Citizen Participation and Public Petitions Committee Wednesday 22 January 2025 1st Meeting, 2025 (Session 6)

PE2016: Raise awareness of Thrombosis in Scotland

Introduction

Petitioner Gordon McPherson

Petition summary Calling on the Scottish Parliament to urge the Scottish Government to raise awareness of the risk factors, signs and symptoms of Thrombosis.

Webpage <u>https://petitions.parliament.scot/petitions/PE2016</u>

- 1. <u>The Committee last considered this petition at its meeting on 20 March 2024.</u> At that meeting, the Committee agreed to write to the Cabinet Secretary for NHS Recovery, Health and Social Care.
- 2. The petition summary is included in **Annexe A** and the Official Report of the Committee's last consideration of this petition is at **Annexe B**.
- The Committee has received a new written submission from the Cabinet Secretary for NHS Recovery, Health and Social Care which is set out in Annexe C.
- 4. Written submissions received prior to the Committee's last consideration can be found on the petition's webpage.
- 5. <u>Further background information about this petition can be found in the SPICe</u> briefing for this petition.
- 6. <u>The Scottish Government gave its initial response to the petition on 2 May 2023.</u>
- 7. Every petition collects signatures while it remains under consideration. At the time of writing, 9 signatures have been received on this petition.

Action

8. The Committee is invited to consider what action it wishes to take.

Clerks to the Committee January 2025

Annexe A: Summary of petition

PE2016: Raise awareness of Thrombosis in Scotland

Petitioner

Gordon McPherson

Date Lodged

3 April 2023

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to raise awareness of the risk factors, signs and symptoms of Thrombosis.

Previous action

I have sent emails requesting meetings to discuss the situation with the Scottish Government between 2011 and 2023 which have been denied. The Scottish Government stated that as awareness was raised in 2011, they have no intention of raising awareness in the foreseeable future.

The MSPs I have spoken to include Anas Sarwar MSP, Jackie Baillie MSP, Douglas Ross MSP, Miles Briggs MSP, Alex Cole-Hamilton MSP, Natalie Don MSP. I have asked for and received assistance from BBC, STV, Daily Record, Glasgow Herald, Scotsman, Scottish Sun, Sunday Scottish Express and Sunday Post.

Background information

Our daughter died of an undiagnosed and therefore untreated DVT (Thrombosis) in 2003. Since then, I have campaigned to raise awareness and been involved as a Layperson in the Scottish Intercollegiate Guidelines Network (SIGN) Guidelines 122 and 129 along with the National Institute for Healthcare Excellence (NICE) VTE2 Guideline.

I am currently the World Ambassador for World Thrombosis Day 2022 which is part of The International Society on Thrombosis and Haemostasis which is a worldwide organisation.

Thrombosis kills approximately 11,400 people per annum in Scotland which is approximately 1 in every 4 deaths recorded (figures quoted are via Freedom of Information requests to the Scottish Government and via Health Ministers FOI).

Annexe B: Extract from Official Report of last consideration of PE2016 on 20 March 2024

The Deputy Convener: Our next continued petition is PE2016, which was lodged by Gordon McPherson. The petition calls on the Scottish Parliament to urge the Scottish Government to raise awareness of the risk factors, signs and symptoms of thrombosis.

We last considered the petition at our meeting on 14 June 2023. At that meeting, we heard that recent research by The BMJ shows that, after a Covid-19 infection, there is an increased risk of deep vein thrombosis for up to three months, of pulmonary embolism for up to six months and of a bleeding event for up to two months after infection.

With that in mind, we agreed to seek a view as to whether it is necessary to undertake more work to raise awareness of thrombosis. The Scottish Government's response stated that it is considering the issues that were highlighted by the research and is looking at what further awareness messaging can be undertaken via social media.

The Government's response explains that, in the parliamentary question answer that is referred to by the petitioner in previous submissions, the figures include all conditions that are all or mostly due to a blood clot forming in a particular location, including both arteries and veins. This therefore includes some of the most common causes of death, including myocardial infarction and stroke. The data that is used in response to the petition reflects clots forming in the veins and includes instances where those clots travel and cause pulmonary embolisms.

The petitioner's recent submission notes that his petition covers thrombosis as a whole, rather than specific subdivisions. He states that the Scottish Intercollegiate Guidelines Network has worked on the guideline that highlights the link between Covid-19 and blood clots, but that no action has been taken by the Scottish Government to raise awareness.

Do members have any comments or suggestions?

Fergus Ewing: I think that we should write to the Cabinet Secretary for NHS Recovery, Health and Social Care seeking confirmation of whether the Scottish Government is undertaking any work to raise awareness of thrombosis—and if not, why not—and seeking his view on whether it is necessary to undertake more work to raise awareness of thrombosis in the light of The BMJ 's research, which connects Covid-19 with an increased risk of thrombosis and pulmonary embolisms.

In the letter making that request, it might be useful to allude specifically to the evidence that we have received. Plainly, Mr McPherson has suffered greatly. He lost his daughter. It is an absolute tragedy. He has provided very detailed information that conflicts with the Scottish Government information. From memory, he said that there were 11,400 cases; the Scottish Government's figure was vastly lower, and I do not think we have really bottomed out the difference. That is very important

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because, if he is right and the Government is wrong, we need to do an awful lot more than we are doing at the moment.

I would also point out Jackie Baillie's representation for Mr McPherson at our meeting on 14 June 2023. It was highly useful to the committee, and I think that it would be useful for the cabinet secretary, who I know takes these things extremely seriously, to peruse for himself. I want to underscore the importance of the matters that Mr McPherson has raised. I hope that the cabinet secretary gets that when he receives our letter and perhaps a copy of the Official Report of this meeting.

The Deputy Convener: Does the committee agree with Mr Ewing's recommendations?

Members indicated agreement.

Annexe C: Written submission

Cabinet Secretary for NHS Recovery Health and Social Care written submission, 19 April 2024

PE2016/E: Raise awareness of Thrombosis in Scotland

Thank you for your correspondence of 25 March 2024 relating to Petition PE2016. Raise awareness of Thrombosis in Scotland.

I welcome the opportunity to respond and also to offer my personal sympathies to Mr McPherson on all that he has experienced, having lost his daughter.

Thrombosis Figures

I note Mr McPherson's concerns and his views regarding the figures provided by Scottish Government previously. While I appreciate that Mr McPherson does not agree with our interpretation of the figures, I would disagree with the concern that the Scottish Government is seeking to minimise the impact of thrombosis deaths.

The risk factors for venous thromboses (deep vein thrombosis (DVT), pulmonary embolism (PE) and venous thromboembolism (VTE)) and arterial thromboses, which can lead to heart attack and stroke, are very different, and therefore the Scottish Government has different strategies for each. These include public awareness raising and issuing clinical guidance. I am aware that Mr McPherson has been advised by officials previously that the definition of venous thromboses more appropriately covers his area of interest.

Awareness Campaign

The Scottish Government receives many requests to run public awareness campaigns and we do not have the financial capacity to accommodate all of them. We assess each request carefully and we keep our plans for awareness-raising activity under regular review. We most recently posted about the signs and symptoms of DVT in December 2023 from our @scotgovhealth channel on X, formerly Twitter, resulting in around 4,000 views.

There is a range of information available on the NHS Inform website on DVT and arterial thrombosis, and on the Thrombosis UK website, and we would refer the public to those sites for further details. Patients themselves are routinely advised in healthcare settings about the symptoms of VTE and the situations in which it is most likely to occur. I therefore do not feel that the cost of a public awareness campaign on thrombosis is justified at this time.

Thrombosis and Covid-19

I note your reference to the study published by the British Medical Journal into DVT after covid-19 infection. While studies such as these are important for the development of understanding and treatment of medical conditions, it is important to recognise that is only an indication of potential higher risk. The article itself states:

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"This is an observational study, so the researchers cannot establish cause, and they acknowledge several limitations which might have affected their findings. For example, VTE may have been underdiagnosed in patients with covid-19, testing for covid-19 was limited, especially during the first pandemic wave, and information on vaccination was not available."

Further research would be required to verify the findings of this study, which is based on a group of subjects from only one country. Therefore we need to exercise caution in basing clinical guidance or public awareness campaigning on its findings.

The Scottish Intercollegiate Guidelines Network (SIGN) published a national clinical guideline on the prevention and management of venous thromboembolism in patients with COVID-19 in December 2021, which recognised the increased risk of thrombosis and associated complications in patients with severe covid infection.

The National Institute for Health and Care Excellence (NICE) also has a guidelines for Venous thromboembolic diseases: diagnosis, management and thrombophilia testing, which was updated in August 2023 following new evidence on the diagnosis of VTE in people with covid-19. Clinicians in Scotland will be familiar with and should adhere to both the SIGN and NICE guidelines.

Finally, I would like to thank Mr McPherson for his engagement so far with the Scottish Government – I know how much that has been valued by the Minister for Public Health and Women's Health and our Deputy National Clinical Director, and I hope this continues.

Neil Gray MSP

Background note for Mr Gray

Thrombosis Figures

Mr McPherson has been sent two sets of figures over time relating to deaths involving thrombosis. The first set, in response to an FOI request, gives for figures for deaths from deep vein thrombosis (DVT), pulmonary embolism (PE) and venous thromboembolism (VTE). The most recent figure, from 2022, shows the total number of deaths from these venous thromboses to be **397**.

Secondly in response to a PQ asked by Dame Jackie Baillie Mr McPherson was sent figures for all thrombosis-related deaths, which includes venous thromboses and arterial thromboses which can lead to heart attack, stroke or peripheral arterial thrombosis. The total number of deaths in 2022 is **9,589**, which we recognise is significant but which is down 19.9% from 11,900 in 2008. The figures here include cases which were "all due" or "mainly or partly due" to thrombosis, and this latter category of "mainly or partly due" may contain an overcount of deaths because of the way cause of death is recorded.