

PE1408/G

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Alison Wilson
Assistant Clerk to the Public Petitions Committee
The Scottish Parliament
Edinburgh, EH99 1SP



3 May 2012

Dear Ms Wilson,

CONSIDERATION OF PETITION PE 1408 - PERNICIOUS ANAEMIA

Thank you for your letter of 17 April to Anne Lillico about this Petition, lodged by Mrs Andrea MacArthur, which calls on the Scottish Parliament to review and overhaul the current outdated and ineffective method of diagnosing and treating Pernicious Anaemia/vitamin B12 Deficiency. Please find attached a response, the terms of which have been cleared by the Minister for Public Health, Michael Matheson.

During the debate on 7 March 2012 the Minister stated that he would write to the Scottish Intercollegiate Guidelines Network (SIGN) to draw attention to the debate to allow SIGN to reflect on the issues raised and the views expressed on the issues raised in the Petition.

I wrote to the Chief Executive of Healthcare Improvement Scotland, which is responsible for SIGN, on 19 April with regard to the content of the debate and seeking their views. I requested the assistance of Healthcare Improvement Scotland in taking forward the following actions, included within the Minister's statement:

- for **NHSScotland** to appropriately disseminate the forthcoming guidance on pernicious anaemia;
- for **Healthcare Improvement Scotland** to consider those actions which should be taken following publication of the guidance; and
- for **SIGN** to consider and reflect upon the contents of the Public Petitions Committee debate

The SIGN senior management considered the points raised in discussion during the debate at its meeting on 25 April and have provided the following comments:

- SIGN welcomes the statement from the Minister that 'it is not for Ministers to tell SIGN which guidelines it should issue'. SIGN's guideline programme is driven by proposals from the NHS in Scotland. Acceptability of proposals is determined by 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.

- SIGN has not received an application for the development of a guideline on Pernicious Anaemia. If such an application is received in the future, then the first stage would be to investigate whether there are high quality extant guidelines in this area, in order to avoid duplication of effort.
- SIGN welcomes the Minister's statement that that the forthcoming guideline from the British Committee for Standards in Haematology will be highlighted to general practitioners when published this summer. SIGN also welcomes the Minister's invitation to the Pernicious Anaemia Society to work with NHS Inform to ensure that information on its website is up to date and appropriate.

The British Committee for Standards in Haematology has indicated that it is due to publish guidance in June 2012 following which it is our intention to disseminate this to primary care.

We have also initiated discussions with NHS Inform colleagues about options for including more detailed information on pernicious anaemia and the Pernicious Anaemia Society on the NHS Inform website.

The Committee asks that the Scottish Government asks practitioners to consider using a person centred approach to treatment based on individual patient's needs, whenever appropriate, rather than a strict timescale of every 3 months.

The Scottish Government is fully committed to ensuring that people living with long term conditions receive the care and treatment that is tailored to their individual needs and this person centred approach is one of the ambitions set out in our Quality Strategy.

We would always stress the importance of discussion between each individual and the health care professionals providing their care, to determine the treatment regime best suited to their personal circumstances.

We recognise that some people receiving treatment for pernicious anaemia experience a recurrence of symptoms prior to when their next injection is due - as we have advised previously we would expect them to be referred to a specialist for any further investigations that may be appropriate.

As noted during the debate we expect that the British Committee for Standards in Haematology guidance will also help guide clinicians with the specific issue of frequency of treatment.

Yours sincerely,

Rachael Dunk
Head of the Clinical Priorities Team