PE1408/I

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Dear Ms Wilson,

CONSIDERATION OF PETITION PE 1408 - PERNICIOUS ANAEMIA

Thank you for your email of 26 June, 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. The Scottish Government's reply to each of the Committee's latest questions follows:

The Committee ask that you forward the recent response provided by the petitioner (PE/1408:H) to the Scottish Intercollegiate Guidelines Network (SIGN)

The Committee has indicated that we should draw SIGN's attention to the issues raised by the petitioner. SIGN welcomes guideline development applications on any topic, however it is yet to receive an application for a guideline on pernicious anaemia. Guideline topics can be proposed using the <u>application form</u> on the SIGN website and information on how to apply can be found here: http://www.sign.ac.uk/about/proposal.html

All guideline development proposals are subject to a number of criteria, including clinical need, variation in practice, existence of an adequate body of evidence and support of a wide range of stakeholders. At this stage, we would suggest that there is a clear risk of unnecessary duplication if SIGN were to initiate a programme of work relating to pernicious anaemia, while the British Committee for Standards in Haematology (BCHS) continues to develop guidance on this subject.

The Committee ask that if progress is made towards developing guidelines, that these guidelines should be flexible enough to deal with the needs of individual patients who may need more frequent injections of vitamin B12 than others.

The Scottish Government's Healthcare Quality Strategy makes it clear that we want care to be delivered in a person centred, effective and safe way. This means treatment should be tailored to individuals' needs. It also means that services and clinicians should provide evidence based care, in line with clinical guidelines.

As the Committee will appreciate, the specific content of any clinical guideline, including SIGN guidelines, is rightly independent of the Scottish Government.

The Committee may be aware that the British Committee for Standards in Haematology (BCHS) is extending the timescale for the development of its guidance on B12 and folate deficiency. The BCHS has said that it is now likely to be published in 2013.

We also understand that the BCHS is consulting closely with the Pernicious Anaemia Society and is fully aware of the Society's concerns. We expect that this additional time to consult with people with pernicious anaemia will help to ensure the final guidance is robust and where appropriate, takes account of the issues raised to date by the petitioner, including those around the frequency of injections.

The Committee also seeks an update on the action that you propose to take following the publication of the British Committee for Standards in Haematology guidance.

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 will be in a better position to consider what further action may be necessary once the guidance is published next year.

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

Yours sincerely

Craig Bell