Thrombosis UK
Awareness • Research • Care

Helen Hayes MP
Member of Parliament
for Dulwich and West Norwood

ROUND TABLE SUMMARY REPORT

INTRODUCTION

On Tuesday 19 September 2023, Helen Hayes MP hosted a round table meeting in Portcullis House. The aim of the meeting was to discuss identified failures in policy and practice which are resulting in:

(i) Failures to prevent avoidable thrombotic events.

(ii) Routinely ensure early diagnosis of a venous thromboembolism (VTE). During the meeting, presentations were given by NHS clinicians, NHS Resolution and members of families who had lost a loved one to an undiagnosed VTE. Discussion was welcomed from all attendees including clinicians, NHS professional bodies and family members.

BACKGROUND

Venous thromboembolism, often referred to as 'blood clots', is an umbrella term for deep vein thrombosis (DVT) and/or pulmonary embolism (PE). VTE is common, with 1 in 20 people experiencing a VTE event at some point in their life. Incidence rates in the UK have been documented as 1–2 per 1,000,[1] and they have been attributed as the cause of many thousands of deaths,[2] while approximately 5–10% of inpatient mortality has been shown to be VTE related[3] Furthermore, blood clots are not only a significant cause of death, but also of long- term disability and long-lasting ill-health problems. As such, VTE related to hospital admission is the number one cause of preventable death and an NHS Patient Safety priority.

IDENTIFIED AREA OF SERIOUS CONCERN: PREVENTION OF VTE

The meeting received presentations from

- Prof Beverley Hunt OBE, Consultant in Haemostasis and Thrombosis and Founder of Thrombosis UK
- Samantha Thomas and Ellen Nicholson from NHS Resolution and authors of 'Cost of Avoidable Errors in VTE'[4] (2023)
- Tim Edwards, Bereaved family member & author of 'Independent Review of Pulmonary Embolism fatalities in England and Wales' (2022)[5]

In 2010 NHS England mandated VTE risk assessment for all patients admitted into hospital. Initially delivered as part of a Commissioning for Quality and Innovation (CQUIN), over the following ten years all NHS Trusts in England and most private sector hospitals reported quarterly VTE risk assessment rates with the 95% target routinely met.

[1] National Institute of Health and Care Excellence: https://www.nice.org.uk/guidance/ta287/documents/pulmonary-embolism-acute-treatment-vte-prevention-rivaroxaban-appendix-b-final-scope2#:~:text=The%20annual%20incidence%20of%20venous,7–8%20per%2010%2C000%20people

[2] https://digital.nhs.uk/data-and-information/publications/statistical/nhs-outcomes-framework/march-2022/domain-5---treating-and-caring-for-people-in-a-safe-environment-and-protecting-them-from-avoidable-harm-nof/5.1-deaths-from-venous-thromboembolism-vte-related-events-within-90-days-post-discharge-from-hospital

[3] Cohen AT, Tapson VF, Bergmann JF et al. Venous thromboembolism risk and prophylaxis in the acute hospital care setting (ENDORSE study): a multinational cross-sectional study. 2008; : 387–394. https://pubmed.ncbi.nlm.nih.gov/18242412/

[4] https://resolution.nhs.uk/wp-content/uploads/2023/03/Did-you-know-VTE-final-amended.pdf

[5] https://thrombosisuk.org/news/post.php?s=2023-01-16-independent-review-of-pulmonary-embolism-fatalities-in-england-and-wales

As a direct result of a system wide VTE prevention policy, supported by VTE prevention and management national guidelines (NICE NG158), which assessed for risk and provided evidenced guidance on management to reduce VTE risk, deaths from VTE related events within 90 days post discharge from hospital were reduced by 20.8% (2007/08-2017/2018). An outstanding achievement.

However, due to the COVID pandemic, reporting of VTE risk assessment was paused in March 2020, but has yet to be reinstated. UK VTE leads including the VTE Exemplar Network are concerned and have evidence that due to delay in reinstating reporting of VTE risk assessment, attention on VTE and VTE prevention is slipping, and patients are at increasing at risk of avoidable harm. Data collected in a Freedom of Information, carried out by Thrombosis UK in 2022, evidenced that more than 50% of NHS Trusts no longer routinely met the 95% VTE risk assessment target.

Retrospective data from NHS Resolution covering 2012-22 showed that not only was failure to prevent and appropriately trat VTE financially costly to NHS Trusts, but common errors were evident in all claims:

• Failure to prescribe or administer anticoagulant
• Failure to carry out a VTE risk assessment
• Incorrect dose of anticoagulant administered

Tim Edwards shared a very moving account regarding failures in his mother's care that resulted in her premature death due to an undiagnosed pulmonary embolism. These included:

- Incorrect initial assessment of VTE risk and subsequent failure to reassess.
- Incorrect of recording of Wells Score.
- Failure to consider suspicion of VTE despite documented symptoms.

VTE prevention is very cost affective.

• £640 million/annum on treatment of VTE
• £400 million/annum on the management of varicose ulcers
• £80 million on medicolegal cases 10 years up to 2005

Costs and savings of thromboprophylaxis per 100,000 population

• Estimated cost of implementation = £16,000
• Estimated saving of implementation = £12,000

Attendees agreed that while VTE risk assessment was an essential initial step in identifying risk of a thrombosis, assessment alone was insufficient, and must be followed by appropriate management. The 2019/20 national NHS Getting It Right (GIRFT) Thrombosis Survey identified common issues and variations in VTE patient care which resulted in avoidable harm. Whilst significant work has been undertaken by the Thrombosis UK, the VTE Exemplar Network, and VTE Specialist Network to support implementation of recommendations made in the GIRFT Thrombosis Survey, post-pandemic and with the suspension of VTE risk assessment reporting, a reassessment of the current state of VTE prevention in hospitals is urgently needed.

Errors and failure in VTE prevention need to be systematically identified in NHS Trusts, for improvement to be targeted, implemented and effective. A second NHS GIRFT Thrombosis survey had been prepared, for 2023 but funding was halted. VTE is a patient safety priority, and it is paramount that funding is found for the second survey (approximately £100,000). Subsequent targeted training, education and quality improvement identified through a GIRFT Thrombosis Survey would further maximise cost benefit, impact, and patient safety.

IT WAS AGREED:

1. A call for the re-instatement of the reporting of VTE Risk Assessment rates for all hospitals was a priority.
2. A second NHS GIRFT Thrombosis survey providing an in-depth reassessment of current variation and challenges in hospital VTE prevention would yield valuable data to inform improvement and therefore urgently needed funding.

IDENTIFIED AREA OF SERIOUS CONCERN: DELAY IN VTE DIAGNOSIS

The meeting then heard from:

- Debbie Budden, whose partner died of an undiagnosed PE despite his GP raising suspicion of a DVT and subsequent presentation at A&E.
- Dr Matt Fay, GP, and Trustee of Thrombosis UK

A pulmonary embolism (PE) occurs when a piece of clot breaks off from a deep vein thrombosis (DVT) and travels through the venous system to the heart and lungs. A PE is a medical emergency and can occur in all races and ethnicities, all age groups, and genders.

THE CHALLENGE

The "classic" presentation with abrupt onset of pleuritic chest pain, shortness of breath, and hypoxia is rarely the case. Studies of patients who die unexpectedly of pulmonary embolism reveal that they complained of nagging symptoms often for weeks before death related to pulmonary embolism.
Forty percent of these patients had been seen by a physician in the weeks prior to their death"[6]

Data from the EMPEROR[7] suggest that appropriate initial medical management of ED patients with severe PE with anticoagulation is poorly standardized and there is a need for research to determine the appropriate threshold for empiric treatment when PE is suspected before diagnostic confirmation.

There is strong indication that training needs to go 'back to basics' to:

1. Think Thrombosis – accounts highlighted there are gaps in access to trained and senior workforce and junior staff poorly educated about VTE including most common signs and symptoms.
2. Carry out a clinical assessment based on enduring and transient risk factors of a VTE.
3. Assess for moderate or low risk people with DVT and PE undertake the Well's score after clinical assessment.

Where local VTE/DVT primary care pathways had been introduced and were easy-to-use within primary care, patient journey to diagnosis was less likely to be delayed or diagnosis missed.

Point of care d-dimer testing had been shown to reduce delay for patients, reduce burden on ED services and be cost-effective (NICE NG158[8]).

There was agreement that patient safety-netting was essential and could easily be improved with:

4. Recognition of the value of D-Dimer, in the initial assessment of those at low/medium risk of thrombotic events (DVT/PE/CVST).
5. Improved access to diagnostics, whether D-Dimer tests in primary care or access to ultra scans and CT scanning at weekends in hospitals.

Patients are dying of undiagnosed pulmonary emboli. What happens when the initial symptoms are dismissed and not investigated? There was consensus that patient safety-netting was also a critical component to saving lives.

[6] Safi M, Rostami RT, Taherkhani M. Unusual presentation of a massive pulmonary embolism. J Tehran Heart Cent. 2011 Winter;6(1):41-4. Epub 2011 Feb 28. PMID: 23074604; PMCID: afi M et al

[7] https://pubmed.ncbi.nlm.nih.gov/21292129/

[8] https://www.nice.org.uk/guidance/ng158/evidence/a-ddimer-testing-in-the-diagnosis-of-deep-vein-thrombosis-and-pulmonary-embolism-pdf-8710588334

Debbie Budden partner's Gary, presented to his GP, where clinical suspicion of a DVT was raised. He then attended A&E, but judgement based only on the lack of swelling in his painful calf, led investigation for VTE to be dismissed. Gary was discharged with no further advice on what to do should symptoms persist or become worse.

Safety netting is imperative to save lives, and there was general agreement that:

- A national awareness campaign to increase knowledge of VTE, risk factors, signs and symptoms would better protect patients.
- Implementation across VTE of 'Martha's Rule' To Ask, To Challenge, To Go Back' would secure the review a potential VTE and empower individuals to ask, "Have I got a clot?"
- HCPs should ensure communication with the patient included guidance on what to do should symptoms persist or become worse.

IT WAS AGREED:

An audit of VTE diagnosis in the past 12 months is needed to track pathways to diagnosis and identify:

- Common barriers.
- Effective pathways.
- Key areas for learning and targeted education.