Con)
*Angus MacDonald (Falkirk East) (SNP)
*Anne McTaggart (Glasgow) (Lab)
*David Torrance (Kirkcaldy) (SNP)
*John Wilson (Central Scotland) (SNP)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Lorraine Cleaver
Lynne Connor
Marian Dyer
Professor Graham Leese (Specialist Adviser to the Chief Medical Officer)
Michael Matheson (Minister for Public Health)
Lesley Metcalf (Scottish Government)
Lyn Mynott (Thyroid UK)
Sinead Power (Scottish Government)
Elaine Smith (Coatbridge and Chryston) (Lab)
Dr Anthony Toft (Spire Murrayfield Hospital)
Julie Wales
Sandra Whyte
Professor Graham Williams (British Thyroid Association)
Tara Willmott (General Medical Council)

CLERK TO THE COMMITTEE

Anne Peat

LOCATION

Committee Room 2

Scottish Parliament

Public Petitions Committee

Tuesday 1 October 2013

[The Convener *opened the meeting at 10:03*]

Decision on Taking Business in Private

The Convener (David Stewart): Good morning, ladies and gentlemen. I welcome you all to this meeting of the Public Petitions Committee. As always, I ask everyone to switch off their mobile phones and electronic devices, as they interfere with our sound system.

Item 1 is a decision on taking business in private. The committee is invited to agree to take item 5 in private. Is that agreed?

Members *indicated agreement.*

Current Petition

Thyroid and Adrenal Testing and Treatment (PE1463)

10:03

The Convener: Item 2 is a round-table discussion on PE1463, on effective thyroid and adrenal testing, diagnosis and treatment. Members have a note by the clerk and written submissions. I thank our experts for giving up their time to come along today. We are also joined by Elaine Smith MSP, who has a lot of expertise in the subject. I thank her for coming along today as well.

The purpose of the discussion is to enable everyone around the table—they all have a lot of expertise in the subject—to discuss the petition by Sandra Whyte, Marian Dyer and Lorraine Cleaver. Contributions to the discussion should be made through me. Anyone who wants to speak should indicate that they wish to do so and I will call them to speak. The microphones will come on automatically—once someone has been called to speak, they do not need to touch anything; our technical team will ensure that the microphones come on.

I ask everyone to introduce themselves. I am a Labour MSP for the Highlands and Islands and the convener of the committee.

Chic Brodie (South Scotland) (SNP): I am a Scottish National Party MSP for South Scotland and the deputy convener.

Dr Anthony Toft (Spire Murrayfield Hospital): I was a consultant physician at the Royal infirmary of Edinburgh until four years ago. I am now in private practice in Edinburgh.

Anne McTaggart (Glasgow) (Lab): Good morning. I am an MSP for Glasgow.

Sandra Whyte: I am one of the petitioners.

Angus MacDonald (Falkirk East) (SNP): I am the MSP for Falkirk East.

Marian Dyer: I am one of the petitioners.

Jackson Carlaw (West Scotland) (Con): I am an MSP for West Scotland and the Conservative spokesman on health.

Lorraine Cleaver: I am a very disgruntled thyroid petitioner.

Professor Graham Leese (Specialist Adviser to the Chief Medical Officer): I am a consultant at Ninewells hospital in Dundee and a member of the Scottish Medical and Scientific Advisory Committee—SMASAC—which supports the chief medical officer.

The Minister for Public Health (Michael Matheson): I am the MSP for Falkirk West and the Minister for Public Health.

Lesley Metcalf (Scottish Government): I am the Scottish Government's policy lead.

Sinead Power (Scottish Government): I am from the Scottish Government's policy team.

John Wilson (Central Scotland) (SNP): I represent the SNP in Central Scotland.

Tara Willmott (General Medical Council): I am from the GMC's education directorate.

David Torrance (Kirkcaldy) (SNP): I am the SNP MSP for the Kirkcaldy constituency.

Professor Graham Williams (British Thyroid Association): I am from Hammersmith hospital, Imperial College, London. I am also the president of the British Thyroid Association and treasurer of the Society for Endocrinology.

Lyn Mynott (Thyroid UK): I am the chair/chief executive of Thyroid UK.

Elaine Smith (Coatbridge and Chryston) (Lab): I am the MSP for Coatbridge and Chryston. I have been assisting the petitioners.

The Convener: Thank you all for your introductions. I have allocated about an hour for our discussion; unfortunately, we will then need to move on to other business. I will kick off with some questions. I have asked my colleagues to ask some questions, too, but I encourage everyone to participate. There is phenomenal expertise around the table and I am keen to get as much information as possible so that we can deal with the petition appropriately.

My first question is a general one—anyone who wishes to answer it should feel free to do so. To what extent are alternative diagnostic tests available?

Sandra Whyte: They are not available—it is that simple. We are requesting that, apart from doctors taking the patient's history, they look for signs such as how the patient looks, what their skin is like—whether there is puffiness or whatever—whether they are putting on weight or losing hair and any other symptoms. For years, we have gone to see doctors with different symptoms but they have not put them all together. We would like them to do that, and we want people then to go on to the free thyroxine 3 hormones—that is what we are after. We also want cortisol deficiency to be taken into consideration, rather than just cortisol total failure. We have some really good paperwork on how much the Government is spending on tackling alcohol and drug problems, and low cortisol can be connected to that. Those are the two things, in particular, that we would like to be added to the testing.

The Convener: Thank you for getting the ball rolling. Does any of the other petitioners want to add anything?

Marian Dyer: It is really important to have cortisol level testing because by the time that I got mine tested I was practically flatlining. My cortisol level was 5 on the scale for a day, when it should have been between 21 and 41. That was in 2010. I have obviously improved a little since then, but I am still nowhere near well. My diagnosis has gone from functional hypothyroidism to Graves' disease, and I could not get treatment.

Lyn Mynott: Part of the problem is that in some areas only a thyroid stimulating hormone test is done, whereas in others a free T4 test is done as well. It is very rare to get a free T3 test done. That needs to change, as the practice is not consistent throughout the United Kingdom. The guidelines state that a T4 test should be done as well as a TSH test, at least.

The Convener: Are you talking about differences between health boards in Scotland or differences between Scotland and England generally?

Lyn Mynott: I think that, all over—in Scotland and in England—testing for thyroid disease is not consistent. I am not sure whether Elaine Smith can confirm that.

The Convener: Could you speak through me? Otherwise, we do not pick up the answers on our sound system.

Lyn Mynott: Sorry. There is evidence from patients that not all the tests are done, which means that things such as secondary hypothyroidism can be missed.

Elaine Smith: I am probably just about to put Dr Toft on the spot, because he says in his book:

> "Thyroid blood tests should not be interpreted in isolation and correct medical care will also depend on careful assessment of symptoms and clinical examination."

One problem is that the thyroid blood tests seem to be the be-all and end-all for many general practitioners. In my case, the GPs did not look at me or listen to my symptoms; they just looked at the blood tests and said, "Your thyroid is absolutely fine," but it was not. Another common problem is the fact that the blood test parameters are different in the UK from what they are in other countries. Dr Toft, can you comment on that?

Dr Toft: I do not quite know where to begin, because quite a lot of questions have been raised. If we deal first with how people interpret the reference range, the criticism that there might not be an appreciation of the issue is probably fair, but more with regard to general practice than specialist practice. For example, if the reference range for TSH is 0.5 to 4.5 and the reference range for free T4 is 10 to 22, and someone is being treated with levothyroxine, ideally you would want the TSH to be about 1 and you might expect the free T4 to be around 18 or 19.

The trouble is that if a GP sees a free thyroxine of 12, which is in the reference range, and a TSH of 4, which is still in the reference range, they regard those results as normal. In specialist practice, one would perhaps increase the dose of levothyroxine based on those tests, so people would perhaps accept the criticism that there is not a feel for what is appropriate within the normal range—in particular, as regards patients who are already being treated with levothyroxine.

On the request that T3 should always be checked, I am sure that my colleagues will agree that, in attempting to diagnose an underactive thyroid gland, T3 is the least useful test, in our experience. It is often misleading—it is often normal in patients with profound hypothyroidism, for example. That is why it is not offered as standard by laboratories for the investigation of possible underactivity of the thyroid.

The Convener: It is quite difficult to make this a straightforward round-table discussion because there is a lot of technical, scientific language, and obviously not all of us here are doctors. I thank you for that technical advice, but could you try to make it as straightforward as possible?

Minister, would you like to come in at this stage?

Michael Matheson: These are largely clinical issues that are not set down by Government policy. Clinicians use guidance from organisations such as the British Thyroid Association, and it depends on how that guidance is applied locally. Of course, we expect clinicians to follow best practice and to work to the best possible standards.

The Convener: Is there anything that Lorraine Cleaver, as the other petitioner, wants to add at this stage?

Lorraine Cleaver: Yes. I understand Dr Toft's point that the T3 range is not considered useful in relation to diagnosis. However, when patients have been diagnosed as hypothyroid and they are on medication, there is a reference range for T3 for a reason, so why is it not being tested?

When many patients insist on T3 being tested, the result comes back way below the healthy range—it is not in the range—which means that they are still profoundly hypothyroid. However, that will never be picked up because nobody will test it. The TSH will look normal; the T4 might even seem to be in the normal range, although it will be low; but the T3 is below the range. If no one tests it, people remain very hypothyroid. I have a question for Dr Toft. Where is the evidence that it is not useful to test T3? He has asserted that it is not useful—I would like to know what the evidence is.

Dr Toft: To some extent, we are perhaps talking at cross-purposes. There is no reason why T3 should not, from time to time, be measured in patients who are being treated for an underactive thyroid gland. I think that most people would accept that. There are situations in which it may be very valuable to measure T3, perhaps to see whether the patient is being overtreated rather than undertreated. I am sure that my colleagues will have views, which may or may not be similar.

10:15

Sandra Whyte: I want to bring up the subject of myxedema, which is a severe form of hypothyroidism. When you are myxedemic, you tend to be unable to convert your T4 to T3. That is not getting picked up. Unfortunately, in my case, the condition was not even picked up with the TSH, which was totally irrelevant to it. As I said when I gave evidence previously, I was going unconscious—I mean into a coma—four or five times a day. I was not just tired but going into unconsciousness until I was in emergency and dying. There are extreme cases.

A lady in America called Dana Trentini, who is a hypothyroid mum, has produced a list of 300-plus symptoms of hypothyroidism. She is looking into miscarriage and infertility among ladies and the importance of testing free T3 and free T4 in the first 12 weeks of pregnancy or in dealing with infertility. It is important to have a healthy, functioning thyroid before you get pregnant or when you are pregnant, but the "UK Guidelines for the Use of Thyroid Function Tests" say:

> "The thyroid status of hypothyroid patients should be checked with TSH + FT4 during each trimester … Measurement of T3 is not appropriate."

I think that that is so sad for people who are losing children.

Lyn Mynott: We hear all the time that GPs are asking for T3 testing, but the biochemists at the local laboratory will not provide it, sometimes because—they say—the TSH is within the range, but sometimes they give no reason. Often, doctors ask for the T3 test, but the biochemist seems to have priority over the GP who is treating the patient, although the biochemist has not seen the patient or the patient's notes. Why is that happening?

Chic Brodie: I have a question on that. The petition asks us to ensure that GPs refer people for testing, which you say some already do. What I do not understand is whether such GPs are going against the general guidance that is given by bodies such as the Royal College of Physicians.

How do the GPs arrive at their level of so-called knowledge of the implications the T3 testing?

Lyn Mynott: Often, that happens because people who have gone on to forums and become more educated about the thyroid system have gone back to their GP to ask, “Could you do this test to see why I still have symptoms?” The doctor has then agreed to refer them for testing. That is a good shared decision-making environment.

Chic Brodie: I understand that and I am not denigrating the knowledge that people can bring, but that is about asking the GPs to be reactive. Should we not ask them to be proactive if they feel that there is clinical evidence that T3 should be tested? Are GPs simply reacting to the circumstances—including, no doubt, emotional circumstances—when people make such a request? I would feel a lot more confident if GPs had clinical evidence that suggests that they should be proactive in referring people for T3 testing.

Sandra Whyte: Even though T3 is the only medication that I am on, my doctor cannot get the laboratory to test it for me. In adjusting my medication, I have to go by how I feel, so I am doing that myself.

The Convener: Does Professor Williams wish to comment?

Professor Williams: It might be useful at this stage to give an overview of our current understanding of the physiology of the thyroid system, because I think that there is a lot of misinterpretation happening.

Our understanding of this area is right at the cutting edge of basic science, both internationally and in the UK. We are talking about an area in which knowledge is progressing quite rapidly but on an experimental basis, often using animal models that may not be representative of human disease. We have to exercise a degree of caution.

I can explain the current understanding, particularly with the conversion issue, which is pretty important. The pituitary gland in the base of the brain produces a thyroid-stimulating hormone, which stimulates the thyroid gland to synthesise—produce—and secrete the thyroid hormones, which are T4 and T3. In humans, about 14:1 or 15:1 more T4 is produced by the thyroid gland than T3. In the peripheral tissues—the liver, kidney, skeletal muscle and bone—about 80 per cent of the body’s requirement of T3, which is the active hormone, is produced by metabolic processes.

Those metabolic processes are carried out by three separate enzymes. That is quite an important issue to think about. Those three enzymes are called the iodothyronine deiodinase enzymes. They take a single iodine atom from T4—thyroxine is called T4 because it has four iodine atoms. They remove one iodine atom to produce T3. Two enzymes are capable of doing that, which are the type 1 and the type 2 iodothyronine deiodinase enzymes.

It very much matters where that iodine is removed from the T4 molecule, because the T4 molecule has two circular rings—so-called benzene rings—each of which has two iodine atoms. There is an inner ring and an outer ring, and if an iodine atom is removed from the outer ring, T3 is produced, which is the active hormone. If an iodine atom is removed from the inner ring, thyroid hormone T4 and T3 are inactivated. That is done by the third deiodinase enzyme.

The three deiodinase enzymes are capable of different reactions—we are getting into complex territory here. It turns out that the type 1 enzyme is found mainly in the liver and kidney, and it is felt that in humans it is probably responsible for the majority of the T3 circulating within the system. Although that is not categorically known, it is our current understanding.

The type 2 deiodinase is a different enzyme altogether. It is expressed in the pituitary gland and many other tissues, including the skeleton and the heart, which has been particularly well documented. That enzyme produces local supplies of T3 when it is required to those tissues that need it.

Interestingly enough, the formation of T3 by the type 2 deiodinase enzyme goes up in situations of hypothyroidism, when circulating levels are low, whereas the type 1 enzyme, which produces the levels of T3 in the blood, is increased in situations of thyroid hormone excess. There is a counterbalance between the two. The regulation of the inactivating enzyme is somewhat less well understood and is a bit more complicated.

At the level of the metabolism, it is extremely difficult to relate the levels of T3—the active hormone in the tissues that you are interested in—to the levels of T3 in the blood. We do not have a good measurement of the T3 level in the tissues. That is one of the major reasons why measuring T3 in this situation is of no value; in fact, it is misleading because it does not help us.

For example, if you have a patient who is on T4, they will convert T4 to T3 in the periphery via the type 1 deiodinase enzyme, and that enzyme will be regulated by the presence of the T4 that you are giving. It will be converted in the tissues by the type 2 deiodinase in the opposite direction. The level that you are measuring in the blood may not reflect what is happening in individual tissues. It is very misleading to be thinking about measuring T3. I agree with Dr Toft that the optimal measurement for patients who are taking T4 and who have hypothyroidism should be the TSH and the T4. I do not think that there is a place at the moment for T3 because we do not understand enough about it.

Chic Brodie: Professor Williams, if there was misdiagnosis or misinterpretations of tests and T3 was provided, what would be the downside?

Professor Williams: In my opinion, the downside would be that there would be a tendency for the people who were not aware of the current literature to prescribe T3, because the level would be seen to be below the reference range. The problem with prescribing too much T3 is that it has detrimental effects on a number of important tissues, particularly the heart—it can increase the tendency of the heart to go out of rhythm and produce emboluses, which are small clots that can cause strokes and so on. That is one definite problem.

Chic Brodie: Is there evidence for that?

Professor Williams: There is considerable evidence of it in population studies and in individual case reports. It is a real risk.

There are long-term consequences, too. We know that if someone is on high levels of T3 for a prolonged period of time, there is an increased risk of loss of muscle mass and loss of bone mass, which can result in osteoporosis and fragility fractures. The risks in doing that in an uncontrolled fashion are considerable on a population basis, so we should be cautious about it.

Lyn Mynott: There has been some recent research about a polymorphism on the DIO2 gene that shows that the tests do not give the true picture. I think that the conclusion was that T3 might be useful for some patients. However, that gene test is not available on the national health service. Do you think that it would be a good idea to make it available for patients who are not doing very well on levothyroxine and then to give them a trial of T3? How could that be done? How can we organise it so that that genetic test can be done on the NHS? At the moment, it is only available privately. If a faulty gene is not showing up in blood tests, how can patients who have that gene get well? It is an important issue.

The Convener: What is your view on that, Professor Williams?

Professor Williams: It is an interesting and important issue, the literature on which is quite small, so it is important to look at it in great detail. Unfortunately, in this situation, the devil is in the detail.

The enzyme concerned is the type II iodothyronine, deiodinase, which is the enzyme that converts T4 to T3 in tissues. There is a polymorphism of the gene. I will explain what a polymorphism is. Every gene on a chromosome encodes production of a protein. In this case, the protein is the type II deiodinase. The sequence of DNA tells us what constituents of the protein need to be incorporated for it to be functional. We know that about 14 per cent of the population can have a misreading of that sequence in both their copies of the type II deiodinase gene—the one that they get from their mother and the one that they get from their father. Approximately 40 to 50 per cent of the population will have that change or difference from the reference sequence in that gene.

The question is what that means and whether it is important. Only three studies have looked at the function of that polymorphism. This is where the devil in the detail lies. The three studies have taken the protein in question and purified it in its entirety, put it in a test tube and measured in great detail the kinetics, or the production, of T3 from T4 by the enzyme in question. Those studies have been done in laboratories in Boston, Rotterdam and Miami by three of the leading groups in the world in the area. All those test-tube studies showed that the enzyme has no effect on production of T3 from T4. Those data are very conclusive and were very clearly produced.

The group in Miami, in collaboration with the group from Boston, also performed studies that looked at the function of the enzyme in tissue extracts. It took extracts from muscle tissue from individuals who had the polymorphism in question, did a comparison with individuals who did not, and studied the efficiency of the enzyme. The initial study suggested that, in people who have two copies of the gene, there may be a deficiency or a reduction in production of T3 from T4. Both authors from that group have subsequently published the fact that the study that they performed of activity of the enzyme was probably flawed.

For technical reasons, it is an extremely difficult assay to perform. The current consensus in the literature and among experts in the field—we have just had a meeting in the United States about the issue—is that there is no difference in activity between the two polymorphisms. A genetic test on the basis of three papers that are quite contradictory—in fact, the initial positive finding from two of the groups has now been retracted, at least to some extent—suggests that the test is way too premature and that it should not be recommended.

10:30

Chic Brodie: Thank you. That is very interesting. Your explanation of the downside and where we are with the research raises in my inexperienced mind some deep concerns.

We have reviewed the petition several times, and on 15 May we received a response letter from the Scottish Government that states:

> "Via the Scottish Government Diagnostic Steering Group advice has been sought from the diagnostic managed clinical networks across Scotland".

Have you heard back from the DSG? Can you give us an update on the issues of TSH-only testing?

Michael Matheson: We are still waiting for formal feedback from the diagnostic steering group. The point on the DSG was one of three in that letter that we said we would take forward. We expect to have all the information for those three points by the end of the year, which will allow us to come to a considered position.

Chic Brodie: Thank you. This is probably an unfair question on what is a difficult issue, but given what we have just heard in evidence, do you know what parameters have been set for the diagnostic testing?

Michael Matheson: Obviously, change to current procedures in clinical care must be led by a clear and strong evidence base that would be sufficient to justify it. The diagnostic steering group will look at the existing range of evidence to see whether there are any grounds for considering changes, and to assess whether what is currently available in Scotland can be improved. When the DSG has considered all the emerging evidence, including the information that we have just heard, it will be able to come to a decision.

Chic Brodie: On that basis, I assume that the Scottish health technologies group has not prepared any evidence on current testing. Or has it?

Michael Matheson: The SHTG is looking at what is presently available in the system and whether any new evidence is emerging around diagnostic testing, but it is not itself undertaking research into different types of diagnostic testing.

The Convener: All three petitioners wish to comment.

Sandra Whyte: I was very interested to hear what Professor Williams said about flawed tests, because the TSH T4 can also be flawed in that it can have false positives and false negatives; it is not really a diagnostic test. Again, we need to look a bit more at the patient's history of signs and symptoms, and take lots of other matters into consideration.

I point out to Professor Williams that there is a serious flaw in the reference ranges that he, the Royal College of Physicians and the NHS go by, because the free T3 is written down in nanomoles instead of picomoles.

Marian Dyer: I just wonder whether anybody has looked at the basic fact that stress can reduce the level of cortisol and interfere with whatever process of thyroid production. Nobody seems to take account of that. Further, there is gut disbiosys, which can stop proper processing of vitamins and minerals. People are looking at the deiodinase effect, or whatever; I am not saying that it does not exist, but it seems to be one small thing in isolation, whereas we should be looking at the big picture for the general population, but we are not doing that.

Lorraine Cleaver: I have to say that I am not liking this meeting or format because what we are hearing is the status quo that thyroid patients have heard for years. This severe problem is a massive drain on the NHS and links to diabetes and heart disease. You will rarely find an endocrinologist who is absolutely interested in your thyroid problem. We are summarily dismissed; it is almost as if they would rather wait until we develop hypoglycaemia and become diabetic.

I have done some digging around. It appears that there is one main player in diabetic treatment in Scotland: Novo Nordisk, which plunged the NHS into chaos when it introduced a new insulin and withdrew an older stable version. Moreover, I believe that a prize—I forget the name of it; I think that it is called the Jacobaeus prize—has been awarded to an endocrinologist who tells us that we have a somatoform disorder; in other words, it is all in our heads.

I am going to put it out there and say that those who talk about a conspiracy theory might have a point. The endocrinologists seem to be happy to leave us with the status quo; they have all the answers for doing that, but we have all the research that proves otherwise. I am not a scientist, so I am not going to rhyme it all off, but the research shows that the status quo does not work. We develop heart disease and diabetes, which I believe accounted for £1 billion, or 10 per cent, of last year's NHS Scotland budget.

In 2012-13, the most common prescribed drug in Scotland was omeprazole, which is an acid suppressor that depletes, among many other things, people's B12 levels. When a hypothyroid person goes to the doctor and says, "I've got acid reflux", the doctor does not test for high or low acid; instead, they give you omeprazole, which completely dries up your stomach acid and prevents you from getting nutrients from your food. The B12 assay is about to be changed, because it is completely ineffective. We are talking about the number 1 drug prescribed in Scotland. Levothyroxine is at number 5 and the top 10 also includes inhalers, angina sprays and co-codamol.

Hypothyroid patients will be on pretty much every one of those drugs. I just do not want to hear any more justification of the status quo.

Marian Dyer: I had a severe deficiency of B vitamins and since I started taking them and other non-pharmaceutical products I have been much better. I was not able to attend the previous two meetings at which this petition was discussed because I was too ill. I am not saying that I am well and healthy at the moment, but I am improving through support from friends and through my own research and treatment.

The Convener: Thank you for that. I must apologise, but we are a bit short of time and still have a lot of material to get through. I want to encourage as many people as possible to contribute to the discussion, but I should say to Lorraine Cleaver that the committee has not come to any decision. We want to listen to all sides so that we can consider our next steps, but I do understand the strength of feeling on this matter.

Dr Toft: There are two issues to highlight with regard to the lack of cortisol in hypothyroidism. First of all, it can be shown experimentally that in those who are severely hypothyroid—in other words, who have a severely underactive thyroid gland—the amount of cortisol that is released by the adrenal glands, which sit on top of the kidneys, will be reduced. However, if you treat the underactive thyroid gland with levothyroxine, the adrenals' cortisol secretion rate will be restored to normal.

Secondly, all endocrinologists recognise that there is an association between failure of the adrenal glands—what we call Addison's disease—and what we call autoimmune thyroid disease, whether through an overactive thyroid gland, because of Graves' disease, or an underactive thyroid gland. However, it is very rare. I am speaking anecdotally, but when I worked at the Edinburgh royal infirmary I must have seen 400 or 500 patients with thyroid disease—mainly autoimmune thyroid disease—each year, but only one or two patients with Addison's disease. That is one of the reasons why we do not test routinely. I hope that we are sufficiently alert to consider the diagnosis if the symptoms and signs are there, but I do not think that any clinic in the world routinely tests for the possibility of adrenal failure or Addison's disease in every patient who comes through the door with thyroid disease.

Sandra Whyte: Convener—

The Convener: Can you make it quick? We are really short of time.

Sandra Whyte: It will not be quick, convener. I have to say that we know that Addison's disease is horrendous. According to the Royal College of Physicians,

> "There are two hormone deficiency syndromes that are rapidly fatal if untreated but which are quite easily managed."

Oh, great. "Easily managed".

> "One is type 1 diabetes, commonly ..."

treated

> "with insulin. The other is"

an Addisonian crisis

> "which requires treatment with hydrocortisone."

Then it actually admits that

> "Unfortunately, too often, healthcare workers do not realise the urgency of treatment for acute adrenal crisis or fail to heed the requests of well-informed patients for hydrocortisone."

I have had to save my son's life five times now because the hospitals did not know what to do. The treatment he has received has been horrendous. He has type 1 diabetes, which requires insulin, as well as Addison's disease, and the problem is that the treatments for the two conditions conflict with each other. The steroids, for example, can affect the diabetes. The severity and speed of a hypoglycaemic attack are horrendous. Just a few months ago, he had an attack and when, in the hospital, he asked for something to eat because he was in such a bad state, he had to wait two hours for two slices of toast to bring him round.

There is a lot of information from Dr Lindner on the connection between cortisol deficiency and fibromyalgia, chronic fatigue syndrome and post-traumatic stress syndrome. Let us not forget with regard to post-traumatic stress syndrome that we are talking about our soldiers coming back from war and sexually abused children having the condition, so in order to deal with counselling, they have to have strong adrenal glands. This is a serious matter. People who have the problem and cannot deal with stress cannot simply tick a box in a benefits claim, so they cannot get benefits and then have to appeal decisions. They simply do not have the stress hormones to deal with such situations.

What is happening is appalling. We are talking about a simple, cheap and effective saliva test, which is actually much more stable than the blood test. I note the amount of money that the Scottish Parliament is spending on other things. It is, for example, spending £270 million on alcohol measures, £336 million on smoking measures and £191 million on obesity—

The Convener: I am sorry to interrupt, Sandra. I certainly appreciate the strength of your view on the matter, but I want to make it clear that we have asked Dr Lindner for a submission. I hope that it will come before the committee at some stage.

We are very short of time. If I do not stick to the agenda, we are not going to get round most of the other witnesses at the table.

Anne McTaggart: On treatment, how common is it for patients with hypothyroidism to be referred to the endocrinologist?

Lyn Mynott: In our opinion and from our experience, it is not common at all. A lot of people have told us that when they ask to be referred to an endocrinologist, the GP refuses to do so because they do not think it important enough.

Lorraine Cleaver: You can get referred if you are lucky enough—I always got referred because I had private insurance. However, it does not solve the problems because you still get the same slavish adherence to a TSH reference range. We now have the evidence to dispute that; the TSH T4 log-linear parameter has been proved to be inaccurate. When I saw the endocrinologist—many people are in the same boat—he found the TSH and T4 to be within range and refused to test the T3. I was told that I had fibromyalgia, depression or whatever. Even getting to see an endocrinologist is not the answer to people's prayers, because endocrinologists still stick by what the RCP says.

I have seen something from the RCP in Edinburgh. It wrote about the Mid-Staffordshire inquiry:

> "If we are serious about driving up standards it is clear there is a need to give patients a louder, more systematised voice which would tell us what we need to know about our performance at the institutional level before it started to seriously fail".

It refused to even engage in this meeting. We as patients have had it up to here with the hot air that we are being fed.

We are not here for the good of our health; we are here for the good of the health of the women of this country. This is a feminist issue. We hear very scientific arguments and we are very grateful for your professional time, but that does not address the problem. People are dying.

10:45

The Convener: I will bring in Tara Willmott first. Do you have any particular view on the questions that were raised earlier?

Tara Willmott: As I outlined in my submission, the GMC's responsibility is to ensure that its doctors are trained to recognise appropriate cases such as those referred to. The GMC does not define the standards. They come from the profession. Provided those standards fulfil our requirements we will agree to them and support them as part of a training programme or a continuing professional development programme for those doctors who have already completed training.

Lorraine Cleaver: I do not want to hog the floor, but Tara Willmott said that the profession decides the standards. The royal colleges usually set them and they devise the training. The royal colleges are registered charities. They could not be compelled to come to this meeting because they do not discharge government functions. Who are they answerable to? They control the health of the nation, but they are charities. They make the rules. The Royal College of Physicians does not even answer freedom of information requests. I would just like to know why the health of a nation is in the hands of a charity.

The Convener: I will ask Dr Toft to answer that question.

Dr Toft: I can answer it and I can speak as a former president of the Royal College of Physicians of Edinburgh. Most of the guidelines about the management of whatever disease, whether ischaemic heart disease or endocrine disease, are brought together by the specialist societies. They may or may not work with the royal colleges.

You made a point earlier about the reluctance of general practitioners to refer patients with hypothyroidism to hospital. That is true. General practitioners by and large are not very keen to refer on. The reason for that—we must not lose sight of this fact—is that the great majority of patients who are treated with levothyroxine for hypothyroidism with a TSH and a pre-thyroxine in the normal range, albeit what I said earlier about what that normal range should be, feel perfectly well.

Lorraine Cleaver: I dispute that. Such patients would be told that they are in normal range and that their symptoms are due to A.N. Other cause so they say to themselves, "Thyroid-wise I am fine, but I have got high blood pressure, or high cholesterol."

The Convener: There are a lot of questioners. I remind people to speak through me, otherwise it will be difficult for us to have a correct record of the meeting.

Dr Toft: I am not persuaded that the great majority do not feel perfectly well while they take levothyroxine because the great majority do not complain. Let me turn to those who do complain and who do not feel well. I have sympathy for that. It is very important for us to make sure that general practitioners realise how to interpret a reference range. If we do establish thyroid hormone levels and TSH levels that we think are correct and the patient continues to complain, I would hope that we would take that seriously.

I have no difficulty as an individual in perhaps treating some of these patients with a combination of thyroxine and triiodothyronine, as long as, while they take that treatment, their thyroid blood tests are all right. I am not doing any damage and there is an increasing move towards the realisation that there may be a role for using both hormones in some patients. Indeed, I remind you that we use both hormones in the form of thyroid extract. I do not for a minute support thyroid extract, but that is all that we had from around 1890 until the second world war. That is how we used to treat patients.

Lorraine Cleaver: Why would you not suggest the use of that now?

Dr Toft: Thyroid extract is often rather variable in its potency from batch to batch. We have evidence for that. Sometimes there is not—

Lorraine Cleaver: I am sorry Dr Toft, there is more evidence for variability in the potency of levothyroxine medicine.

The Convener: I am sorry, but I remind you that you must go through the convener, otherwise the meeting will be very difficult to manage.

I will bring in the minister. We have heard some views from clinicians and I understand that, in terms of Scottish Government health policy, you are still waiting for some reports to come back that will look at guidance. The petitioners have lodged a very good petition and rightly have strong feelings about their individual treatment and the treatment of their colleagues. Can you indicate where you see Government policy going in the future? There is clearly dissatisfaction with some aspects. For example, do you envisage a potential change to SIGN guidelines? There has also been an issue around the genetic tests. It is useful that a few issues have already come out of the evidence. Can you give us some hints as to whether there is a mood in the Scottish Government to change its policy in this area?

Michael Matheson: You mentioned several issues, one of which was SIGN guidelines. We do not control SIGN guidelines and it is for SIGN to determine whether it wishes to take forward specific guidelines in this field. It would draw the guidelines together on the basis of the expertise within the clinical community.

The Convener: Sorry for interrupting, but I want to get the situation clear for everyone. If I understand the situation correctly, SIGN is an agent of the Scottish Government and you could invite it to look into the guidelines that it has produced in this area. Is that correct?

Michael Matheson: SIGN acts entirely independently of Government in determining which guidelines it takes forward. We do not direct it on what guidelines it needs to bring forward.

We set out in our letter in May the three areas that we are taking forward. The issues around things such as genetic testing have already been explored in the meeting. Any changes to how clinical care is provided would have to be made on a very clear clinical evidence base. We are guided by experts in the field—the Royal College of Physicians and their colleagues—on what the policy should be. In the NHS in Scotland, policy will continue to be made based on existing clinical evidence. If changes in the clinical evidence suggest that there should be changes to the treatment regime, we would expect that to be reflected in the practice of clinicians in the NHS in Scotland. However, we do not direct SIGN on what it should and should not do, because that is based on clinical evidence and practice, which the royal colleges lead on.

The Convener: Thank you. That is very helpful. I should have said that SIGN is the Scottish Intercollegiate Guidelines Network. It is within the remit of the Scottish Government, so who is it accountable to, if it is not accountable to the Scottish Government?

Michael Matheson: It is not a case of our directing SIGN that it has to produce guidelines in this area. That is a matter for SIGN itself to determine. I know that the committee has already contacted SIGN, which has indicated that it has no plans to make guidelines in the area. We do not tell it which guidelines it has to publish; it is for SIGN to determine that itself.

The Convener: Thank you. I will perhaps bring you back in when we conclude.

Can I bring in Jackson Carlaw?

Jackson Carlaw: Well, no, because you have asked my question for me, convener, which is very kind of you and relieves me of the responsibility.

However, I observe that it is my impression that this is not proving to be a very satisfactory discussion. We have here a number of people who are suffering from the condition and the impression seems to be that the establishment, in considering their views, does so to a background soundtrack of voodoo drums. There does not seem to have been a productive discussion that would help me to see how things might progress in a way that would satisfy the petitioners. As a layman, I am a bit bamboozled by the technical stuff—which I have to respect and would have to read in some detail again in the *Official Report*—and the experience of the people in the room. That is where we have a difficulty.

Chic Brodie: In view of the answer that I got previously, I almost hesitate to ask this question: where is the clinical evidence? There is a lot of understandable emotion and alleged evidence around this, from both sides. We should not talk about anybody beating voodoo drums on a very serious issue. A fundamental issue is for us all to try to establish what hard evidence there is, rather than to circumlocute what we think is the situation.

Elaine Smith: I agree that there needs to be such a meeting, as the two sides are currently poles apart. More consideration needs to be given to the evidence from patients. As Dr Toft has often said, you need to look at the patient.

Although Dr Toft said that patients do not complain, patients complain about different things. To take my own circumstance, I complained about having headaches, feeling tired and having hot flushes about 10 years ago. I was told that I had the menopause, but that was not the case. Then I complained about sore bones, and I was told to take some paracetamol. Then I complained about depression, so I was given diazepam and depression tablets. Then I complained about general malaise. When I collapsed and was taken to hospital in an ambulance I was told that I had a kidney infection, which I did not have.

In the end, after two years of that, I was referred to a hospital but not to an endocrinologist, despite the fact that I had an underactive thyroid and had had for many years. I might add that as soon as I was put on T4, after 10 years of marriage, I finally had the baby that up until then I was told that I could not have—that was an interesting point that someone made earlier. All that culminated in my being sent to a specialist, who was a neurologist, not an endocrinologist. At the end of all that, I was told that I had myalgic encephalomyelitis or ME. Had I accepted that diagnosis, I would not be sitting here talking to you today, but I did not accept it. I demanded to see an endocrinologist—I saw Dr Toft—and I was put on T3 and came back from the dead, quite literally.

I think that about 20-odd per cent of people who have been diagnosed with ME have an existing underactive thyroid condition. For a start, I would like to see those people put on T3 to see how they get on. Yes, let us monitor their heart and monitor their bone density, but if they make a comeback from the dead, surely it is worth trying them on that. I would also like to see something done for people who are told that they are borderline. For example, my sister, whose mother and sister have underactive thyroids, is not being given T4 or anything, despite being quite ill, because she is told that she is borderline. What exactly does that mean? Surely she should be put on T4 under the guidelines and given a chance to see whether that makes her better.

The thing that is missing today is a fuller discussion—perhaps the committee could consider an inquiry—with patients. We should hear their experiences, pull all those together and then present that evidence to the establishment and say, “Maybe you have to think about things a little bit differently.” For example, I point out to the GMC representatives that Dr Toft has said that, until the drug companies invented T4 and made money out of it, prescribing desiccated thyroxine was for many years the only way of treating hypothyroid conditions, but that is now not even looked at. When a GP prescribes desiccated thyroxine and finds that the patient comes back from the dead—I mean that quite literally, because that is how people feel—the GP is reported to the GMC. That is just completely unacceptable.

Professor Williams: I will make a general comment and say that I do not think that it is helpful to talk about voodoo language. In my experience, every doctor has the wellbeing of patients at heart. We spend a lot of time listening to our patients and trying to do what we think is the right thing for our patients by prescribing what we think is the best treatment.

The British Thyroid Association works closely with the British Thyroid Foundation—surprisingly, it is not represented here today—which is a patients charity that has more than 3,500 members. Of those, 20 per cent are Scottish residents, so the charity is highly relevant here. I am a trustee of that patients charity, as are two other members of the British Thyroid Association. The foundation organises 11 or more regional meetings, which, depending on the region, take place approximately once a month or once every two months. At those meetings, representatives from the British Thyroid Association will give a talk, answer questions and engage with the public and patients about thyroid disease. That is a good example of the medical profession engaging with patients with thyroid disease, trying to find common ground and trying to help.

The issue of genetic testing is interesting because, again, we are right at the cutting edge of science. I think that the view of most people is that individuals vary according to their genetic make-up, and it is highly likely that, in the future, we will be able to identify individuals who have different set points in their thyroid status compared with the general population range. The trouble is that the current understanding of science does not give us the ammunition to personalise treatment in the way that has been suggested, and we could do harm to people without that knowledge. That is a real difficulty. We are in limbo a little bit until we get further information and know. There is certainly intense study in the area. People are really trying to find a way of taking the matter forward.

I do not think that we are too far apart. We need to work together rather than be adversarial.

11:00

Professor Leese: I am afraid that Professor Williams has made all the points that I was about to make. I emphasise that the medical profession cares about the matter. I agree with Dr Toft that a small minority of patients do not feel brilliant on thyroxine.

Lorraine Cleaver: I am sorry, but where is the evidence for a small minority not feeling brilliant on thyroxine?

The Convener: I will let Professor Leese make his point. I will then be happy to bring in the petitioners.

Professor Leese: The science is potentially being overinterpreted. It is right at the cutting edge, so we need to be cautious about it. As Professor Williams said, the bottom line is that we want to give and advise treatments that are safe.

I suppose that there is one area in which there may be some evidence, which we are being asked for. The percentage of patients on thyroxine who have expressed problems in large trials is perhaps 10 or 12 per cent or so. That is the same percentage of patients who express similar adverse effects in other trials for patients who are not on thyroxine at all. There is a general symptomatology around for whatever reason. I agree that the medical profession perhaps does not have a good handle on what is causing that, but that does not necessarily mean that it is a thyroid cause.

Marian Dyer: I was given thyroxine, and I could not take even one tablet. I had instant tracheitis. Actually, it could not be tracheitis, which is an infection, but it really affected me.

I have gone through my whole life having symptoms of endocrine disorder. [*Interruption*.]

The Convener: Will the person who has that mobile phone please turn it off? It interferes with our sound system. Thank you.

Marian Dyer: I had eczema, dermatitis, severe premenstrual tension, morning sickness to the point of not putting on weight and being hospitalised, pre-eclampsia and postnatal depression. I was told that I had chronic fatigue for a year. I had to give up my job and I lost everything, including my house, through illness. All those things are symptoms of thyroid or endocrine disorder and not one professional seems to know that. If they do, they keep it to themselves; they do not treat people for it. It is absolutely appalling.

Sandra Whyte: Why could there not be a trial to test the peripheral tissues? There could be a study for a period of time to check all the patients with free T3 and T4 and reverse T3 to see what comes of it. There is adrenal testing and the optimal nutritional evaluation, which is another fantastic test that looks into amino acids, vitamins, minerals, enzymes and neurotransmitters. It is a £300 test for a person’s whole body chemistry.

One tablet is handed out and whether we are deficient in something else that could cause the problem of hormones not getting to the cells is not taken into account. If there was even just a trial over a period of time, there would be some scientific evidence.

Professor Williams: I will come back on that specific point. First, those kinds of tests are not very specific, so it is very difficult to ascribe cause and effect. That has been addressed in considerable detail.

We are getting into technicalities again, but a specific group of patients has been identified who have mutations in their receptors for thyroid hormones. Those mutations were first described in 1988 and mutations in the second form of the receptor have been described as recently as 2012; there are only four patients in the literature with mutations in that gene. We know that those individuals are unable to respond to thyroid hormones specifically in the tissues that thyroid hormones activate, so people have been trying to identify markers of the tissue response to thyroid hormones in patients who have absolutely no response, well documented by clear mutations in the receptors, as opposed to normal individuals. Unfortunately, the tests that have been done do not discriminate satisfactorily enough, even with those people who have absolutely no response to thyroid hormone in that tissue, so the problem is a lack of specificity in ascribing cause and effect to the results of such tests. In a situation in which we have a graded problem in terms of the responsiveness to thyroid hormones, if it exists, the tests that are being proposed are actually not discriminating, and that is why they are not helpful.

Sandra Whyte: All three of us have followed those tests and the deficiencies that came up in them, and we have all got better. We have come to health ourselves, so the tests do work and they are not any worse than the blinking TSH T4 test at the moment, which is also flawed, as you must agree. That test is not a superb test itself. We are asking you to consider the new test, for the sake of the guidelines, to see whether there is a way forward. Let us not forget natural thyroid extract either. We all have different chemistry and we all need a different mix to make us better. What could be better than doing tests and seeing what the results are, so that we can come to a final agreement?

We are the worst patients, believe me, because we will not go away. We are the ones with the symptoms, so we will keep coming back and we will not give up. If we do not get satisfaction here, there will be thousands coming up behind us. There are people in England at the moment trying to bring the issue to the Government's attention; they need 100,000 signatures before they can get the Government even to listen to them. The majority of patients have fibromyalgia; they do not even know that they have thyroid problems, so they need help. Here in Scotland, one signature is all that is needed to get an important petition heard, and we should be proud of ourselves for that.

The Convener: I appreciate those comments from Sandra Whyte.

Lorraine Cleaver: I shall keep my remarks brief. I had a twitter conversation with Sir Muir Gray, who is the chief knowledge officer for the NHS, and he said that thyroid disease is "much more complex" than most doctors realise, never mind patients. If we are waiting for new trials and guidelines, we have to bear it in mind that the guidelines are based on trials, 50 per cent of which are never put forward or published and are skewed in favour of the positive trials that reflect well on the pharmaceutical company that funded them. Doctors are already treating us with a biased parameter, because they have only ever been shown the good, positive trials.

There is also evidence—Lyn Mynott knows more about this than I do—about stacking the panels that made up guidelines in favour of the clinicians who hold the party line. Michael Matheson may be looking into all that and signing whatever he is given, but we have to bear it in mind that the guys who hold the party line are the ones who make up the guidelines.

Professor Leese: I am unaware of any pharmaceutical industry trials in thyroid disease for a number of years. Clearly, there have been trials in other areas, such as diabetes, but if there is not a strong pharmaceutical push it is partly because there are no new treatments. I agree that that is a problem, but—

Marian Dyer: If they cure it they will not make any money out of it.

The Convener: We are now running over our time limit, but I am prepared to extend the discussion for a short period. I ask members and witnesses to keep their remarks brief.

Angus MacDonald: I know that we are under pressure for time, but I would like to return briefly to the issue of treatment. We have touched on desiccated thyroid extract already and I am curious as to why it does not have a licence. Is it because there has been no application for a licence, or have applications been refused?

Lyn Mynott: Desiccated thyroid extract was introduced many years ago, before licensing. It did not have to go through the licensing process because it is so old—licensing did not start until later. It is approved in Canada and America, but it has not gone through the licensing process here because the companies feel that that is not necessary. It is grandfathered, if you like. It is an old product that has worked well for many years, and licensing is not felt necessary.

Dr Toft: What I said about thyroid extract is correct, but I agree with what was said after that about levothyroxine being a little unreliable. In my experience and that of others, if patients are given a prescription and take it to the pharmacist for a refill, they will be given the cheapest form of levothyroxine that is available in the pharmacy at the time. I do not know where many of the tablets are made, but there is a problem. The advice to patients is to insist that they are given the same manufacturer's levothyroxine at each prescription refill. That is as good as one can do. However, that is not to say that that company is not going to have some inter-batch variability, which is an issue. I do not know how often that is checked once a company has got its licence to produce levothyroxine.

Professor Williams: Thyroid extract is produced from pigs—it is porcine extract—and the ratio of T4 to T3 in the pig thyroid is approximately 4:1 or 5:1, whereas in the human thyroid the ratio of T4 to T3 is about 14:1 or 15:1. The constituents that you are starting with are different from those in humans, which makes it pretty difficult to manage the dosage and what is being done with it. That is one of the reasons why there has been a lot of debate and discussion in the area.

Elaine Smith: I will comment briefly on what Dr Toft has just said. The problem is that GPs are being told that they must generically prescribe, so if people want a Goldshield Pharma product—that is what I was on, but it suffered the same fate that arose with the lack of T3, which the committee knows all about, because it was made by the same company, Mercury Pharma—they have a terrible fight on their hands to get their GP to prescribe them that product.

Lyn Mynott: A lot of doctors are prescribing T3 and Armour Thyroid, and the patients are doing very well. They are not finding it difficult to monitor or control the dosage. These are some of the things that we hear from patients:

> "My doctor wants to prescribe T3/Armour but is afraid to … My doctor wants to prescribe T3/Armour but his colleagues have said no … My doctor wants to prescribe T3/Armour but the endocrinologist has said no … My endocrinologist wants my doctor to prescribe T3/Armour but my doctor has said no."

There is no consistency and the situation needs to be sorted out. There are now European guidelines for the use of T3 with T4 on an experimental basis. I think that a lot of GPs are not aware of that, but they need to be made aware of it. They need to be made aware that it is okay to prescribe T3 on a trial basis to see whether it helps the patient. Something needs to be done about this, and it needs to come down from the Royal College of Physicians.

Chic Brodie: This is probably heresy as far as the professionals—the doctors and professors—are concerned. We have talked about these medicines, and Tony Toft has raised concerns about doctors not consistently prescribing the same registered medicine. I am sure that we have not heard the end of that. Has anyone considered homoeopathic cures for the conditions?

Sandra Whyte: If we do not get anywhere with the petition, the only answer for us is to go down the homoeopathic route.

Professor Williams: Lyn Mynott is correct in saying that the European guidelines mention T4 and T3 therapy as an experimental therapy. The research was written by a chap from Amsterdam called W M Wiersinga, who has been well respected in the field for many years. However, the European Thyroid Association was very cautious about the therapy. First, it cautioned that it does not mean that larger numbers of patients should be given T3 and T4. Secondly, it said that the experimental therapy should be trialled for three months only and that the trial should be conducted in a specialist department. That is a bit different from representing it as being a treatment that should be given by GPs. That is absolutely not the case.

11:15

I think that Wiersinga’s article was very balanced and recognised that the science is moving and that, at the moment, we do not really understand more than the situation that I have tried to outline.

Professor Leese: My only additional observation is that presumably a reasonable amount of T3 is being prescribed in Scotland. When production went down, there was a noticeable problem—many patients had problems. To me, that reflects the fact that a significant minority of patients may be on T3.

Marian Dyer: Professor Williams, might you be more interested or more passionate if members of your family were suffering from this and you were trying to get them better, rather than objectively sitting on whatever body?

The Convener: I think that we are trying to look at the general trends behind the petition.

Marian Dyer: Yes, but it is just that if everybody is going to be objective, nothing will ever happen, because everybody will say, “We can’t do this because,” or, “We can’t do that because.” We are saying that we have to do something.

The Convener: We are well over time and I still have a question from John Wilson.

John Wilson: Thank you, convener. My question is about the issue that has been raised by Elaine Smith and Lyn Mynott regarding doctors treating patients with hypothyroidism who are being either disciplined or reported—one situation has been referred to the GMC. What evidence do we have that doctors are or might be in fear of being reported to the GMC, the British Medical Association or whoever for using treatment methods that may be deemed inappropriate?

Tara Willmott: That is a question for the GMC but, as I said, I am from the education side of the GMC. On the fitness to practice side, our guidance to doctors is that they need to follow the published standards and that working outwith those standards and guidelines could cause them to get into difficulties. However, that would be an interpretation that they and their colleagues would discuss and, obviously, they are allowed to go through research and so on. I am sure that medical colleagues in the room will have worked in those areas.

Dr Toft: Perhaps I can help the committee with regard to the individuals who prescribed thyroid extract and were reported to the GMC. Those individuals prescribed thyroid extract without doing any thyroid blood test to begin with in order to prove the diagnosis. They also did not record any blood test results after prescribing thyroid extract, and they were giving very high doses of thyroid extract. That was the reason for the referral to the GMC.

John Wilson: You refer to doctors who were reported for not carrying out blood tests. We heard earlier that biochemists refused to carry out certain blood tests. Would the blood tests that you refer to be included in those that the biochemists refused to carry out?

Dr Toft: No.

John Wilson: Can you give us an assurance on that?

Dr Toft: Most laboratories—I think possibly now all laboratories—will provide T4 and TSH for the diagnosis of an underactive thyroid. There was a spell, for which I was partially responsible, when we thought that TSH alone was a perfectly adequate test in the diagnosis of hypothyroidism. The foolishness of my claim was soon discovered.

Lyn Mynott: Could I have that in writing, please?

We need to get together and have another meeting to try to change things. I do not know of any NHS doctors being taken to the GMC for treating patients with Armour Thyroid, but we are afraid that that will happen. Patients regularly phone us to say that they have asked for a trial of T3 or Armour and their doctor has told them, “I am sorry—I will get into trouble if I prescribe you this medication. I can’t do it.” That is where the conversation finishes.

The Convener: I will conclude by asking you a question, minister, because I know that you have to go very soon. Can you update the committee on any correspondence with the British Thyroid Association and on whether you have come to any conclusion about the establishment of a short-life working group?

Michael Matheson: One of the three points in the letter that we wrote to the committee in May indicated that we had written to the British Thyroid Association. We are also taking forward the points on the diagnostic testing aspect and the evidence base that the Scottish health technologies group at Healthcare Improvement Scotland is considering. Once we have information on all three points, we will come to a considered view on whether we should take further measures.

As I said, I expect that we will have that all in place by the end of the year, after which we will be able to respond to the committee. We will consider at that point whether there is any merit in establishing a working group or any need to do so. I am sure that the committee will appreciate that before establishing a working group, we must be very clear about its intentions and whether there is anything that it could meaningfully take forward. Once we have had detailed responses on the three points that I indicated, we will be in a position to determine whether there is a need for a working group.

The Convener: Thank you for that.

Just to be clear to everyone around the table, the committee will now look at how we deal with the petition. I ask everyone to stay for that discussion.

Clearly, the Scottish Government has done some work on the issue and we have just heard from the minister that the Government will be able to give us more insight into that at the end of the year. There has been some reference to SIGN guidelines and we have heard the minister’s view on the technical aspect of that. I think that it was Lyn Mynott who talked about a role for patients.

As always, the committee will be aware that we must look clearly at the petition’s terms of reference. We obviously have the advantage of having the three petitioners in front of us. Certainly, we need to continue the petition, but I look to the committee for guidance on our next steps. One option, of course, is that we continue the petition until we have had the full picture from the Government, which I hope will be in a few months, as we have heard. There will certainly be some advantage in looking at that. The Government cannot direct SIGN to change guidelines. SIGN could take it upon itself to look at the issue, but the correspondence that we have had from it indicates that it does not wish to do so. I ask for the committee’s views on our next steps.

Chic Brodie: We must continue the petition and wait for further information from the Scottish Government on the work that it has undertaken. However, I make a plea again about having real evidence from whichever side. It is not beyond the powers of the people in this room to get together outwith the Parliament to try to rationalise some of the information that is available and bring that back to the committee as we progress the petition. You might not have total unity on the issue, but perhaps you could have some unity so that some of the understandable emotion could be taken out of the discussion and you would have a better understanding of one another’s positions. I hope that that would allow us to progress the petition in a much more meaningful way.

The Convener: So one point, Mr Brodie, would be to look at the patients’ side, which I am sure the petitioners will do, and get more raw data from patients who are experiencing difficulties, so that we can—

Chic Brodie: No—not just that. I would like to see the petitioners working with the doctors and professors to get better understanding on both sides, so that we can take out some of the emotion—and some of the magic—around the discussion.

Jackson Carlaw: I am not sure what Mr Brodie means.

Chic Brodie: It is about trying to take the voodoo out of the whole thing.

Jackson Carlaw: That is to mischaracterise what I said earlier. I think that there is clear merit in what the Government proposes to do, but the advice that it is receiving seems to me to be predisposed to follow a particular path. Unless we are able to harness in some way something from the group of patients beyond the petitioners—I think that Elaine Smith followed me in saying that it was not being properly represented here—I can already anticipate what the professional advice might say. In that sense, I do not know that we will advance at all. It is not a case of rather naively hoping that people will have a pow-wow in the park afterwards; I think that we might need to be just a little bit more proactive than that in trying to bring out some of what I agree is difficult evidence for us to put our fingers on. However, I feel that the patients' side has been missing this morning.

The Convener: The mood of the committee is clearly for this excellent petition to be continued. The timescale for that is partly governed by the Government—we want to hear what the Government's views are at the end of the year. There seems to be consensus in the committee on that. Is there anything that committee members wish to add?

Elaine Smith: In Edinburgh this Saturday, the British Thyroid Foundation is holding a big conference, which will bring together medical people with patients. The intention is to record it, and it might be of interest to the committee to see what comes out of that.

The Convener: We would welcome information on further research or work that is done by patients or medical practitioners—I am sure that I speak on behalf of the committee. If it is possible to get a transcript of that conference, through Elaine Smith, that would be very useful.

Does any member of the committee have any converse view to my suggestion to continue this excellent petition and to await the Government's view on the issue? We can consider the matter again in light of the Government's next steps.

John Wilson: I am not saying that we should not take the petition forward, but I make a plea that we ask the medical profession, along with the Government, to examine the issues that have been raised by patients more widely—not only by the petitioners and Thyroid UK. What I heard today was very much a defence of the medical profession—that it is doing the right thing because so many patients do not complain about their treatment. The difficulty that I have is that patients may not know how to complain or what they could complain about in relation to the symptoms that they feel or suffer following a medical intervention. We need to consider how we can follow that through with patients so as to build their confidence in the treatment that they receive. I heard in the background from people in the public gallery responses to what they heard from the committee table. We have to instil confidence in patients that they are getting the best medical treatment available, and we need to deliver a medical service that actually treats the individual.

A number of individuals have come down with different symptoms after treatment. Marian Dyer gave a perfect example to do with her experience of one type of medication. The Government and the medical profession need to gather together real patient experience of what and how they are suffering in relation to the treatment that they are receiving. I make this plea to everybody around the table: get that information in and get it collated, such that it reflects the way that we should be treating people with these conditions.

The Convener: John Wilson makes some excellent points. The conference on Saturday will be a really good coming together of patients and medical practitioners.

Chic Brodie: I have a question for Elaine Smith. My concern is about the lack of cross-communication. I sympathise with everybody on this, but will there be people like Professor Williams—I am not saying Professor Williams specifically—who can explain the downside of where we are at medically, and the implications for patients if there is a misdiagnosis?

Elaine Smith: Do you mean on Saturday?

Chic Brodie: Yes, on Saturday.

Elaine Smith: I am not organising the conference, although I hope to get along to it. I know that one of the speakers is Dr Nicola Zammit, who is from the RIE, where Dr Toft used to work. Other medical professionals are speaking at it, too. Patients may go along to the conference, and presumably they can interact with medical professionals.

The Convener: I call Dr Toft—very quickly.

Dr Toft: I want to challenge Mr Wilson's view a little. We know that most patients feel well. We follow up in hospital patients whom we have been treating with levothyroxine for an underactive thyroid gland, and we know that they are well. You are not going to expect—

John Wilson: Dr Toft, how often do you follow up with patients in relation to the treatment that you provide?

The Convener: Colleagues, sorry—I do not want to reopen the whole argument. I will let Dr Toft finish his point, and I will then bring John Wilson in.

Dr Toft: I am not for a minute—

John Wilson: Convener, this is supposed to be the committee's summation on the petition—the purpose of the discussion is to allow the committee to decide how to take the petition forward. You reopened the debate. If you want to continue the debate, I would like us to do that as a committee. My understanding, however, is that we had moved on to the committee's summation on the petition, so that we can move on to other petitions.

11:30

The Convener: This is the committee's summation, but we allowed others in. I remind members that the witnesses are not necessarily familiar with our procedures. I believe in being as polite and courteous to witnesses as possible. Technically, however, Mr Wilson is correct. I will not allow any further involvement by the witnesses, although I note that this is a very important petition on which strong feelings have been reflected over the past hour and a half. We extended the discussion by half an hour, which I feel was the right decision.

We will continue this important petition until the Government has come to conclusions on a number of areas of work. We obviously invite people to submit other evidence, for example from the conference on Saturday. I leave it open to the petitioners, other patients and, indeed, the medical fraternity to write to us. The committee's decision is to continue the petition.

I thank the three petitioners. I know that it has been very difficult to come along and explain your personal circumstances. I appreciate all three of you coming along. I also thank Elaine Smith, who is in a similar position. I thank all the other witnesses. The discussion has sometimes been quite tense and difficult as people have put across their points, but I really appreciate your giving up your time and the efforts that you have made. Obviously, the issue will run and run. I also thank the minister and his team for coming along. I appreciate his openness on the subject.

11:31

Meeting suspended.

11:36

On resuming—

New Petition

Primary 1 Class Sizes and Sibling Placing Requests (PE1486)

The Convener: The next item of business is consideration of PE1486, by Julie Wales. As previously agreed, the committee will take evidence from the petitioner. Members have a note by the clerk, the SPICe briefing and the petition.

I welcome the petitioner, Julie Wales. I invite her to give a short presentation of about five minutes to set the context, after which we will move to questions.

Julie Wales: Thank you. Until the upper class limit of 25 in primary 1 was introduced, parents thought that it was an urban myth that five-year-old children could be segregated from the familiar school that their elder brothers or sisters attend. While Scotland is going forward to the historic referendum in 2014, it is ignoring the needs of five-year-olds and relying on a 33-year-old act to claim that schools or classes are too full, which impairs the family unit and sibling bonds by turning younger brothers and sisters away from their elder siblings' school.

Primary school and effective learning need to be characterised by the findings of Maslow, whose proven research indicates that the basic human needs should be met for effective learning to take place. Primary schools in an independent Scotland should surely be a secure environment, but parents in this developed nation are being forced to consider extracting elder children and moving them to other schools, while younger siblings are displaced into alternative schools. Appeal boards pay lip service when they state that a school is too full before they turn their backs on parents, who are then forced to make repeated placing requests at two-monthly intervals while their professional lives are eroded.

Parents have to try to balance work with multiple impractical arrangements. My associate Lynne Connor, who is with me, runs between two schools that are 7 miles apart, before 9 am, to drop off two children. The irony is that, even where placing requests take cognisance of the siblings in the pipeline, nowhere does it state that the strategy of placing requests for the education of the first child in the family is high risk. Parents who struggle to deliver children safely to school before 9 am are forced into a dangerous rush against the peak-time traffic or, as an alternative, expensive private childcare, which is another hidden tax on the working population.

The cost of breakfast clubs in East Renfrewshire, at £4.95 per day, equates to a forced spend of nearly £1,000 in each academic year. After-school clubs often finish at 5.40 pm, in some cases incurring charges that can vary from £8 to £15 per session in Glasgow city. The 5.40 pm stop precipitates another rush in the rush hour when children have to be collected from multiple addresses.

As the dark mornings draw ever closer, each parent who is in this predicament is faced with the prospect of leaving youngsters alone in dark playgrounds, which is a further impediment to child safety. If the Government is committed to increasing the workforce that contributes to the country, the policy of sibling rejection goes against the direction of the target. Parents are left to struggle with in-service days that vary from school to school, parents' nights, holidays, clashing homework burdens and so on. Historic investment in college and university education pre-parenthood becomes a waste if skills and qualifications cannot be utilised owing to this barrier, which is so rigidly held in place.

The maximum class size of 25 in primary 1 looks effective on paper. However, the National Records of Scotland states that it is not possible to calculate pupil teacher ratios for primary 1 to 3 pupils separately as it is unable to identify the proportion of time for which teachers work with P1 to P3 classes. Class size information is available for them, but it includes only the class teacher and not input that is received from other teachers such as headteachers, specialist teachers of music, physical education and so on, as it is not possible to allocate their time to a specific group. Might that data not support a movement towards flexibility on 25 as a maximum class size to assuage the possibility of sibling rejection?

There is a wealth of evidence from the UK and elsewhere that lower class sizes improve educational outcomes for children. However, the scale of the effect of a class of 25 as opposed to 30 is smaller than the effect of a class of 18. If the Government could provide resources for lower class sizes in P1, that would be far more effective.

I was forced to consider resigning from my post as a college lecturer because, having invested in childcare to the tune of as much as £1,500 per month for the past four years, I realised—I had a horrible wake-up call—that my placing request strategy had suddenly become very risky. As in most households, it is my role as the mother to deliver the children to school and I had anticipated a drop in the rate of childcare this year with one more child going to school. With the third child still costing me an average of £500 per month, I feel cold at the thought that I will have to put more money into childcare should she not get into school alongside her two sisters.

I represent a significant investment of public money given the years that I spent in education at college and university, and thousands more pounds have been invested in me as a college employee in the form of continuing professional development and training. I feel that, if my last child does not get into the school, I will have to draw the line and say, "No more", and I cannot be alone in this situation.

The number 25, as a maximum limit for P1, restricts choice for parents and forces children to be separated. The practicalities of five-year-olds being managed into separate schools creates an enormous struggle on the ground for parents. Stressed parents result in stressed children, resulting in a negative learning experience. Flexibility on the number 25 can be supported with sustainable improved contracts for probationers, investment in information and communications technology and greater use of composite classes to improve the pupil teacher ratio significantly. Any parent would rather see a five-year-old happily settled into a class of 26 than see them forced into a separate school.

The Convener: Thank you for your submission. I should also have welcomed Lynne Connor. Please feel free to intervene at any time if you wish to answer a question or just make a point. I will ask a couple of questions and I will then throw the discussion open to my colleagues.

You mentioned some statistics. According to the Scottish Government information that I was given, in 2012, most primary 1 children were in classes of between 21 and 25 pupils. Do you object to the numbers that are put forward?

Julie Wales: I object where children who would otherwise, before now, have managed to get a place are squeezed out. The increase in the birth rate in 2008 has caused this situation. There has also been an increase in the population that is migrating to Scotland—a further 43,000 people aged between 16 and 34 came to Scotland between July 2010 and July 2011—so I only see another problem for the future. The volume of primary 1 pupils has increased but the schools have not kept up.

11:45

The Convener: The statistics show that three local authorities have average P1 class sizes of between one and 18. In effect, there is a postcode lottery, which is something that the committee sees a great deal in other spheres. Do you agree that it is a bit of a lottery, given that some authorities have an issue while others do not?

Julie Wales: Yes.

Lynne Connor: Yes. I am in the same situation just now. My daughter goes to a school in East Renfrewshire Council's area, but when I placed a request for my son to go there, he did not get in. I am now going between two schools in the mornings, which is ridiculous—it is an absolute nightmare. Julie Wales talked about stressed kids and stressed parents—well, that is what I am.

Chic Brodie: Because of the various other factors that you have mentioned, these things sometimes take time to implement. I do not wish to defend my Government but, in 2006, 32.9 per cent of pupils were in classes of 26 or more, and that figure has now dropped to 0.9 per cent, while 15.9 per cent of pupils were in classes of one to 18, and that figure has now risen to 27.7 per cent. It is clear that you want to see another nudge, but do you think that things are moving in the right direction?

Julie Wales: Class sizes might be moving in the right direction, but a percentage means nothing to a five-year-old who is not allowed to attend school with their bigger brother or sister.

Chic Brodie: So, is the real issue that the petition raises the placing of siblings?

Julie Wales: Yes. In essence, it concerns the sibling's right to attend the same school as their bigger brother or sister. I cannot imagine that the Government would publicly perform a significant U-turn on the number 25, which is why—

Chic Brodie: The Government's objective is to get class sizes down to 18 as soon as possible, and the figures that are presented indicate that that is happening, although perhaps not as fast as we would like. I am trying to get to the real rationale behind the petition, which seems—understandably—to be the placing of siblings and the impact that that might have on sibling attendance.

Julie Wales: Yes. Siblings are certainly the motivation for the petition.

John Wilson: As a parent who used the placement request system for my daughter when she went into education, I know that, due to economic and other circumstances such as childcare problems, issues sometimes arise regarding placement requests. When someone makes a placement request, the system is often perceived to be a lottery because local authorities have to make the catchment area a priority, and they will then consider placement requests beyond the catchment numbers.

The petition concerns not just placement requests, but requests that would favour applicants who already have children at a particular school, which could be to the detriment of other people with children who live in the catchment area.

You make a couple of statements in your written submission about playing around with the number 25, which is the maximum P1 class size that the Scottish Government allows. You give an example from Glasgow, where the catchment limit for a school is 50 children, which gives two classes of 25, and you suggest going for three classes of 19 because of the seven placement requests that were rejected.

You also ask why we do not just go for class sizes of more than 25 because it is an arbitrary number and changing it would not make any difference to children and how they are taught. Are you, in effect, saying that you want to turn round the perceived thinking on educational attainment and class sizes to accommodate placement requests where there are siblings in the school?

Julie Wales: If every class was full and the opportunity did not exist to improve the pupil teacher ratio by adding another classroom to the school, I would not—if it was Battlefield primary school, where my daughter goes—like to see another P1 class being created and taught in the unsuitable environment of the dining hall. Unless considerable investment is made in the physical resources of schools, it is not possible simply to add classes. However, if there are 25 pupils in a class and one more has to be squeezed in, that additional pupil will surely not make a significant difference to the 25 pupils who are already in the class, if it has been proven that 18 is the effective number to aim for.

John Wilson: The issue that I am raising is that the class size—26—will be, or should be, its size throughout primary education, until the pupils go to high school.

I have in mind a question that I need to ask. What are the school rolls in the area where you live? Placement requests could result in school rolls in some areas falling dramatically and the local authority deciding to close primary schools—as Glasgow City Council did—because there is not sufficient uptake or demand in their catchment areas. Is the school to which you should send your children oversubscribed or undersubscribed? Do you know the size of classes in that school?

Julie Wales: You are asking about the school to which I should send my children.

John Wilson: Yes—the designated catchment school.

Julie Wales: My catchment school is in Dalry, which is in North Ayrshire. However, I work on the south side of Glasgow, so it is impossible for me to drop my children off at that school and get to work and to get back home in time to pick them up. It was always our intention to move house to be closer to work but, by the time my children started school, the economic climate meant that that was impossible.

I have been in the primary school in Dalry. It is a beautiful new-build school that received an excellent report from Her Majesty's Inspectorate of Education, but it is not physically possible for me to school my children there without missing out on being able to drop them off at school, pick them up, complete their homework with them et cetera. I do not know what the uptake is at the local school.

John Wilson: It is clear that the issue is about more than just class sizes; it is about the economic circumstances in which the petitioner finds herself and her ability to maintain her economic status. I thank the petitioner.

Anne McTaggart: My question has just been asked. It was about the designated catchment school that the petitioner's children should have gone to.

I would like us to ask the Scottish Government and the Convention of Scottish Local Authorities whether they are minded to look at class sizes. I hear the petitioner's pain—I have been there. Difficulties are being experienced, so I think that we should ask the Scottish Government and COSLA whether they are minded to look at the situation.

The Convener: That is really a question for the Scottish Government. Thank you for that.

Jackson Carlaw: I have toured the school in Dalry. It is a nice modern facility.

I hope that this does not sound unfriendly, but I will try to get to a point at the end of it. You referred to a sibling right, but I am not sure that I recognise it as such. I have no evidence that siblings who have been educated at different schools have suffered. In fact, some parents have consciously chosen to have their children educated at different schools so that one is not bound by the reputation of the other and they can both operate individually.

I understand the desirability of sending siblings to the same school from a parental point of view, and I respect the fact that, in some families, that might be what the children would like and it proves to be of benefit to them. However, I do not know that I would accept that their not being at the same school is in some way fatal or will undermine their confidence or their education.

I think that the essential point that you are trying to make is that, with the anticipated or forecast increase in the primary 1 population, the current drive to reduce class sizes will, in the years immediately ahead of us, exacerbate the problem for siblings that you have identified. What is needed is some flexibility through this bubble to ensure that things are not totally prejudiced against siblings in the way that you think is currently the case. Is that essentially your point?

Julie Wales: Yes. That was beautifully put. Thank you.

The Convener: That has made Jackson Carlaw's day. Lynne, do you wish to add anything?

Lynne Connor: All that I want to add is that, when my son was seen by a child psychologist about his development and his behaviour, it was suggested that it would be beneficial for him to attend the same school as his sister. He still does not understand why he is not doing that. Every day, when he goes to school, he says, "Why am I not going with Grace?" He just cannot understand it. It is difficult for me as a parent to say, "Tough luck, son. You need to go there."

Jackson Carlaw: That is why I tried to say that there needs to be a degree of flexibility. Some families might take the contrary view, as I know that some siblings cannot stand the sight of each other in the room and would hate to think that they had to attend the same school. What you are saying is that the system precludes any judgment based on the appropriate need. Although the current drive is towards a perfectly desirable objective, we are in a situation where a population bubble is exacerbating the problem. I think that I understand that point.

David Torrance: As someone who has dealt with many requests from constituents about certain highly sought-after primary schools in my area, I know that schools in certain areas tell any parent whose child gets a place that, given the predicted rolls in two or three years' time, there is no guarantee that any further children will be admitted. At the same time, parents who live within the catchment areas of certain schools cannot get their children into those schools because the number of placement requests that have been accepted is so high. For me, someone who lives in the catchment area should be the first priority.

Julie Wales: I agree to a certain extent. However, if the school is so good, why can we not invest in providing a portakabin and a probationer teacher—perhaps from among the 25 per cent of probationers who did not get into work between 2011 and 2012—to bolster that fabulous school so that it continues to produce fabulous pupils and a sustainable workforce for Scotland in the long term?

David Torrance: One of the schools that I mentioned has so many portakabins that the playground has totally disappeared. That is because the school is so popular and there is such a big population in the local area. That school is now struggling to accept any placing requests because, for example, new houses have been built in the catchment area. There is real strife between parents who live in the area and are trying to get their children into the school and those who want a second child to attend the same school as their sibling.

Julie Wales: That makes me wonder why the council planners did not consider that when they allowed the houses to be built. It is clear that family homes are likely to house more primary pupils, who will then be within the school's catchment area. It does not make sense if the school has not kept up.

David Torrance: Most primary schools in Kirkcaldy have occupancy rates of less than 60 per cent. Many primary schools have high underoccupancy rates because of placing requests. I can see where you are coming from, but I have had to deal with both sides of the argument. In certain areas, there is real strife between parents who live in the area and those who want siblings to go to the same school.

Angus MacDonald: The petition suggests that there is a fairly simple solution to the problem of the displacement of siblings in areas of high population growth, such as Falkirk and—according to our briefing—Stirling, Perth and Kinross and East Lothian. The petition asks:

> "Could each council not facilitate better planning for sibling requests by requesting information about family members likely to want to join same schools in the future?"

I hope that local authorities already do that to a degree, but it strikes me that local authorities cannot plan to take into account situations such as that of Julie Wales, who commutes from Ayrshire to work in Glasgow. Local authorities cannot second-guess what will happen a few years down the line and whether there will be situations such as hers. That is just an observation.

12:00

The Convener: In your experience, when a placing request has been made from outwith the area, is the decision based purely on the capacity in the school or is an informal approach taken that involves considering whether the family has other children at the school? I know that that is not necessarily in legislation, but is it a factor?

Lynne Connor: Not in my experience. I am in the enviable position that my daughter got into her school. However, there was no guarantee that my son could get in, and if I wanted my children to go to the same school, I would have to move my daughter.

The Convener: So, in effect, the regulations would need to be changed to establish a statutory right for siblings to be schooled together. That is what the petition argues for. Have I understood that correctly?

Julie Wales: Yes.

The Convener: As my colleagues have no more questions for the petitioners, we will now consider our next steps. Anne McTaggart suggested that we ask the Scottish Government and COSLA for views on the petition. Do members agree to that course of action?

Jackson Carlaw: Our briefing refers to a Government response in March, in which it said that there would be a consultation on class sizes. It would be useful to write to the cabinet secretary to ask how the population bubble over a specific period might be accommodated in any consultation or strategy. The situation does not require additional building in the long term but, in the immediate term, it requires us to take account of a population bubble. In the light of that, it would be interesting to know what the policy is in the areas of the country where it is necessary and whether the consultation will take that into account.

Chic Brodie: I basically agree with Jackson Carlaw, but school planning and building take time and the reaction is not immediate. Given the various elements that Ms Wales introduced of increased immigration and another baby boom, as well as asking COSLA, it might be worth asking some of the city councils how they are applying their priorities and what account is taken of issues such as catchment areas and sibling representation.

John Wilson: I support Chic Brodie's suggestion about writing to local authorities. Our briefing mentions a range of local authorities, from those that have the lowest average class sizes, such as East Renfrewshire Council, through to local authorities such as Glasgow City Council, which has been mentioned today. I am keen for the committee to write to a couple of local authorities to find out how they make decisions on class sizes and about potential constraints on increasing the number of classes. If memory serves me correctly, Battlefield primary school might be bursting at the seams and might have no spare capacity to actually—

Julie Wales: There is spare capacity in the school.

John Wilson: It would be useful to check that out.

Another interesting point goes back to class sizes. I note that East Renfrewshire has one of the highest figures in Scotland on educational attainment in secondary school—I am sure that Jackson Carlaw, as a close follower of what happens there, will be able to confirm or deny that. It would be interesting to know whether there is a correlation between the average primary 1 class size of 15.5 and educational attainment in years 5 and 6 in secondary school because of the advantages that have been given to pupils from an early age.

The Convener: That is a useful point. It might also be useful to contact a mixture of urban and rural local authorities that have lower class sizes.

Chic Brodie: One of the things that concern me—although I know that there are reasons for it—is that a parent can ask where their child is on the waiting list and receive no information. That keeps a closed lid on the matter, but it is important that there be some communication, because that could inform decisions by a family about where they stay and about their children's education. I wish that councils would get the message that they must be much more open with information than they currently are.

The Convener: Do members agree that we should continue the petition? We shall ask the Scottish Government when it expects to consult on class sizes and we shall write to COSLA and a cross-section of local authorities, as John Wilson suggested.

Members *indicated agreement.*

The Convener: I thank our two petitioners for coming along. I know that it is always difficult to come into Parliament to give evidence, but you were both models for how that should be done, so thank you very much.

12:06

Meeting suspended.

12:07

On resuming—

Current Petitions

Access to Insulin Pump Therapy (PE1404)

The Convener: Item 4 is consideration of current petitions. There are five current petitions, the first of which is PE1404, by Stephen Fyfe on behalf of Diabetes UK Scotland, on access to insulin pump therapy. Members have a note by the clerk and the submissions.

For the record, members will be aware that I convene the cross-party group on diabetes and that Diabetes UK Scotland provides a secretariat to the group, so members know that I have a particular interest in the subject. I also draw members' attention to the fact that there are additional papers—one from the Scottish Government and one from Diabetes UK Scotland.

At the back of Stephen Fyfe's submission are four questions that Diabetes UK Scotland is keen to have asked and which I would like us to put to the Scottish Government. The first question is about how confident the Scottish Government is about meeting the new deadlines, given the slippage in achieving targets. Members will remember that, when we met in Stornoway, concern was raised about the postcode lottery—some health boards are good, some have special measures and some are just about there—and there is a feeling that some of the targets will not be met.

I have always made it clear that I think that the Scottish Government targets for insulin pumps for patients under 18 and those over 18 are good and should be encouraged. The problem is not the targets but what we should do with the health boards that are not achieving those targets.

The second question is about the mechanisms that are in place to monitor and support health boards, and the third is about the assurance that can be given to parents that, once a child has gone through the initial transition to the pump, they will have access to continuing support. On those three questions, it is vital that we get a response from the Government, so I recommend that we put those questions to the Government and that, once we get a response, we make a decision about whether we need to terminate the petition.

John Wilson: When the minister gave evidence to the committee on insulin pumps, he gave an assurance that he expected all health boards to meet the targets by 2014. However, following that committee meeting, he had to issue a statement saying that, following discussions with NHS Highland and NHS Lanarkshire, the targets would have to be revised, because those boards now expect to deliver the targets in 2015.

I suggest that, when we write to the Government with our questions, we also ask it what assurances those health boards have given that the targets will be met within the revised timescale and why the targets for those two health boards do not seem to match the national targets that are set for other health boards throughout Scotland. We could ask about the individual circumstances in both those health boards that mean that they will not be able to reach their targets in line with every other health board.

The Convener: Does the committee agree to follow up John Wilson's points, along with the points that were made earlier?

Jackson Carlaw: Certain petitions come before us in relation to which the will expressed is not matched by the deed in action. When we have been confronted with such petitions, it has been sensible to leave them on the table until we have seen evidence of the realisation of their objective.

This is one such petition in relation to which, over a number of years, promises have been unfulfilled. In giving evidence, the minister more or less had to say that he was waving a big stick. We would like to see the evidence in practice of the outcome arising from that. In addition to the other actions that have been suggested, I would like the petition to remain open until we are satisfied that the action has matched the will expressed.

The Convener: That is well put. I agree with Jackson Carlaw's point.

Chic Brodie: Jackson Carlaw's point is pertinent. The minister came here and gave the commitment that NHS Highland had given, but he then had to correct that, because NHS Highland said that it could not meet the commitment. After some persuasion, NHS Highland said that it would meet the commitment. However, the minister's latest letter states:

> "NHS Highland's public comments following my evidence to the Committee on the 14th appear to suggest that the Board may still be working to a longer trajectory."

I would like to know what the penalties are for people who mislead the Government or us and who do not meet their commitments. There may be issues with other health authorities, but NHS Highland is clearly not taking the matter seriously.

The Convener: The clerk tells me that we have already asked that question, and the Government's response was that there are no penalties for health boards.

Chic Brodie: Maybe there should be.

John Wilson: I suggest that we ask the Government whether it would consider producing recommendations on penalties that may be applied to health boards or other public agencies if they fail to meet the targets that have been set in agreement with the Government.

The Convener: Does the committee agree to continue the petition, to ask the first three questions that came from Diabetes UK and to ask the follow-up questions that John Wilson and Jackson Carlaw have raised?

Members *indicated agreement.*

Organ Donation (Opt-out System) (PE1453)

The Convener: The next current petition is PE1453, by Caroline Wilson on behalf of the *Evening Times* and Kidney Research UK (Scotland), on an opt-out system of organ donation in Scotland. Members have in front of them a letter that came from Drew Smith over the weekend.

The committee will recall that we took evidence from the *Evening Times* on this well-researched and polished petition. I draw your attention to Drew Smith's letter, in which he suggests that we take evidence from the Welsh Government and directly from Mark Drakeford AM. The Scottish Government is seeking evidence from Wales on the issue, and we could facilitate its argument by getting further information from the Welsh Government—probably a little quicker than the Scottish Government might get it.

Anne McTaggart: The issue is too important for us not to do that. It will further the petition if we are able to get the evidence from Wales as soon as possible.

The Convener: The clerk reminds me that 15 December is the date for the introduction of the new procedures in Wales. Nevertheless, it would be interesting to look at the thought processes that led to the proposals in Wales.

12:15

Jackson Carlaw: If I am right, most parties allow their members to come to an individual and personal conclusion on the issue. Even though there is sympathy for the proposition, concerns have been expressed on all sides—and even though I, too, am in sympathy, I have posed some of those concerns myself.

I read Drew Smith's letter with interest and I have some sympathy with the idea of taking evidence. However, I want to float with colleagues the question whether this is the right committee to take on that work or whether the petition should be referred to the Health and Sport Committee, to allow those who deal with health issues in more detail to take the evidence. It is sensible to take evidence, but I am not necessarily clear about whether it is the right action for this committee.

The Convener: Jackson Carlaw makes a reasonable point. Under the committee's current procedure, we do not automatically refer petitions just because they are about education, health or whatever, as we cannot guarantee that the other committee will be able to carry out the work straight away. As you know—and as I know from comments that I regularly get back from other conveners at Conveners Group meetings—some committees, such as the Justice Committee, are extremely logjammed and find it difficult to do anything other than deal with legislation.

The clerks work closely together and, as our papers make clear, it is strongly recommended that if a petition relates to work that another committee is carrying out we should refer it to that committee, which makes a lot of sense. However, I understand that the Health and Sport Committee is not doing any work on organ donation immediately and it is up to us to decide whether we wish to do the work.

Jackson Carlaw makes a fair point. If members think that it is better to refer the petition to the Health and Sport Committee, that is fine.

Jackson Carlaw: I was going to suggest that we establish whether the Health and Sport Committee is undertaking such work but, if that is not likely to be the case, I do not know whether we can compel another Parliament to present itself before us but I would be minded to see whether it would be prepared to share its evidence with us.

The Convener: The suggestion is that we contact the Welsh Government and invite the minister—I think that Mr Drakeford is a minister—to give evidence at a future date. Do members agree?

Members *indicated agreement.*

Gender-neutral Human Papillomavirus Vaccination (PE1477)

The Convener: PE1477, by Jamie Rae on behalf of the Throat Cancer Foundation, is on a gender-neutral human papillomavirus vaccination. Members have received the clerk's note and various submissions. I note that a number of submissions from individuals and organisations are pending—that is not uncommon, unfortunately—and it could be argued that we should wait until we have a full picture of the evidence before we make any decision. Do members agree to wait until we have that full picture?

Members *indicated agreement.*

Angus MacDonald: Given the number of responses outstanding, it is only right to wait until we have sight of them.

Solicitors (Complaints) (PE1479)

The Convener: PE1479, by Andrew Muir, is on complaints about solicitors. Members have the clerk's note and submissions. I suggest that, under rule 15.6.2 of standing orders, we refer the petition to the Justice Committee, which is looking at some of the issues that have been raised. The minister will also update us on developments. Do members agree?

Members *indicated agreement.*

Blacklisting (PE1481)

The Convener: The final petition is PE1481, by Pat Rafferty, Harry Donaldson and Harry Frew on behalf of Unite, the GMB and the Union of Construction, Allied Trades and Technicians, calling for an end to blacklisting in Scotland. Members have the clerk's note and submissions. There is an argument for referring this very good petition to the Infrastructure and Capital Investment Committee to aid its scrutiny of the forthcoming procurement bill. I think that the Scottish Trades Union Congress, among others, thought that that was an important route. Do members agree with that suggestion?

Members *indicated agreement.*

Chic Brodie: I hope that any of our colleagues who come along to give evidence will read the committee's report before they rush off to the press.

The Convener: I thank Chic Brodie for his comments.

As agreed under item 1, the committee will now move into private session to deal with the last agenda item.

12:19

Meeting continued in private until 12:54.

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