

PE1566/V

Petitioner Letter of 25 September 2015

PEO1566: National Service Delivery Model for Warfarin Patients

Dear Mr McMahon,

Thank you for providing me with the opportunity to comment on the replies from 12 of our Regional Health Boards, there has been no response from NHS Ayrshire & Arran and NHS Tayside regarding our Public Petition for a National Service Delivery Model for Warfarin Patients. My response to the questions answered by the Health Boards in Scotland is detailed accordingly:

1/ Does your NHS Board have a protocol, e.g. a service delivery model or similar policy, on self-testing and self-management for warfarin patients?

There is a consistent message across the 12 Health Boards with the exception of **Greater Glasgow & Clyde and NHS Fife**. NHSGGC provides a single comprehensive INR/warfarin monitoring service (Glasgow and Clyde Anticoagulant Service - GCAS) for adults. NHS Fife also has an existing service delivery model. All other Health Boards have no protocol, service delivery model or similar policy. This provides both a clear and consistent message to the Scottish Government that there is a clear level of inequality in the provision of self testing and self management care and support across Scotland, where warfarin patients are not being given the same access, care provision or that ever important "Person Centred Care" approach. I refer you to the key objective of the Scottish Governments Self Management Strategy highlighted by the then Minister for Public Health Michael Matheson at a debate on self testing initiated by Nanette Milne on 1st April 2014. "Gaun Yersel" was written by patients with long term conditions for patients with long-term conditions in Scotland, written to cheer a person as he or she embarks on a challenge, where people can access timely and appropriate information and support to make well-informed decisions about their life. From the replies received, one of which I detail below it would seem the key objective of this strategy is failing warfarin patients across the vast majority of our Health Boards in Scotland.

*"NHS Lanarkshire **does not** have a specific training programme or guidance to NHS staff regarding self-testing and self-management for warfarin patients."*

*"NHS Borders has a Point of Care Testing policy which specifically **excludes** home testing as part of its remit. Therefore, there is no formal Borders protocol available for any home monitoring service. We do not have a clinical service comparable to that of the Diabetes Service that offers a service delivery model."*

2/ What guidance and training does your NHS Board provide to its NHS staff on self-testing and self-management for warfarin patients and is its implementation monitored?

With the exception of NHS Fife and NHS Greater Glasgow and Clyde, Health Boards across Scotland provide no training to staff to deal with patient queries, education, support or the sharing of best practice. The Scottish Governments 2020 vision

details “there is a focus on prevention, anticipation and supported self-management”; from the responses received we can conclude that this 2020 Vision has not been the focus for the majority of Health Boards across Scotland with regards to self testing and the self management of warfarin patients.

*“NHS Lanarkshire **does not have a specific training programme** or guidance to NHS staff regarding self-testing and self-management for warfarin patients.”*

*NHS Borders : “There are **no training programmes** available in the Borders to train NHS staff to assist in the education of home testing, monitoring and self management for warfarin patients.”*

3/ What is your NHS Board doing to promote self-testing and self-management amongst its warfarin patients? If it does not promote self-testing and self-management, please explain the reasoning behind this decision.

The replies from 12 of our Health Boards again with the exception of NHS Greater Glasgow and Clyde and NHS Fife, reaffirm the reluctance to promote self testing and self management. The promotion of self testing and self management would increase patient awareness, reduce the burden for our health care providers in an ever growing ageing population to ensure healthcare was provided at the point of need.

“NHS Lanarkshire does not actively promote self-testing and self- management for patients on warfarin.”

“NHS Grampian does not promote self- testing. We consider that with the current evidence that it is best to restrict the use to the small number of patients who clearly benefit and those who travel a lot and are not suitable for newer anticoagulant therapies.”

4/ What protocol, guidance or measures are in place in paediatric hospitals or paediatric care facilities in your area to provide support for warfarin patients who move from paediatric to adult services? Is there any oversight of this process, especially in circumstances where an individual is moving between different NHS Board areas, and what training or guidance is provided to staff on this issue?

The National Service Framework published by the Department of Health in 2006 states transition should be “a purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents with chronic physical and medical conditions as they move from child-centred to adult-oriented healthcare.”

Reflecting on the guidance of the National Framework it is deeply concerning that the echoing response across our Health Boards with the exception of NHS Greater Glasgow and Clyde, is that there is no protocol, guidance or measures for young people with long term conditions who are prescribed warfarin. Children prescribed warfarin in paediatrics (parents and/or carers) are taught to self test safely as there is no alternative infrastructure. These patients (parents and/ or carers) already have

the knowledge and the resources to safely and effectively take ownership of their long term condition. It is no surprise that many patients moving in transition encounter difficulties because there is no co-ordinated infrastructure or service delivery model in adult care, to ensure there is 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.

One particular comment from “NHS Grampian” states: *“We are not aware of any children locally who are on warfarin at present. Children on this therapy in this Board are very few. And if we did have any, their management would almost certainly involve specialist input from a tertiary team who would be involved in transition processes also.”*

“We do not have a specialist service or pre-determined pathways for transition. Any cases that we would have would be so infrequent and so specialised that we would develop a tailored pathway suited to the needs of the individual child / young person.”

5/ How many warfarin patients are there within your authority and, of those, how many self-test and/or self-monitor?

The responses detail that 11/12 Health Boards either don't know how many people self test in their authority or have self testing rates of less than 1% for those using warfarin.

“There are 8574 patients attending the NHS Lanarkshire Anticoagulant Service. A smaller group is monitored by primary care in the rural part of South Lanarkshire (Biggar, Douglas, Carnwarth and Forth). Only 3 patients attending the Anticoagulant clinic do self-testing and were previously paediatric patients transferred to adult service. There are a number of patients, who may have bought INR testing machine at their own expense but this has not been endorsed by the Anticoagulant clinic. NHS Lanarkshire does not have data on how many patients self- test or self-monitor.”

Conclusion:

The Scottish Government's position is that it is for Health Boards across Scotland to consider how best to progress discussions between clinicians and patients on the delivery of care. However the responses from Scotland's NHS Boards clearly show that they are not living up to the government's commitment to provide person centred care and patient self management. There is a serious inequality in the service delivery of warfarin self testing and self management across Scotland. Services should be as widely accessible and inclusive as possible to ensure that they contribute to tackling health inequalities. The responses from our Health Boards would strongly suggest that a standardised national approach should be adopted for the self testing and the self management of warfarin patients in Scotland to data collect, train, educate, evaluate, share best practice and provide a person centred care approach in line with the Scottish Government's 2020 Vision, the self management strategy “Gaun Yersel”, NICE guidelines updated in September 2014,

SIGN guideline 129 and The Royal College of Physicians Edinburgh Consensus Statement.

WARFARIN SELF-TESTING

IN

SCOTLAND



SUMMARY OF NHS RESPONSES



The percentage of people self-testing in Scotland...



...that's just 209 people out of 55,498 warfarin patients.



NHS boards do not have protocols for patients to self-monitor



NHS boards could not say how many patients were self-testing

60 / 4,721

NHS Fife has the highest percentage of people self-testing

But that's still only 1.2%

3 / 8,574

NHS Lanarkshire has the lowest percentage of people self-testing

That's just 0.03% of patients

That's why we're calling for:

a **National Service Delivery Model** to ensure that all NHS boards can assess warfarin patients who request to self-test their condition.