



PUBLIC PETITION NO.

PE01566

Name of petitioner

Mary Hemphill and Ian Reid

Petition title

A National Service Delivery Model for Warfarin Patients

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to implement a National Service Delivery Model to ensure that all NHS boards have the resources to assess warfarin patients who request (i.e. self-present) for self-testing and/or self-management their condition.

Action taken to resolve issues of concern before submitting the petition

On 8 October 2013, Nanette Milne MSP sponsored a round table meeting held at the Scottish Parliament, which involved clinicians who support patients on anti-coagulation therapy and politicians.

In 2014, a number of MSPs have also tabled PQs on this issue: Richard Simpson (S4W-06247); Richard Lyle (S4W-20108, S4W-20110, S4W-20111), Jackie Baillie (S4W-20102, S4W-20103, S4W-20104) and Margaret McCulloch (S4W-20176). On 1 April 2014, Nanette Milne's motion S4M-09430: "Self-management of Anticoagulation Therapy" was debated. In response, letters were published in national newspapers and the AntiCoagulation Self-Monitoring Alliance (AC SMA) sent letters to the Members of the Health and Sport Committee.

The petitioner wrote on numerous occasions to Michael Matheson MSP in his capacity as Minister of Public Health at the time. The petitioner also published a letter in the Herald on 16 May 2014.

Following this publicity, the petitioner met with the CEO of Greater Glasgow and Clyde Health Board and the Clinical Manager of Anti Coagulation Services who are now developing a local model of care for paediatric warfarin patients moving to adult care services in the area.

Petition background information

CALL FOR A NATIONAL SERVICE DELIVERY MODEL

The petitioner is calling on the Scottish Parliament to urge the Scottish Government to implement a national service delivery model for warfarin patients who request the option to self-test or self-manage their condition. Currently no such model exists for Scotland's 80,000 warfarin patients.

All warfarin patients require regular monitoring of international normalised ratio (INR): daily at the start of treatment and, once stable, every 6-12 weeks. INR monitoring is normally managed by local anticoagulant clinics, but suitable patients can be trained to self-test (where patients record their readings to send to clinicians to review) and/or self-manage their condition (where patients are completely responsible for their readings and dose). Both arrangements can be safe, reliable and more convenient for many patients.

It is imperative a national service delivery model is created to support suitable patients who wish to self-test or self-manage their condition. The petitioner is already working with Greater Glasgow and Clyde Health Board to create a local service delivery model for warfarin paediatric patients moving to adult services within the area. The petitioner believes a plan of this type should be developed at the national level for all warfarin patients, including those moving from paediatric to adult care services. Ultimately, the aim of this model would be to improve awareness, training and support for clinicians and warfarin patients who wish to self-test or self-manage. The petitioner believes a national service delivery model should incorporate the following:

An immediate review of those patients on warfarin who request the ability to self-test their INR and/or self-manage their condition:

Although there is funding for INR testing devices in Scotland, only 1% of people receiving warfarin therapy undertake self-testing. It is not clear why the number of patients self-testing is so low, or why suitable patients encounter resistance to self-test or self-manage. It could be attributed to a number of different factors, which will have very different consequences for what a national model should address and these issues must therefore be investigated.

Create effective training and safe clinical support services to be delivered in every NHS Board for NHS staff and suitable patients (or their carers) who are assessed as both physically and cognitively able to self-test and/or self-manage:

Clinicians across our Health Boards remain reluctant to support individuals to self-test or self-manage. The Scottish Government therefore needs to provide training and relevant infrastructure for clinicians, so that they feel confident and able to properly provide a patient-centred approach, to assess requests for self-testing or self-management from suitable patients and to support those who do.

A national service delivery model for warfarin patients would align with many of the Scottish Government's policies, such as the Health Directorate's *2020 Vision* initiative; and "Gaun Yerself", a policy written by patients with long term conditions that seeks to "Cheer a person as they embark on a challenge, a vote of confidence and a message that the person has your support".

A national service delivery model could also result in significant savings to NHS Scotland (approximately £600,000 or more), as studies have shown self-testing can reduce costly complications, such as thromboembolic events.

Update the Evidence Note in accordance with the latest evidence and recommendations:

The Scottish Government's Evidence Note on this issue has not been updated to include the latest evidence and recommendations from relevant bodies, including:

- SIGN Guideline 129 makes the following Grade A recommendation: "Self monitoring and self dosing is safe and effective and can be considered for some patients";
- The Royal College of Physicians Edinburgh Consensus Statement states that "Anticoagulant control may be improved by near patient testing and engaging patients in their own care; patient education should be supported at every stage"; and
- NICE recommends the use of some coagulometers by people taking long-term anti-blood clotting therapy if they prefer and are able to effectively use this type of monitoring (see guideline published in September 2014)

An outdated Evidence Note undermines the confidence of NHS staff in self-testing or

self-management and must be amended accordingly.

Incorporate a care support plan and infrastructure to provide co-ordinated and uninterrupted health care services for warfarin patients who move from paediatric to adult services:

All children and adolescents (or their parents/guardians) are offered support/training to self-test, as there is no alternative service in place for regularly testing their INR readings. However, when they move to adult care, many encounter difficulties because there is no co-ordinated infrastructure, or service delivery model, in place to ensure a consistent and uninterrupted care plan for them. This can cause many negative consequences for young adult patients, ranging from psychological distress and anxiety, to medical catastrophe.

As noted above, the petitioner is already working on a local service delivery model for these patients with NHS Greater Glasgow and Clyde. This has been very well received. Her work demonstrates that it is possible to develop such models and they are welcome at all levels: Board, staff and patient. A national service delivery model which addresses this issue would provide support, education and confidence for NHS staff and young adult patients to ensure warfarin therapy and delivery continues to remain safe and effective.

Unique web address

<http://www.scottish.parliament.uk/GettingInvolved/Petitions/warfarinselftesting>

Related information for petition

The petitioner's campaign website:

- <https://selftestingpetition.wordpress.com/>

The petitioner's Herald article on 16 May 2014:

- <http://www.heraldsotland.com/comment/letters/give-those-with-coagulation-problems-the-freedom-to-self-manage.24243764>

Studies on the benefits of self-testing and self-management:

- <http://www.thelancet.com/journals/lancet/article/PIIS0140673606681397/abstract>
- <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2095473/>
- <https://www.nice.org.uk/news/press-and-media/nice-recommends-self-monitoring-tests-for-people-on-long-term-anticoagulation-therapy>
- <http://www.pharmaceutical-journal.com/news-and-analysis/news/patients-taking-warfarin-should-self-monitor-their-coagulation-status-says-nice/20066631.article>
- <http://www.sign.ac.uk/pdf/SIGN129.pdf>

Information on paediatric care for warfarin patients:

- https://www.adolescenthealth.org/SAHM_Main/media/Advocacy/Positions/2003-Transition_from_Child-Centered_to_Adult_Health_Care_Systems_for_Adolescents_with_Chronic_Conditions.pdf
- http://www.rcn.org.uk/__data/assets/pdf_file/0010/157879/003227_WEB.pdf
- <http://www.transitioninforonetwork.org.uk/media/2731/growing-up-ready-for-emerging-adulthood.pdf>

Do you wish your petition to be hosted on the Parliament's website to collect signatures online?

YES

How many signatures have you collected so far?

0

Closing date for collecting signatures online

04 / 05 / 2015

Comments to stimulate online discussion

Please sign this petition & help us change the fact that not everyone in Scotland who takes warfarin routinely is supported or enabled to self test and self manage their condition, even where they specifically request to do so. Currently in Scotland only 1% of people receiving warfarin therapy self test.