



Briefing for the Public Petitions Committee

Petition Number: [PE1408](#)

Main Petitioner: Mrs Andrea MacArthur

Subject: Updating of Pernicious Anaemia/Vitamin B12 Deficiency understanding and treatment

Calls on the Scottish Parliament to urge the Scottish Government to review and overhaul the current out-dated and ineffective method of diagnosing and treating Pernicious Anaemia/Vitamin B12 Deficiency.

Pernicious Anaemia and Vitamin B12 Deficiency

Vitamin B12 is found in meat, eggs, dairy products and green vegetables and is important for the production of red blood cells and maintenance of the nervous system. Deficiency in vitamin B12 can result in anaemia, with symptoms including fatigue, lethargy, breathlessness, headaches, disturbed vision and mouth ulcers ([NHS Choices](#)). The most common cause of vitamin B12 deficiency is pernicious anaemia which has an estimated prevalence of 127 per 100,000 population, increasing with age to about 1% prevalence at age 70 ([SPICEpc Criteria 15: Management of Pernicious Anaemia](#)). Pernicious anaemia is an autoimmune disease where the body attacks stomach cells that produce intrinsic factor, a binding protein needed for absorption of vitamin B12. This leads to a deficiency in B12 as it can no longer be absorbed from food. Pernicious anaemia is more likely to affect:

- Women
- People aged around 60
- People with a family history of pernicious anaemia
- People with other autoimmune diseases

Prevalence

The Minister for Public Health, Michael Matheson MSP, in answer to [Parliamentary Question S4W-01764](#) concerning the numbers of people in Scotland who have been diagnosed with pernicious anaemia, responded:

“The exact number of people who have been diagnosed with pernicious anaemia in Scotland is not available centrally. However, national estimates can be given of the number of patients consulting a GP or practice-employed nurse for this condition based on information obtained from a sample of Scottish general practices participating in PTI (Practice Team Information). This sample covers the full range of age, sex, and deprivation classes existing

in Scotland. Based on PTI, there were an estimated 12,200 patients who had a face-to-face consultation for pernicious anaemia in Scotland in the financial year 2009-10 (the latest year available), with a 95% confidence interval of 9,200 to 15,100.

PTI estimates of the rate of patients consulting should not be regarded as identical to the population prevalence of a given condition. This is because PTI measures active problems; a lifelong or previous condition will not be recorded unless the patient had a contact with the practice that was directly related to that condition...The confidence intervals provided indicate the uncertainty around the estimate provided. These are reasonably wide, reflecting among other things considerable variation between practices. This indicates that the estimate provided is not exact and should be treated as approximate.”

Diagnosis

Diagnosis of vitamin B12 deficiency or pernicious anaemia is usually made using a blood test. The blood sample is examined for haemoglobin levels, the size of red blood cells (they may be larger than normal), amount of vitamin B12 and antibodies against stomach cells which may appear in pernicious anaemia. Folate levels will also be checked as this is another common vitamin B deficiency causing similar symptoms.

An alternative test recently made available at one lab in England¹ for the first time is the active B12 test. Whereas standard tests measure the total amount of B12 in the blood, the active B12 test measures the amount of B12 present in a 'bio-available' form². This addresses problems with diagnosis where blood B12 levels appear normal but the amount of B12 in a form that is usable by cells is very low. In response to [Parliamentary Question S4W-01761](#) on guidelines for GPs on using the active B12 test, the Cabinet Secretary for Health, Wellbeing and Cities Strategy, Nicola Sturgeon MSP responded:

“No guidelines have been given to GPs on using the Active-B12 test for diagnosing and treating pernicious anaemia as this is not the generally used way of diagnosing this condition in NHS Scotland.”

[Parliamentary Question S4W-01759](#) asked “what is being done to improve accuracy in diagnosing pernicious anaemia” and the Minister for Public Health, Michael Matheson MSP responded:

“Healthcare professionals are expected to follow agreed local and national guidelines, and are supported by the agreed pathways in NHS boards for the management of various health conditions, including Pernicious Anaemia.

Doctors are expected and professionally required to keep up to date by their Regulatory Body, The General Medical Council (GMC), through Continuing Professional Development activities. Personal development needs are

¹ [GSTS Pathology](#) – a partnership between two primary care trusts, Guys and St Thomas' and King's College

² i.e. in a form that can be taken up and used by the body.

identified through the process of appraisal and reflect the healthcare service needs of their local population that is served by the doctors.

The education and training of doctors delivering care to patients is supported by the NHS boards where they are employed and contracted, as well as by other organisations such as NHS Education for Scotland and the Medical Royal Colleges and peers. The training materials are available to them in various formats such as lectures, articles, e-learning modules and others. This will include any updates in the management of Pernicious Anaemia.”

Guidelines for Treatment and Management

Vitamin B12 deficiency that is not diet-related is treated using injections of vitamin B12, usually in the form of hydroxocobalamin. These injections are administered every other day for two weeks or, if there are neurological symptoms, until there is no further improvement, and then usually once every two to three months depending on whether neurological symptoms are present ([NHS Evidence: Clinical Knowledge Summaries](#)).

Scottish Programmes for Improving Effectiveness in Primary Care (SPICEpc) was a programme developed by the Royal College of General Practitioners in 1999 and supported by NHS Quality Improvement Scotland (now Healthcare Improvement Scotland). It developed 24 sets of criteria for managing different patient conditions to promote consistent recording and use of clinical data. [Criteria 15: Management of Pernicious Anaemia](#) contained a number of criteria based on good clinical practice.

Previous work by the Scottish Parliament

No work on pernicious anaemia or vitamin B12 deficiency has been conducted by the Scottish Parliament or its Committees, nor has it been the subject of any debates.

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4 November 2011

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