

PE1408/K

The Quality Unit

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Committee
The Scottish Parliament
Edinburgh, EH99 1SP

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Dear Ms Wilson,

CONSIDERATION OF PETITION PE 1408 - PERNICIOUS ANAEMIA

Thank you for your email of 3 October, about Petition PE 1408, lodged by Mrs Andrea MacArthur, which calls on the Scottish Parliament to review and overhaul the current out-dated and ineffective method of diagnosing and treating Pernicious Anaemia/vitamin B12 Deficiency. Our response to each of the Committee's latest question follows:

Can you confirm when you expect the British Committee for Standards in Haematology guidance to be made available to you? Further, can you clarify if you intend to implement the findings of the report fully or whether, given the high prevalence of MS sufferers in Scotland and the lack of information on patients who suffer from pernicious anaemia will you carry out your own study into the crossover between pernicious anaemia and other conditions?

The Committee will be aware that the British Committee for Standards in Haematology (BCHS) has extended the timescale for the development of its guidance on B12 and folate deficiency. We have been advised by the BCHS, which is entirely independent of the Scottish Government, that the guideline is now likely to be published in summer 2013. The BCHS' taskforce guideline lead has noted the complex nature of producing a guideline on this subject, no doubt reflecting many of the issues raised by the Petitioner on this subject.

As I advised in my previous letter of 12 August, the Minister for Public Health has committed NHSScotland to making the BCHS guidance on B12 and folate deficiency available to clinicians across NHS Scotland including those in primary care. We

hope that the Committee will appreciate that we are not able to confirm that NHSScotland will implement the findings of the report prior to its publication.

It is for NHS Boards to plan and provide services that meet the needs of their resident populations in line with local and national guidelines. We will be in a better position to consider what further action may be necessary once the guidance is published next year.

With regard to your question concerning the crossover between Pernicious anaemia and other conditions, such as MS. It may be helpful to note some of the wider work underway to improve services for people living with Multiple Sclerosis (MS). The Scottish Government provided £1.2 million to Healthcare Improvement Scotland (HIS) to help NHS Boards to implement the neurological clinical standards developed by HIS. The programme lasted two years and has achieved real improvements in neurological care including for MS. Standards 14 to 16 are specific to multiple sclerosis (MS) and cover:

- Access to specialist MS services: an effective and comprehensive specialist MS service is available across all NHS Scotland boards;
- Diagnosis: the NHS board provides a co-ordinated MS diagnosis service with access to a multidisciplinary team experienced in the diagnosis of MS;
- Ongoing management: patients with MS have ongoing access to MS specialist services appropriate to their needs. This will cover services for the management of chronic pain, cognitive issues, continence, fatigue, motor problems (mobility, tremor, spasticity, and weakness), nutrition, speech and language, visual problems, psychological issues and sexual dysfunction.

The Scottish Government has provided the Neurological Alliance with funding to establish a Neurological National Advisory Group to ensure that the standards improvement work continues, now that the Healthcare Improvement Scotland work has come to an end. The group will support Boards as they take their neurological service improvement plans forward.

You may also be interested to know that in 2009, the Scottish Government provided funding to support the set up of a Scottish Multiple Sclerosis Register. The register is key in helping to deliver service improvements, given the incidence of MS in Scotland is higher than anywhere else in the world.

It is also intended to be an important resource for facilitating research both in Scotland and internationally and should provide a valuable source of data for clinical trials. Further information regarding the Scottish MS register can be found at: <http://www.msr.scot.nhs.uk/>.

The Committee may also be aware that the Chief Scientist Office (CSO) within the Scottish Government has responsibility for encouraging and supporting research into health and healthcare needs in Scotland, they primarily respond to requests for funding by the research community in Scotland. Their role is well known among the research community in Scotland.

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I hope that the Committee finds this reply, the terms of which have been approved by the Minister for Public Health helpful.

Yours sincerely

Rachael Dunk