

Mr Sean Lyons
Chair of Hull University Teaching Hospitals NHS Trust
Hull Royal Infirmary
Anlaby Road
Hull
HU3 2JZ

15 February 2023

Dear Mr Lyons,

Re INADEQUATE SECONDARY CARE THROMBOSIS SERVICES IN HULL

Thrombosis UK is a registered charity working with patients and healthcare professionals to increase awareness, extend understanding and support research into prevention, management, and optimum recovery from, venous thromboembolism (VTE) and related thrombophilias.

Thrombosis remains a major cause of death in the UK therefore prevention and optimum management remain a priority for NHS Patient Safety.

For those affected by thrombosis, there is a life-long legacy, which includes, increased risk of further events, painful and life-changing complications including pulmonary hypertension, post thrombotic syndrome and mental health issues as well as increased risks in pregnancy, with certain medications, including hormone therapy, future surgery procedures or hospital admission, to list just a few. For those with more multiple or complex thrombosis histories, the impact is life-changing impacting significantly on their everyday life choices.

Due to associated risks and complexities, it is essential that patients diagnosed with a VTE or at known risk thrombosis, have access to information, and, where appropriate, haematology specialists and anticoagulation services, where their medical needs can be assessed and safely managed.

I am writing today to raise concerns on the number of VTE patients living in the Hull Teaching Hospitals NHS Trust region, who have contacted Thrombosis UK because they are struggling to access or have been denied access to haematology services or have received conflicting guidance without review or consultation (virtual or other). We are very concerned that patient needs are not being safely met and would seek your urgent review of this matter.

Below are three anonymised accounts as examples of contact Thrombosis UK has received in the past few months. Each raises concerns for patient safety, adherence to NICE VTE guidance and general sub-optimal provision of care in anticoagulation and haematology for VTE patients.

Case One: Female, DVT indicated provoked

- Diagnosed in Hull A& E
- Told it was due to taking oral hormone replacement therapy (HRT).
- Prescribed apixaban for six months and advised to stop taking HRT.

Unclear on her future options, the patient sought a referral, via her GP, to a haematology service to discuss her diagnosis.

After referral, a response was received by her GP that the haematologist based in Hull had replied and advised the individual needed to be on lifelong apixaban.

No appointment made, no further tests or investigation carried out.

No physical or verbal consultation between the patient and haematologist (or other nominated healthcare professional).

No follow up appointment advised.

Concerned, the individual sought a private referral. The private consultant advised six months on apixaban then anticoagulation could stop as the provoking factor (oral HRT) was no longer being taken.

Conflicting advice caused considerable anxiety. However, despite requests, reasons for recommendation to remain on long term anticoagulation could not be provided. This conflicted with NICE guidance on provoked DVT in NG158.

Case Two: Male (aged 27) history of recurrent DVTs whilst anticoagulated.

- Individual presented at Hull A&E and ambulatory care unit after recognising symptoms of thrombosis in his leg.
- A DVT was confirmed.
- The ACU doctor, concerned as to why this had happened to a young patient already anticoagulated, referred the individual to the Clinical Haematology Dept.

Referral declined giving the reason that the young man was overweight and therefore it was not surprising he had a DVT. No further follow up or investigations advised. NICE guidelines advise all patients receive medical review after a DVT.

GP arranged a CT scan which revealed he had IVC Agenesis, the absence of an inferior vena cava. An incredibly rare abnormality but likely to be a significant factor for his repeated DVTs whilst anticoagulated.

Despite the diagnosis, the individual has still not been able to secure an appointment for review with Hull haematology service, neither does he receive any monitoring or contact with the service. His only option is to manage his condition alone. He suffers constant pain due to the damage caused by the DVTs.

Case Three, Female Multiple DVT's, Antiphospholipid Syndrome (APS)

- Spanning approximately six years
- Awaiting IVF treatment

After a second DVT and unable to obtain a haematology consultation in Hull, her GP carried out tests for thrombophilia screening including APS.

The initial tests came back positive for APS at which point the GP diagnosed her with the condition.

A specialist would have known, a minimum of two tests, six-twelve weeks apart, should have been carried out to confirm APS, but there was no specialist support for the GP to access on behalf of the patient in Hull.

The individual wanted to start a family, unable to get a referral to the Hull haematology service, and mindful of her clotting issues her GP prescribed dalteparin injections whilst she was trying to conceive.

Within a week of starting dalteparin the lady was diagnosed with a further DVT.

At this point the individual insisted on a haematology consultation. The consultation was very brief, and she was advised to return when pregnant as they 'did not understand what all the fuss was about'.

After twelve months, still on dalteparin, the patient was accepted for IVF treatment. The IVF doctor requested that she is closely monitored by clinical Haematology during her potential treatment. The patient was unable to secure monitoring in Hull.

A London NHS hospital who had seen the individual after the consultation in Hull, offered to do this, but the distance is too far and expensive. Referral was sought to Sheffield, where a one-off consultation was offered but Sheffield stressed, she needed to be monitored locally, especially during pregnancy.

There are now few options for the individual as no Clinical Haematology monitoring is available in Hull. As a result, the IVF treatment is delayed. Mental health is declining, and she remains on injectable dalteparin.

Whether complex or 'standard' these three examples, reflect the extremely poor quality of provision for VTE patients in Hull.

- Patient One: would have remained on an anticoagulant unnecessarily for the rest of her life. Oral anticoagulants are classified as high-risk medications due to risk of major bleeding.
- Patient Two: dismissed without consultation or investigation, yet later was diagnosed with a vascular abnormality that significantly contributed to his repeated clotting. Despite risk and history, no monitoring or review has been actioned.
- Patient Three: with complex haematological needs yet denied basic monitoring in Hull and remains under non specialist GP care, IVF on hold and health needs unmet.

In each example patient safety has been put at risk and basic standard care, denied.

In a freedom of information request carried out by Thrombosis UK in 2022, Hull NHS Hospitals Trust responded and included the following answers:

- **Q: Does the Trust provide all patients with an unprovoked VTE a medical opinion from a thrombosis physician?**
A: 'No specific thrombosis physician?'
- **Q: Per week, how many clinics are devoted to seeing patients with VTE in the Trust**
A: 'there are no dedicated hospital clinics for follow up. There is ad-hoc follow up of patients at the discretion of the physician who manages their acute VTE but no single dedicated service.'
- **Q: How many full-time equivalents are employed by the Trust to provide thromboprophylaxis and care of thrombosis patients from?**
A: Nursing – there are none specifically for VTE
A: Pharmacists - the Trust does not have a specific "VTE Pharmacist"
A: Medical - none specifically for VTE
- **Q: Does the Trust routinely meet the 95% VTE Risk Assessment level required by NHS England?**
A: No

The FOI response and case accounts evidence cause and outcomes for significant issue and inadequate provision of VTE prevention and management within the Hull Trust. As a result, there is little or no protection from harm for VTE patients or monitoring of their ongoing care.

We would urge you to review your current provision and welcome meeting with you to offer HCP education, patient resources and sign posting to organisations including the VTE Exemplar Network for peer-to-peer support and guidance on improving current levels of in patient thromboprophylaxis. We would ask you to urgently address the lack of consultant expertise in Thrombosis provided by your Haematology Department, a Trust of your size should offer out-patient clinics and in hospital support from a consultant with a special interest in Thrombosis.

Yours sincerely



Prof Simon Noble
Medical Director, Thrombosis UK



Dr Ian Franklin
Chair of Trustees, Thrombosis UK



Jo Jerrome
CEO Thrombosis UK

cc.
Prof Stephen H Powis,
National Medical Director of NHS England