Briefing for the Public Petitions Committee

**Petition Number:** PE01726

**Main Petitioner:** Fiona Killen

**Subject:** Primary hyperparathyroidism

Calls on the Parliament to urge the Scottish Government to:

- raise awareness, particularly amongst GPs and other medical practitioners, of the symptoms, diagnosis and effective treatment of Primary Hyperparathyroidism (PHPT) caused by adenoma;

- provide access to minimally invasive surgery in Scotland for the treatment of this condition and;

- provide funding for research into PHPT caused by adenoma

**Background**

Hyperparathyroidism is an endocrine disorder where the parathyroid glands, which are in the neck near the thyroid gland, produce too much parathyroid hormone. This causes blood calcium levels to rise (hypercalcaemia). Left untreated, high levels of calcium in the blood can lead to a range of problems (NHS UK).

**Primary and secondary hyperparathyroidism**

Most cases of primary hyperparathyroidism (approximately 80%) is caused by the over-production parathyroid hormone due to a non-cancerous tumour called an adenoma on one of the parathyroid glands (NHS UK, BMJ Best Practice).

**Guidelines**

In May 2019, the National Institute for Health and Care Excellence (NICE)¹ published a guideline on Hyperparathyroidism (primary): diagnosis.

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¹ NICE guidance relates to England. However, there are agreements to provide certain NICE products and services to Wales, Scotland and Northern Ireland (NICE). Both NICE and the Scottish Intercollegiate Guidelines Network (SIGN) have a shared interest in the drive to improve quality of care for patients through the development of clinical guidelines. The two organisations work together to, where possible, reduce overlap and duplication (SIGN/NICE Joint Statement).
assessment and initial management. This aims to improve the recognition and treatment of the condition, reduce long-term complications and improve quality of life.

The NICE guidelines make a number of recommendations around diagnostic testing in primary care, testing and assessment in secondary care, referral for surgery, surgical management, non-surgical management, monitoring, pregnancy and information and support.

It also makes recommendations for research on bone turnover markers, management after unsuccessful first surgery, long-term outcomes of different management strategies and managing primary hyperparathyroidism during pregnancy.

**Awareness of primary hyperparathyroidism**

The NICE guideline (rationale and impact) notes that the Committee “agreed that primary hyperparathyroidism is an under-recognised condition among both the general population and healthcare professionals. They emphasised the importance of accurate, balanced and up-to-date information so that people with the condition can understand it and make informed choices, particularly with regard to surgery”.

The NICE guideline aims to “improve recognition and treatment of this condition, reducing long-term complications and improving quality of life” and is written for healthcare professionals and people with suspected or confirmed primary hyperparathyroidism, their families and carers.

BMJ Best Practice has also published a subject brief on primary hyperparathyroidism (reviewed June 2019), which is available by subscription.

**Referral for surgery**

The NICE guideline provides recommendations on referral for surgery:

Refer people with a confirmed diagnosis of primary hyperparathyroidism to a surgeon with expertise in parathyroid surgery if they have:

- symptoms of hypercalcaemia such as thirst, frequent or excessive urination, or constipation or
- end-organ disease (renal stones, fragility fractures or osteoporosis) or
- an albumin-adjusted serum calcium level of 2.85 mmol/litre or above.
Consider referral to a surgeon with expertise in parathyroid surgery for people with a confirmed diagnosis of primary hyperparathyroidism even if they do not have the features listed in these recommendations.

The rationale for these recommendations is that:

“There was no evidence available on surgery compared with non-surgical treatment for people with a confirmed diagnosis of primary hyperparathyroidism and symptoms or other indications for surgery. However, the committee reasoned that the lack of evidence is likely to reflect the broad consensus that surgery is beneficial for these people. The committee also agreed that surgery is cost effective because, although the initial cost is high, it can be expected to result in a cure and eliminate the need for further treatment. It relieves symptoms of hypercalcaemia such as thirst, polyuria and constipation, and can prevent future adverse events such as renal stones and fragility fractures. Non-surgical treatment, such as calcimimetics, is an ongoing cost with no curative benefit.

For people with a confirmed diagnosis of primary hyperparathyroidism but no symptoms or indications for surgery, the committee based their recommendation on limited evidence together with their clinical experience. They noted that surgery has shown benefits for this group. Although specific symptoms of primary hyperparathyroidism are absent, people in this group can experience non-specific symptoms such as fatigue, depression or muscle weakness that affect their quality of life. Furthermore, future decrements in quality of life and events associated with end-organ damage may occur. Therefore surgery can be considered as a means of resolving non-specific symptoms and avoiding further deterioration in health.”

The NICE guideline goes on to comment that the recommendations are broadly in line with current practice.

Research

The Chief Scientist Office (CSO) is part of the Scottish Government Health Directorate. Its aims to support and increase the level of high-quality health research conducted in Scotland.

The CSO funds research in a way that aims to complement and support other funding sources and addresses priority health challenges. Its approach is to provide broad-based support through investments in key infrastructure and wide-remit research grant and fellowship schemes.

The Chief Scientist Office has responsibility with Government for the funding of clinical research. However, any research is dependent upon a proposal being brought forward.
Research can also be commissioned by a range of bodies and organisations such as commercial funders, including industry and private companies, and non-commercial funders, such as government departments, research councils, charities and the European Commission (SPICe briefing on PE1463).

Scottish Government Action

In a debate on Thyroid and Adrenal Testing, Diagnosis and Treatment on 4 December 2018 the Minister for Public Health, Sport and Wellbeing, Joe FitzPatrick MSP stated that:

“The deputy chief medical officer, “Dr Gregor Smith met representatives from NHS Education Scotland to discuss the development of an endocrine learning module for GPs, which would set out helpful steps to diagnosis and pathways of care for GPs”.

He also noted that:

“The chief medical officer’s specialty adviser for endocrinology is also leading work to support a consistent approach to specialist input across the country. That includes exciting work to develop an endocrine information technology system to support the modernisation of outpatient endocrine care and to facilitate clinical audit and research”.

Scottish Parliament Action

There have not been any recent Parliamentary questions, motions or debates on primary hyperparathyroidism.

Lizzy Burgess
SPICe
9 July 2019

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