

Citizen Participation and Public Petitions Committee

5th Meeting, 2024 (Session 6), Wednesday
20 March 2024

PE2016: Raise awareness of Thrombosis in Scotland

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	https://petitions.parliament.scot/petitions/PE2016

Introduction

1. The Committee last considered this petition at its meeting on [14 June 2023](#). At that meeting, the Committee agreed to write to the Scottish Government.
2. A petition summary briefing can be found at **Annexe A** and the Official Report of the Committee's last consideration of this petition is at **Annexe B**.
3. The Committee has received new responses from the Scottish Government and the Petitioner which can be found at **Annexe C**.
4. Written submissions received prior to the Committee's last consideration can be found on the [petition's webpage](#).
5. Further background information about this petition can be found in the [SPICe briefing](#) for this petition.
6. The Scottish Government's initial position on this petition can be found on the [petition's webpage](#).
7. Every petition collects signatures while it remains under consideration. At the time of writing, 9 signatures have been received on this petition.

Action

The Committee is invited to consider what action it wishes to take on this petition.

Clerks to the Committee

Annexe A

PE2016: Raise awareness of Thrombosis in Scotland

Petitioner

Gordon McPherson

Date Lodged:

03 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 14 June 2023

The Convener: The first new petition is PE2016, which was lodged by Gordon McPherson. It calls on the Scottish Parliament to urge the Scottish Government to raise awareness of the risk factors, signs and symptoms of thrombosis. Jackie Baillie has stayed with us for this petition as well, having an interest in it.

According to NHS Inform, deep vein thrombosis—DVT, as I think that many now know it—is “a blood clot that develops within a deep vein in the body, usually in the leg. Blood clots that develop in a vein are also known as venous thrombosis. DVT usually occurs in a deep leg vein, a larger vein that runs through the muscles of the calf and the thigh. It can also occur in the pelvis or abdomen. It can cause pain and swelling in the leg and may lead to complications such as pulmonary embolism.”

The Scottish Government’s response to the petition explains that it carefully prioritises the issues to which funding and staff resource are allocated, with the close input of clinicians. Given that it has already provided updated material to clinicians and revised the guidance available to the general public on NHS Inform on thrombosis, the Scottish Government does not consider that this is the right time for a major public awareness campaign. It does, however, commit to running a “package of activity” on the Scottish Government’s health social media account on thrombosis awareness later this year.

The petitioner’s further submission responds to the Scottish Government’s cited statistics on thrombosis, highlighting that the higher numbers provided in his petition were taken from a ministerial answer to a question lodged by Jackie Baillie MSP. Therefore, before I ask members whether they wish to come in, especially in the light of the Scottish Government’s quite clear direction, is there anything that Jackie Baillie would like to say to the committee?

Jackie Baillie: Thank you very much, convener. I am very grateful for the opportunity to speak.

Gordon McPherson is, in fact, a world ambassador for world thrombosis day. He has been campaigning on this issue for 20 years, and I feel that I have known him for each and every one of those years. He is persistent, and rightly so, because he is asking the Scottish Government to raise greater awareness of deaths in Scotland that can be attributed to thrombosis, as you have outlined, and to show the risk factors, signs and symptoms to look for in order to reduce mortality and morbidity.

The petitioner lost his daughter, Katie, who was an occupational therapist, in 2003, when doctors at two hospitals failed to spot a blood clot in her leg and she was sent home with painkillers. Mr McPherson feels that if medical staff had been more aware of the risk factors, plus the signs and symptoms, Katie may not have died from untreated thrombosis.

The Scottish Government has not run an awareness campaign on the condition since 2011, and Mr McPherson feels that it is not treating the matter as seriously as is required. As a result of a lack of awareness on the part of both the public and medical professionals, he is concerned that there will be increased cases of thrombosis. He is keen that the Government does more than it is already doing. He is not looking for something that is hugely expensive—he has suggested practical stuff. For example, he has talked about blood clot alert cards, such as are available in Ireland. They inform patients of the risks and signs of clots and of the need to get medical attention fast in the event of a clot. That strikes me as something that the Scottish Government could do effectively without too much cost. He has raised issues such as that with the Scottish Government over the past 20 years and it has been particularly unhelpful in trying to progress the matter.

What makes the issue more significant—and is I think the reason why he has lodged a new petition—is that new research by the BMJ shows that, after a Covid-19 infection, there is an increased risk of DVT for up to 3 months, pulmonary embolism for up to 6 months and a bleeding event for up to 2 months after infection. The circumstances around thrombosis have changed since the Government's last awareness campaign in 2011 when Covid-19 was not the health risk that it is now. In that light, I would be most grateful if the committee could consider whether it would be wise for the Government to take another look at public and medical professional awareness of thrombosis so that more lives such as Katie's are not lost.

The Convener: Thank you. Your evidence was helpful and compelling. Do colleagues have any suggestions?

Fergus Ewing: I am grateful to Jackie Baillie for shedding light on the new information that there are linkages between Covid-19 and thrombosis, as well as other linkages, which would suggest that there is a need for further consideration of what preventative interventions may be appropriate in identifying cases where there is a risk predisposition. It would be well worth putting to that to the minister.

I am new to this and I do not know the petitioner, but having read through the papers, I picked up that the loss of his daughter was a crushing blow. He has been through the mill. One death is one too many and I bear that in mind when I refer to numbers. However, there is a clear conflict between the figures that he has provided, which indicate that there are 11,400 deaths per annum in Scotland, whereas the figures in the Scottish Government's submission indicate that there were 380 deaths from blood clots in 2021 and a total of 1,925 where blood clots were mentioned on the death certificate—380 as an underlying cause and 1,545 as a contributory cause. In turn, the petitioner replied saying that:

“It is not the first time the Scottish Government has quoted one set of figures when there are other figures which reflect the case I put forward”.

I would be interested to learn more about that and to tease out why the figures that he refers to are roughly 10 times greater than the figures that the Scottish Government uses.

Whether or not there have been 1,000 or 10,000 deaths, it is such a serious thing; the consequences can be fatal in serious cases. Whether there is a public information campaign or other specific actions that are taken on the basis of proper clinical considerations about preventative action, we need more information on the matter from the Scottish Government. I do not have a view on whether we want to do that by letter or in an evidence session.

The Convener: If Jackie Baillie does not mind, I will ask her for clarification. The petitioner feels that his figures came from a ministerial response received to one of your questions. Have you been able to understand or establish why there might be a discrepancy between the two sets of figures?

Jackie Baillie: No, but he is accurate in saying that the first set of figures that he quotes were provided to me in answer to a parliamentary question, I think. I am happy to provide that information to the committee if you do not already have sight of it.

The Convener: It would be useful to write to the Scottish Government to seek an explanation for the discrepancy in the figures. We should also draw attention to the report that has suggested that there could be a link with Covid. We could refer back to the petitioner's long-standing association with the issue, the fact that it is all about prevention and that circumstances have changed. In the light of all of that, it could be that it is necessary to do a little more than had previously been suggested. Are colleagues content with that?

Members *indicated agreement.*

David Torrance: I wonder whether we should write to the Scottish Government. It will be running a health awareness messaging campaign on social media later this year, and given the fact that Covid has been brought into the matter, perhaps it can be put into that social media campaign.

The Convener: Okay—we will keep the petition open on that basis.

Annexe C

Scottish Government submission of 24 August 2023

PE2016/C: Raise awareness of Thrombosis in Scotland

Thank you for your correspondence on 27th July 2023 regarding the Petition PE2016. I am responding as Deputy Director for the Planning and Quality Division, which has responsibility for public awareness campaigns related to patient safety.

The number of deaths associated with thrombosis-related conditions is a very broad one, as it essentially includes any condition caused by a blood clot forming at that site. It is not always possible to tell whether the clot formed at that site (thrombosis), or travelled from elsewhere (thromboembolism), hence the categories of 'all due to' and 'many due to' thrombosis used in the [PQ answer \(S6W-07943\)](#).

The data that was used in response to the petition is more specific to venous thrombosis and thromboembolism. In this group the blood clot has formed within the vein, and then either caused a problem where it is (venous thrombosis), or travelled elsewhere in the body and caused a problem (venous thromboembolism).

In addition, there is an overlap between the three conditions, deep vein thrombosis (DVT), pulmonary embolism (PE) and venous thromboembolism (VTE) when listed as in the PQ answer. Cases of PE may develop from DVT therefore a single death may be coded under both DVT and PE. There is also some overlap between DVT and VTE for the same reason. As a result of this you can't add together the underlying cause deaths.

In summary, the PQ answer includes all conditions that are all or mostly due to a blood clot forming in that location, including both arteries and veins. This therefore includes some of the most common causes of death, for instance myocardial infarction and stroke. The data used in response to the petition reflects clots forming in the veins, and includes instances when these travel and cause pulmonary embolism. From the

context that we understand the petitioner is wanting to raise awareness on, the figures quoted in the response to the petition more accurately reflect the number of deaths recorded in Scotland.

Updated material has been provided to clinicians and the guidance available to the general public on NHS Inform on thrombosis was updated in May 2023. The Scottish Government is looking at what further awareness messaging can be taken forward on thrombosis via the Scottish Government's health social media accounts. The issues highlighted by the research found in the British Medical Journal (BMJ), regarding the risks post Covid-19 infection, are being considered.

Planning and Quality Division

Petitioner submission of 29 September 2023 PE2016/D: Raise awareness of Thrombosis in Scotland

I am glad to note that the Scottish Government state their data used in response to "the petition is more specific to Venous Thrombosis and Thromboembolism", even though my petition covers Thrombosis as a whole rather than specifically concentrating on subdivisions of Thrombosis i.e. Venous Thrombosis and Thromboembolism. This is accentuated by the title of my petition namely: to raise awareness of Thrombosis in Scotland.

What the Scottish Government is doing, yet again, is trying to belittle the volume of deaths per annum in Scotland attributed to Thrombosis in general. The Scottish Government is concentrating or trying to divert attention away from the bigger problem, risk factors, signs and symptoms of Thrombosis, and hoping that by concentrating on a subdivision of Thrombosis i.e DVT and PE they can "show" that Thrombosis is not a major problem both for the general public and the medical profession.

By stating "only" 380 deaths per annum rather than the 000s of deaths per annum due to Thrombosis, they hope to minimize the impact of the actual death total. Many of those deaths could be reduced and indeed

the morbidity attributed to Thrombosis could reduce the burden on the NHS.

The Scottish Government stated in their response "From the context that we understand the petitioners wanting to raise awareness on, the figures quoted in the response to the petition more accurately reflect the number of deaths recorded in Scotland." I would say all the Scottish Government have done is revisit figures sent to me regarding a question of the then Cabinet Secretary for Health and Social Care, now First Minister, raised some time ago without referring to the wording of my petition namely raising awareness of THROMBOSIS in Scotland, not raising of DVT and or PE in Scotland.

I would also put forward that recent research shows a relationship between Covid/Long Covid and the dangers of blood clots to sufferers.

SIGN has worked on a guideline where they highlight the relationship between Covid and Blood Clots but as per the existing SIGN guidelines 122 and 129, there has been no action taken to raise awareness to the general public of risk factors plus signs and symptoms to be aware of.

Without heightened awareness of Thrombosis risk factors and signs and symptoms, the incidences of Thrombosis mortality and morbidity will increase and the only way I see the Scottish Government doing anything is to make use of statistics in the hopes they can "confuse" the general public.

I look at a possible example being that if a question was asked of deaths due to addictive substances the Scottish Government would choose to either quote deaths due to narcotics, alcohol or tobacco all of which are addictive rather than quote total deaths. This way the actual figures quoted are recorded as lower than the "true" total.

At the end of all responses from the Scottish Government, it always states that it is "looking at what further awareness messaging can be taken forward on Thrombosis". I have been corresponding with the Scottish Government since 2003 and there has been no awareness messaging taken forward since then, hence my petition.