

PE1463
Public Petitions Committee
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Convener
T3.60
The Scottish Parliament
Edinburgh
EH99 1SP

18 June 2018

Thank you for the report on petition PE1463: Effective thyroid and adrenal testing, diagnosis and treatment, published 29th March 2018. I appreciate that the petition has spanned over five years and over that time a significant range and volume of evidence has been gathered and I am very grateful to all of those who have dedicated their time and resource to the petition and in particular Lorraine Cleaver and Elaine Smith.

I want to assure the committee that the Scottish Government is committed to ensuring that everyone living in Scotland is able to access the best possible care and support, and benefit from healthcare services that are safe, effective and put them at the centre of their care.

Aileen Campbell, Minister for Public Health and Sport met Elaine Smith MSP, and petitioner Lorraine Cleaver on 7 March 2018 to discuss further issues raised about the management of Hypothyroidism in both the petition and members' debate on 22 November 2017. The outcome of this meeting has led to some very positive actions in terms of improving diagnosis and treatment of Thyroid conditions, which will be detailed throughout this letter.

In the following sections I have set out the Scottish Government's consideration of the committee's conclusions and our response to the recommended actions of the committee relevant to the Scottish Government

Guidance Framework

The Scottish Government welcomes the committee's conclusions in relation to the development of guidelines by experts, and these be informed by the available research. As does the report, we acknowledge the work of the petitioners and the committee in raising awareness of this condition and the challenges experienced by patients and the influence this has brought to the additional sources of guidance which have been produced during the life of the petition.

The committee is aware that NICE intend to develop a guideline on thyroid disease, with publication expected in November 2019. I appreciate that this is still over a year away but this reflects the extensive and rigorous process of guideline development which includes a

wide consultation across stakeholders including, very importantly, with patients and service users. The Scottish Government encourages anyone with an interest in thyroid conditions to engage in the guideline development. . More information, including how to register an interest in the development of these guidelines can be found at <https://www.nice.org.uk/guidance/indevelopment/gid-ng10074>.

The committee recommends that the Scottish Government ensures bodies within Healthcare Improvement Scotland (HIS) also contribute to this work, and that HIS provide an outline of how that contribution can be made.

HIS have advised us that through the Scottish Intercollegiate Guidelines Network (SIGN) and Scottish Health Technologies Group (SHTG), they have been involved with the issues raised in this petition throughout the petition's lifespan and that they are happy to continue to contribute to appropriate actions arising from the report. I should stress that the Scottish Government have no formal role in the development of revised standards. That process is wholly independent and owned by HIS.

The committee will wish to be aware that when the Minister for Public Health and Sport, Ms Aileen Campbell MSP, met with petitioner, Lorraine Cleaver, there was a mutual consensus that stronger links of communication and consistency of approach between GPs, in both the diagnosis and primary care referral for those with Thyroid conditions could be developed. Since that meeting the Deputy Chief Medical Officer, Dr Gregor Smith, has met with representatives from NHS Education Scotland (NES) and I understand that an endocrine learning module has recently been produced for GPs. Dr Smith has asked the Chief Medical Officer's (CMO) Speciality Adviser for Endocrinology to review this in light of the issues raised through the petition.

Diagnosis & Testing–recommendations

The Scottish Government fully supports the committee's view that accurate and accessible information for patients to inform their treatment decisions and options is crucial. Through the hard work of the committee I am pleased to see that Lab Tests online now provide people with the relevant information regarding testing options. It is important to highlight that in relation to diagnosis The British Thyroid Association guidance recommends that clinicians take account of patients' symptoms as well as test results. The Scottish Government expects all clinicians to demonstrate a person centred approach through full engagement and shared decision making on mutually agreed outcomes. This approach is at the heart of all Scottish Government policies and in particular the Chief Medical Officer's Realistic Medicine philosophy.

In regards to the committee's recommendation to alert the Scottish Clinical Biochemistry Managed Diagnostic Network to evidence received in relation to variation in testing I am pleased to advise that the network's Demand, Optimisation and Innovation subgroup has agreed to review the evidence and report back to National Services Division.

Treatment - recommendations

The Scottish Government's position is that treatment for Hypothyroidism in Scotland should be consistent with the BTA guidance in relation to Liothyronine (T3) and clinicians in Scotland can prescribe T3 where it is safe and clinically appropriate, on the advice of a consultant in endocrinology. The CMO Speciality Advisor is leading discussions across

endocrinology specialists to support a consistent approach and management in secondary care.

As the committee acknowledges the regulation for the licencing of medicines is currently reserved to the UK Government. We have checked the position with the Medicines and Healthcare products Regulatory Agency (MHRA) who have confirmed that they granted a marketing authorisation to Morningside Healthcare Limited for Liothyronine Sodium 20 microgram tablets on 15 June 2017 and granted a marketing authorisation to Teva UK Limited for Liothyronine Sodium 20 microgram tablets on 14 August 2017.

The Scottish Government are aware of the provisional ruling made by the Competitions and Markets Authority (CMA) against Concordia and their ongoing investigation. The prices charged by the pharmaceutical companies for generic and branded drugs are generally competitive. However, where excessive costs on drugs are identified it would be for the independent CMA to take appropriate action against those companies.

While the regulation of pricing of medicines is matter which is reserved to the UK Government, Scottish Government officials have been working with the Department of Health and Social Care and the other Devolved Administrations in the passage of the UK wide Health Service Medical Supplies (Costs) Act, given Royal Assent in April 2017. In summary, the Act sets out a range of measures to monitor and control the cost of drugs, including powers to limit the price of medicines, including generic medicines and special preparations, where competition in the market fails and companies charge the NHS unreasonably high prices.

The Scottish Government could not speculate on the impact that two new licensed suppliers of T3 would have on the market. While we would expect there to be a level of competition to the market with additional manufacturers, there is no guarantee that this would indeed be the case. As advised the regulation of pricing of medicines is matter which is reserved to the UK Government.

Research

In regard to the listening exercise carried out in October 2015, commissioned by Thyroid UK, the Scottish Government agrees that the limitations to the survey design meant that it did not meet the objectives in which it was intended.

Ensuring that the voices of people who use healthcare services are heard and can influence the design and delivery of healthcare services is a priority for the Scottish Government. That is why we have a number of programmes in place to capture this.

The Scottish Care Experience Survey Programme is a suite of national surveys which provide local and national information on the quality of health and care services from the perspective of the people who use them. The surveys allow local health and care providers to compare with other areas of Scotland and to track progress in improving the experiences of people using their services.

The Scottish Health Council (SHC) was established in April 2005 to support and monitor the work carried out by NHS Boards to involve people using services and the wider public in the planning and development of health services and in decisions that affect the running of those services.

The Scottish Government is supporting the development of Our Voice , in partnership with the NHS, COSLA and third sector partners including the Alliance, which is supporting people to be involved in the design and continuous improvement of health and social care services at individual, local and national level.

Care Opinion is an independent website that provides an online route for people to share their experiences of care – whether good or bad – directly with those providing NHS services, and to engage in constructive dialogue with them about how services can be improved. The Scottish Government has provided funding and support for NHS Boards to engage with the site since 2013.

I would also draw the committees attention to The CMO' s third annual report, Practising Realistic Medicine, published on 20 April 21018. It sets out a range of work, support and guidance that aims to help strengthen relationships between healthcare professionals and patients and promote more meaning conversations to ensure people are able to make an informed choice about their treatment and care. The report can be accessed at: <http://www.gov.scot/Resource/0053/00534374.pdf>

Overall conclusions

Scottish Government welcomes the committee's conclusion regarding the effective and successful treatment for the majority of people and share the committee's view for those people who do not respond well to first line treatments. I hope the committee are assured by the actions which the Scottish Government has taken and are progressing which aim to ensure that everyone experiences care that is person centred – with shared decision making – built on values of respect and dignity.

I trust that this letter will be helpful to the Committee.