HEALTH AND SPORT COMMITTEE

AGENDA

17th Meeting, 2011 (Session 4)

Tuesday 6 December 2011

The Committee will meet at 10.00 am in Committee Room 1.

1. **Subordinate legislation:** The Committee will consider the following negative instrument—

   The National Health Service (Primary Medical Services Performers Lists) (Scotland) Amendment Regulations 2011 (SSI 2011/392).

2. **Petition PE1056:** The Committee will consider a Petition by Gordon, Jane and Steven McPherson calling for the Scottish Parliament to urge the Scottish Executive to introduce mandatory assessment tools for all health boards for the diagnosis of deep vein thrombosis (DVT); to ensure commonality of patient guidance information regarding DVT; and to introduce a newborn screening programme for the Factor V gene, which has been shown to increase susceptibility to DVT.

3. **Welfare Reform Bill (UK Parliament legislation) (in private):** The Committee will consider a revised draft report on legislative consent memorandum LCM(S4) 5.1.

Douglas Wands
Clerk to the Health and Sport Committee
Room T3.60
The Scottish Parliament
Edinburgh
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The papers for this meeting are as follows—

**Agenda Item 1**
Note by the clerk HS/S4/11/17/1

**Agenda Item 2**
Note by the clerk HS/S4/11/17/2

**Agenda Item 3**
PRIVATE PAPER HS/S4/11/17/3 (P)
Overview

There is one negative instrument for consideration. This instrument is an amendment to the National Health Service (Primary Medical Services Performers Lists) (Scotland) Regulations 2004.

A brief explanation of this instrument, along with the comments of the Subordinate Legislation Committee, is set out below. If members have any queries or points of clarification on the instrument which they wish to have raised with the Scottish Government in advance of the meeting, please could these be passed to the Clerk to the Committee as soon as possible.

In keeping with existing practice, this instrument has not been provided in hard copy but can be accessed online.

<table>
<thead>
<tr>
<th>Name</th>
<th>Deadline</th>
<th>Motion to annul</th>
<th>Purpose</th>
<th>Drawn to attention by Subordinate Legislation Committee (SLC)?</th>
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<tbody>
<tr>
<td>The National Health Service (Primary Medical Services Performers Lists) (Scotland) Amendment Regulations 2011 (SSI 2011/392)</td>
<td>19 December</td>
<td>No</td>
<td>This instrument amends the National Health Service (Primary Medical Services Performers Lists) (Scotland) Regulations 2004 in consequence of the new vetting and barring scheme, introduced by the Protection of Vulnerable Groups (Scotland) Act 2007. It places requirements on Health Boards and medical practitioners seeking inclusion on a PMS list to make appropriate use of the PVG scheme and disclosure records, and also makes amendments to allow for a ‘Lead Board’ to carry out all the pre-listing suitability checks.</td>
<td>The SLC has not made any comments on this instrument.</td>
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Public Petition PE1056

Introduction

1. This paper invites the Committee to consider for the second time petition PE1056 which was lodged on 15 May 2007:

   Petition PE1056 by Gordon, Jane and Steven McPherson calls for the Scottish Parliament to urge the Scottish Executive to introduce mandatory assessment tools for all health boards for the diagnosis of deep vein thrombosis (DVT); to ensure commonality of patient guidance information regarding DVT, and to introduce a newborn screening programme for the Factor V gene, which has been shown to increase susceptibility to DVT.

2. At its meeting on 13 September 2011 the Health and Sport Committee agreed to write to the Scottish Government for further information.

3. SPICe have produced a Briefing Paper regarding the Petition which contains the recent correspondence between the Committee and the Scottish Government on the issue.

Recommendation

4. The Committee is invited to consider whether it wishes to —

   a) close consideration of the petition on the grounds of the information received from the Scottish Government; or

   b) propose an alternative approach.

Rebecca Lamb
Assistant Clerk
Health and Sport Committee

Public Petition PE1056

Introduction

On 13 September 2011 the Committee considered Public Petition PE1056. Members will recall Paper HS/S4/11/5/2 (Appendix 1) which outlined consideration by the Public Petitions Committee from 2 October 2007 until 28 June 2011, at which point it was referred to the Health and Sport Committee.

At the Committee meeting on 13 September 2011 Members decided to write to the Cabinet Secretary for Health, Wellbeing and Cities Strategy (see Appendix 2) to clarify progress that had been made in a number of areas. This paper briefly outlines the response of the Cabinet Secretary to the questions posed by the Committee before discussing further information raised by the petitioner.

Progress reported by the Scottish Government

The Cabinet Secretary responded to the Committee on 9 October (see Appendix 3). It is suggested Members consider the letter in full, however below is a summary of what actions the Government has taken according to the points raised by the Committee. However, it should be noted that the letter was not written using these headings:

1. The outcome of the meeting of the Scottish Association of Medical Directors as relayed to the CMO

One of the recommendations of the report ‘The Venous Thromboembolism (VTE) Challenge in Scotland’ (concerning the need for robust audit arrangements for VTE) was that each NHS Board should set up a Thrombosis Committee. This was discussed by the Scottish Association of Medical Directors. The association has written to the Chief Medical Officer indicating its support for the creation of such Committees, or assigning these responsibilities to existing Committees in the case of smaller NHS boards.

2. Development of a measurement strategy for VTE

As noted above, the report ‘The Venous Thromboembolism (VTE) Challenge in Scotland’ concerns the need for robust audit arrangements for VTE. The letter from the Cabinet secretary contains a range of other information relevant to this point posed by the Committee:
Guideline 122 calls for data on the incidence of deep vein thrombosis (DVT) and (pulmonary embolism) PE within 90 days of admission to hospital to be available annually, as part of the surgical profiles for all NHS Boards. This data is analysed by ISD Scotland, whilst Healthcare Improvement Scotland (HIS) has the responsibility of working with NHS Boards to consider what the data means and to follow up any issues raised. That work is to be complemented by the inclusion in the new medical profiles of indicators for mortality and re-admissions for VTE. The first edition of these medical profiles is due in March 2012.

SIGN has developed two separate audit tools based on the recommendations in SIGN Guideline 122. These aim to measure current practice in VTE prophylaxis in relation to general surgery, with the goal of achieving the correct use of anti-embolic stockings and low molecular weight heparin for every patient. They are also intended to facilitate implementation of Guideline-based practice by providing a risk stratification tool for use across acute medical and surgical specialties. This should ensure that each patient gets correct prophylaxis, adjusted for clinical setting.

Achieving reliable VTE prophylaxis in surgical patients is part of the Scottish Patient Safety Programme (SPSP)'s peri-operative workstream. The target is 95% of patients assessed and receiving appropriate VTE prophylaxis. At least 42 teams are now reporting data, and the average team is achieving reliability in 98% of patients. Guideline 122 has picked up on recognised good practice in NHS Grampian by including its VTE risk assessment algorithm. This is included in the audit tools, and will help encourage other NHS Boards to adopt it. The SPSP also agreed last year that VTE risk assessment and appropriate prophylaxis will be extended to all patients, medical as well as surgical.

3. Publication of SIGN Guideline 122
SIGN Guideline 122, *Prevention and management of venous thromboembolism*, was published in December 2010. In order to promote better awareness and use of SIGN Guidelines, an application for smart phones and tablets. It contains quick reference guides from 14 recent Guidelines, including Guideline 122. The Scottish Government states that by the end of August, more than 25,000 copies of the application had been downloaded, making the Guideline 122 recommendations readily available to healthcare professionals.

4. Work with SIGN on implementation of the Guideline
In addition to the work undertaken as noted above, the Government has funded the Lifeblood charity to produce information leaflets which are now contained as appendices in Guideline 122.

5. Coding solution for auditing the number of hospital acquired VTE
All measures outlined in the letter are discussed in answer to Question 2, above.
6. **Further development of a Guideline implementation plan**

There was no mention of a specific implementation plan, though the letter outlines the actions the Scottish Government and other bodies have taken.

7. **Other**

The Scottish Government discusses newborn screening for the Factor V Leiden gene. The letter from the Cabinet Secretary states that this has not been discussed by the UK National Screening Committee because the defect does not cause problems in babies and children, and there is considerable uncertainty about the implications of a positive test. However, it also discusses how it is usual for adult relatives of patients who have Factor V Leiden (and other similar genetic conditions) to be offered genetic testing and given appropriate advice in the light of the result of that test.

**Further correspondence from the Petitioner**

The Petitioner’s response (see Appendix 4) has referred the Committee to the NICE publication *Venous thromboembolic diseases: the management of venous thromboembolic diseases and the role of thrombophilia testing*. The Petitioner believes that this go further in the promotion of thrombophilia testing than exists in Scotland. As noted by the petitioner, this publication is draft guideline for consultation. The consultation is due to finish on 21 December 2011, with the final report being published in June 2012. It is important to note that the provisional recommendations presented in the consultation document do not constitute NICE’s formal guidance on this topic. They may change following the consultation. It should also be noted that NICE clinical guidelines have no formal status in Scotland though may be referred to NHS Board’s for information.

**Jude Payne**

**SPICe Research**

**05 December 2011**

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Note: Committee briefing papers are provided by SPICe for the use of Scottish Parliament committees and clerking staff. They provide focused information or respond to specific questions or areas of interest to committees and are not intended to offer comprehensive coverage of a subject area.
5. This paper invites the Committee to consider for the first time petition PE1056 which was lodged on 15 May 2007:

Petition PE1056 by Gordon, Jane and Steven McPherson calls for the Scottish Parliament to urge the Scottish Executive to introduce mandatory assessment tools for all health boards for the diagnosis of deep vein thrombosis (DVT); to ensure commonality of patient guidance information regarding DVT, and to introduce a newborn screening programme for the Factor V gene, which has been shown to increase susceptibility to DVT.

6. At its meeting on 28 June 2011 the Public Petitions Committee (PPC) agreed to refer petition PE1056 to the Health and Sport Committee for further consideration.

Consideration by Public Petitions Committee

7. The petition has been open for four years now and a good deal of material was gathered by the previous PPC in its consideration of the petition.

8. A number of developments have occurred since the petition was lodged and this note focuses on those developments and also some pending action on the petition.

9. The petition was first considered by the PPC in the last session at its meeting on 2 October 2007 and considered again at its meetings on 29 January 2008, 13 May 2008, 16 December 2008, 2 June 2009, 11 January 2011, and 25 January 2011. The petition has been considered by the PPC in the current session, on 28 June 2011.

10. The PPC agreed the following actions:

- **2 October 2007** – sought views on the petition from the Scottish Government, NHS Quality Improvement Scotland, Scottish Intercollegiate Guidelines Network, LifeBlood, the National Screening Committee and the Association of British Insurers.

- **29 January 2008** – wrote to the Scottish Government, NHS Quality Improvement Scotland and the National Screening Committee seeking updates on how each is taking forward initiatives in this area and why guidelines would take 26 months to prepare.

- **13 May 2008** – agreed to suspend further consideration of the petition until NHS Quality Improvement Scotland has collated information from all NHS Boards and reported to the Chief Medical Officer and to invite the Scottish Government to respond on how the
new policies address the particular issues raised in the petition. Further, that the Scottish Government and other agencies should continue to communicate and work with the petitioner on the revision of written policies.

- **16 December 2008** – agreed to write to the Scottish Government seeking a response to the specific points raised during the meeting.

- **2 June 2009** – agreed to suspend consideration of this petition until revised SIGN guideline 62 on venous thromboembolism was published in October 2010.

- **11 January 2011** – agreed to give further consideration to the petition at its subsequent meeting on 25 January 2011.

- **25 January 2011** – agreed to invite, in its legacy paper, the Session 4 PPC to give further consideration to the petition.

- **28 June 2011** – agreed to refer the petition to the Health and Sport Committee under Rule 15.6.2 for further consideration.

11. Hard copies of the relevant PPC Official Reports and all correspondence relating to the petition are available on request from the Clerk.

**Recent action on the petition**

12. In its most recent correspondence addressing the petition, in a letter to the PPC on 10 June 2011, the Scottish Government detailed a number of actions:

- *The Venous Thromboembolism Challenge in Scotland: A Report into VTE Prevention in Scottish Health Boards*, published by Lifeblood, the thrombosis charity, called on the Scottish Government to ask each NHS board to set up a VTE committee, suggesting, on the basis of experience in England, that the advantages these would bring include: promoting best practice; adapting local protocols and providing local audit of thromboprophylactic practice; and acting as a source of education and training for all staff.

- The Cabinet Secretary for Health, Wellbeing & Cities Strategy, asked the Chief Medical Officer (CMO) to address the matter with NHS Board Medical Directors. The Scottish Association of Medical Directors will consider this at their next meeting and will provide its views on whether setting up VTE committees is the best way to deliver the perceived benefits, or whether there is a more appropriate solution now that SIGN Guideline 122 on the prevention and management of VTE has been published.

- The Association expects to reply to the CMO by September.
• VTE risk assessment and family history arose during the PCC’s last discussion and the issue of VTE prophylaxis is one the Scottish Government takes very seriously, underlined by the Scottish Patient Safety Programme (SPSP) taking the issue forward, in particular through the extension of assessment of VTE risk to medical, as well as surgical, inpatients.

• Following the SPSP VTE Learning event on 17 November 2010, all NHS Boards are developing a risk assessment tool which will help achieve a consensus on prophylaxis.

• The Scottish Government are organising a further meeting to be held in September 2011 for NHS Boards to share their work on this. The SPSP, Scottish Government and the Quality Improvement Hub will also be involved in this meeting to develop a measurement strategy for VTE.

• The measurement strategy is about ensuring all patients in Scotland have a risk assessment and receive VTE prophylaxis where appropriate.

• In terms of family history, SIGN Guideline 122 on the prevention and management of VTE highlights that a family history of VTE is an indicator of increased risk of first VTE. Part 16 of the Guideline covers the provision of information and clearly states that, at initial presentation or assessment, it should be explained to the patient/carer what VTE is and what causes it. There should also be a discussion with the patient/carer about the risk factors for VTE, including family history, and it should be explained to patients who have tested positive for VTE that the thrombotic tendency may run in the family in some cases.

• Discussions about family history also form part of the Grampian risk assessment tool which is provided as an example of an algorithm for assessing the risk of VTE.

• SIGN Guideline 122 also notes that heritable thrombophilia further increases VTE risk in those on combined oral contraceptives, but that the risk of recurrent VTE is not increased in patients with Factor V Leiden.

• The Guideline also notes that all women should be assessed for risk factors for VTE when booking for antenatal care and at each subsequent maternity contact. Women should also be asked about a personal and family history of VTE and whether an objective diagnosis was made.

• SIGN Guideline 36, on anti-thrombotic therapy, is being revised, and the new version is expected to be published this summer (2011).
- The SPSP continues to working closely with SIGN on implementation of the Guideline. An important step in its implementation is gaining an understanding of current clinical practice, and the guideline recommends that the rate of healthcare-associated VTE should be recorded and monitored to identify areas where the risk assessment policy may need to be reviewed.

- On the issues of the availability of appropriate codes for recording VTE, the work underway in Ninewells Hospital adopting good practice in VTE risk assessment and prevention for patients coming into hospital, and experience of problems in attempting to audit the number of hospital acquired VTEs to provide information on the success of their prophylaxis, these are being investigated with the Information Services Division of NHS National Services Scotland (ISD). A coding solution is being actively pursued.

- SIGN has begun work to develop a Guideline implementation plan. This work is in its early stages and it is too soon to determine the long term impact of the guideline on the assessment and diagnosis of DVT. But in terms of progress made to date –
  
  - As an aid to standardising the provision of patient information throughout NHSScotland, SIGN has included the text of the model patient advice leaflets sent to all NHS Boards by the CMO on 26 January 2008, as appendices in the Guideline.
  
  - The information leaflet on DVT for the general public has been available for download from the SIGN website since April 2011.
  
  - Distribution of paper copies will be led by the SIGN Patient Involvement Officer and will take place by the end of June 2011. This should promote continuity as well as consistency of message.
  
  - SIGN is continuing to work with its partners to embed the Guideline’s recommendations into general practice decision-making software, and has been working with an IT company to develop decision support screens for GP IT systems. The first of these was developed for asthma and has been piloted in a number of GP surgeries. VTE is one of the next guidelines and SIGN is awaiting the outcome of the evaluation report for the asthma guideline screens before it commissions the next batch.
  
  - SIGN is now part of the eForms group run by the Scottish Government eHealth team and will support eForms developers to create tools based on SIGN guidelines, and
Guideline 122 will be one of these when this work commences.

- The Guideline acknowledges the importance of auditing current practice as part of their training. All junior doctors must carry out an audit and so to encourage them to focus on VTE prophylaxis, SIGN has now made audit tools for junior doctors available to download.

- An iPhone application is also now available on the SIGN website, and it is expected that an Android application will be available by the end of June 2011.

Petitioner’s views

13. In his latest communication to the PPC on 27 June 2011, petitioner Gordon McPherson suggested – in light of the meeting of medical directors to consider DVT guidelines, the outcomes of which are due to be reported to the CMO this month (September 2011) – that a further committee meeting may be required to discuss their decisions and ensure “commonality of information”.

14. Copies of the most recent responses from the Scottish Government and the Petitioner are attached at Annex A of this cover note.

Recommendation

15. At its recent business planning day, the Committee agreed to frame its work on petitions within the general approach set out by the previous Health Committee’s legacy paper outlined below.

16. The expectation is that there will be a significant increase in the number of petitions referred to the Health and Sport Committee compared to the previous session. This is due, in part, to the expanded remit of the new committee.

17. The previous Health and Sport Committee dealt with 11 petitions last session. Where possible, consideration of these was incorporated into other committee work. This approach proved to be the most effective and efficient in terms of enabling the committee to scrutinise as many petitions as possible in the time available.

18. Alternatively, the Committee could initiate a stand-alone inquiry in response to issues raised by a petition. An example of this approach in session 3 was the inquiry into out-of-hours healthcare provision in rural areas.

19. After a petition has been referred, there is the option of closing it, either as soon as it has been considered or following further action by the Health and Sport Committee.
20. In light of the Committee’s current work programme, there does not appear to be scope for incorporating the petition into its planned work.

21. The Committee is, therefore, invited to consider whether it wishes to —

   a) write to the Scottish Government requesting an update on the progress of all three strands of the petition but with particular regard to: the outcomes of the meeting of the Scottish Association of Medical Directors as relayed to the CMO, development of a measurement strategy for VTE, publication of SIGN Guideline 36, work with SIGN on implementation of the Guideline, a coding solution for auditing the number of hospital acquired VTEs, and further development of a Guideline implementation plan; or

   b) close consideration of the petition on the grounds of the earlier work carried out by the PPC and information previously given; or

   c) propose an alternative approach.

Rodger Evans
Senior Assistant Clerk
Dear Nicola

PETITION PE1056

Petition PE1056 by Gordon, Jane and Steven McPherson calls for the Scottish Parliament to urge the Scottish Executive to introduce mandatory assessment tools for all health boards for the diagnosis of deep vein thrombosis (DVT); to ensure commonality of patient guidance information regarding DVT, and to introduce a newborn screening programme for the Factor V gene, which has been shown to increase susceptibility to DVT.

The Health and Sport Committee considered the above petition at our meeting on Tuesday 13 September and it was agreed that we write to you for further clarification on its progress.

It seems from the most recent correspondence between the Public Petitions Committee and your officials that there has indeed been progress. However we and, I’m sure, the petitioners would now welcome your overall assessment plus details of any recent and pending action.

I’d be grateful, then, if you could detail progress on 1) each of the three strands of PE1056 as regards actions by the Scottish Government and other parties and 2) the following specifics–
Agenda Item 2  
6 December 2011

- the outcomes of the meeting of the Scottish Association of Medical Directors as relayed to the CMO
- development of a measurement strategy for VTE
- publication of SIGN Guideline 36
- work with SIGN on implementation of this Guideline
- a coding solution for auditing the number of hospital-acquired VTE
  and
- the further development of a Guideline implementation plan

The importance of petitions in the Parliament's work is often and rightly praised in the interests of promoting a more accessible and participative approach. The Health and Sport Committee wishes to play its part in ensuring that concerns of petitioners are given fair consideration and I have no doubt this is an ethos to which you share.

Yours sincerely

Duncan McNeil MSP
Convener of the Health and Sport Committee

Cc. Gordon McPherson, petitioner
Craig Bell, Healthcare Planning Division/Long Term Conditions Unit
Thank you for your letter of 15 September about this Petition, which asks for the introduction of mandatory assessment tools for deep vein thrombosis (DVT) by all the territorial NHS Boards, for commonality of patient guidance information on DVT and the introduction of a newborn screening programme for the Factor V Leiden gene. The first of these 2 issues are closely linked to the implementation of the recent SIGN Guideline on the prevention and management of venous thromboembolism (VTE), which was published in December 2010 as Guideline 122 (not Guideline 36 as referred to in your letter).

The 2 elements of VTE are DVT and pulmonary embolism (PE). The Petition was triggered by the sad death of Katie McPherson from a PE caused by an undiagnosed DVT. SIGN Guideline 122 includes as Appendices 6 and 7 the information leaflets which we funded the thrombosis charity Lifeblood to produce, with help from Mr McPherson. The leaflets have already been distributed twice to all GPs in Scotland, but their inclusion in the Guideline will be extremely helpful in promoting the consistency of message called for in the Petition.

I’m in no doubt that we need to make the maximum possible use of the opportunity Guideline 122 gives us to bring about a real change in our approach to VTE assessment and prophylaxis in Scotland. I am therefore very pleased that SIGN developed a detailed package of measures for the implementation of this Guideline. It calls for data on the incidence of DVT and
PE within 90 days of admission to hospital to be available annually, as part of the surgical profiles for all NHS Boards. That's a very active process, through which ISD analyses these data and Healthcare Improvement Scotland (HIS) works with Boards to understand what the data show, to follow up any issues and to make changes where necessary. That work will be complemented by the inclusion in the new medical profiles of indicators for mortality and re-admissions for VTE. The first edition of these medical profiles is due in March 2012.

SIGN also wants to integrate the recommendations in the Guideline into decision-making software in general practice. That strikes me as a very effective approach. From the experience of sending the Lifeblood leaflet to GPs we know that it's difficult to get this sort of information into their surgeries, because of the sheer amount of information that's sent to them. SIGN is now having discussions with the eHealth leads in the Scottish Government Health Directorates about putting this approach into practice, and the next step will be to explore with the suppliers of the GP IT systems, EMIS and Vision, how SIGN can develop tools that plug into the software.

SIGN has also developed 2 separate audit tools based on the recommendations in Guideline 122. These aim to measure current practice in VTE prophylaxis in relation to general surgery, with the goal of achieving the correct use of anti-embolic stockings and low molecular weight heparin for every patient. They are also intended to facilitate implementation of Guideline-based practice by providing a risk stratification tool for use across acute medical and surgical specialties. This should ensure that each patient gets correct prophylaxis, adjusted for clinical setting. It’s encouraging that since the tools were published in April this year, they have been downloaded nearly 1,000 times. SIGN has put in place arrangements to collate all the individual audits, and that will help address the concern about the need for robust audit of activity at ward level expressed in the report *The Venous Thromboembolism Challenge in Scotland* published last year. It’s a big incentive that NHS Education for Scotland supports this work by recognising completed audit cycles as a significant educational achievement.

SIGN has also, and I think very imaginatively, developed an application for smartphones and tablets. It contains quick reference guides from 14 recent Guidelines, including Guideline 122. By the end of August, more than 25,000 copies of the application had been downloaded, making the Guideline 122 recommendations readily available to all these healthcare professionals.

Achieving reliable VTE prophylaxis in surgical patients is part of the Scottish Patient Safety Programme (SPSP)’s peri-operative workstream. The target is 95% of patients assessed and receiving appropriate VTE prophylaxis. At least 42 teams are now reporting data, and the average team is achieving reliability in 98% of patients. We must continue to build on this work. The report on the VTE challenge made clear that we needed to raise our game to a similar level when assessing medical patients in our hospitals. The Guideline picks up on recognised good practice in NHS Grampian by including its VTE risk assessment algorithm. That’s now included in the audit
tools mentioned earlier, and will help encourage other NHS Boards to adopt it. The SPSP also agreed last year that VTE risk assessment and appropriate prophylaxis will be extended to all patients, medical as well as surgical.

The SPSP’s VTE care bundle will be available shortly on the SIGN website. SIGN is working with the Quality Improvement Hub and the SPSP to promote this care bundle as an evidence-based intervention that will improve patient safety in Scotland.

One of the recommendations in the VTE Challenge document was that each Board should establish a Thrombosis Committee. I had given undertakings that the Chief Medical Officer would arrange for this to be discussed by the Scottish Association of Medical Directors. I understand that this discussion has now taken place, and the Association has written to CMO indicating its support for the establishment of these Committees, or the assignation of this responsibility to an existing committee in some of the smaller NHS Boards, as the key to making real progress with the implementation of SIGN Guideline 122.

The issue of neonatal screening for Factor V Leiden has not been discussed by the National Screening Committee, which advises all 4 UK Health Departments, for the specific reason that the defect does not cause problems in babies and children, and there is considerable uncertainty about the implications of a positive test. It is not considered good practice to carry out genetic tests on children unless this is deemed to be of immediate value to the child. Where late onset disorders are concerned, geneticists (and ethicists) consider that children have the right to decide for themselves whether or not they want such a test, when the time is appropriate.

It is usual for adult relatives of patients who have Factor V Leiden (and other similar genetic conditions) to be offered genetic testing and given appropriate advice in the light of the result of that test. This may be important if they are considering going on to the combined oral contraceptive pill. The pill itself carries an increased risk of VTE, and in individuals who carry the Factor V Leiden gene this is increased by a factor of 3. Females who carry the Factor V Leiden defect are therefore generally advised not to take the combined oral contraceptive pill. Clinicians providing maternity services would be expected to assess pregnant women for risk factors for DVT as part of their overall clinical assessment, and to provide further management in line with current clinical guidelines including SIGN and the Royal College of Obstetricians and Gynaecologists. Although this is a different process from population screening, it means that those most at risk should be picked up.

I hope it will be apparent from the terms of this rather lengthy reply that the Government is serious about implementing the Guideline, because of the clear evidence of the enormous benefits to be gained from doing so, in terms of both illness avoided and lives saved. An integral part of our Quality Strategy is that care should be not only effective, but also person-centred and safe. Implementing Guideline 122 will satisfy all 3 of those ambitions.

NICOLA STURGEON
APPENDIX 4 – Correspondence from Petitioner

I have read Ms Sturgeons letter and agree that the situation in Scotland is improving. I contacted you today because NICE have sent me a copy of their latest Guideline which is out for consultation. The title of which is "Venous thromboembolic diseases: the management of venous thromboembolic diseases and the role of thrombophilia testing". This seems to show Scotland falling behind regarding the forward thinking I have been pushing for in my request for Thrombophilia testing to be made more known about to the general public and also for the medical profession in Scotland to be more accepting of. Can I ask that the Committee are advised of the NICE Guideline prior to their next meeting.

Kind Regards

Gordon McPherson