



**ALL-PARTY PARLIAMENTARY
THROMBOSIS GROUP**

Awareness, Assessment, Management and Prevention

**VENOUS THROMBOEMBOLISM (VTE)
IN CANCER PATIENTS**

CANCER, CHEMOTHERAPY AND CLOTS

OCTOBER 2015

www.apptg.org.uk

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AntiCoagulation Europe, a patient charity, receives support from Bayer HealthCare, Leo and Pfizer (in association with Bristol-Myers Squibb) by way of unrestricted grants to provide secretariat services to the group. AntiCoagulation Europe employs Insight Consulting Group, a consultancy, to provide these services.





ABOUT VTE

Venous thromboembolism (VTE) is a condition in which a thrombus – a blood clot – forms in a vein. Usually, this occurs in the deep veins of the legs and pelvis and is known as deep vein thrombosis (DVT).

The thrombus or its part can break off, travel in the blood system and eventually block an artery in the lung. This is known as a pulmonary embolism (PE). VTE is a collective term for both DVT and PE.

With an estimated incidence rate of 1-2 per 1,000 of the population, VTE is a significant cause of mortality and disability in England with thousands of deaths directly attributed to it each year.

One in twenty people will have VTE during their lifetime and more than half of those events are associated with prior hospitalisation. At least two thirds of cases of hospital-associated thrombosis are preventable through VTE risk assessment and the administration of appropriate thromboprophylaxis.

CHAIR'S FOREWORD



Dear Colleague,

As the Chair of the All-Party Parliamentary Thrombosis Group (APPTG), I am delighted to launch the publication of this new report on the risks of VTE in cancer patients.

The APPTG has long been concerned about the risks of VTE in cancer patients, and in particular that awareness of the issue is low in the NHS. This new report was commissioned to establish the links between cancer, cancer treatment and the increased risks of VTE in England and Wales. The APPTG was also eager to establish if hospitals are providing patients with information about the risks; and if pathways are in place to manage patients who develop clots whilst undergoing treatment.

Since its inception in 2006, the APPTG has produced annual reports to support the implementation of best practice in VTE prevention in the NHS. Drawing on the evidence gathered by our Annual Surveys of Acute Trusts and CCGs, our reports provide a comprehensive overview of progress in implementing best practice; identify areas for future improvement; and offer recommendations on what more can be done to ensure that NHS services are underpinned by high quality VTE prevention and management.

The findings of this report paint a worrying picture across the whole of England and Wales for cancer patients. Potentially avoidable deaths from VTE are occurring in our hospitals; a risk that could be alleviated by increasing clinical awareness and by providing patients with basic information as has been done for the majority of hospital inpatients already. More needs to be done for more patients with cancer, many of whom are treated as outpatients, where mandatory risk assessment and prophylaxis policies do not apply. It is a tragedy that in today's NHS a patient can beat their cancer, only to then die of a clot. We hope that by raising awareness of this overlooked issue, we can drive up patient safety and provide better outcomes for patients.

Ahead of World Thrombosis day on October 13th, I hope you find our report informative and that it inspires you to continue your work in helping to spread awareness of best practice in VTE prevention and management, whatever your role in the health system.

A handwritten signature in black ink that reads "Andrew Gwynne". The signature is written in a cursive, flowing style.

Andrew Gwynne MP
Chair, All-Party Parliamentary
Thrombosis Group

SUMMARY OF FINDINGS

Cancer and VTE Diagnosis

The number of patients diagnosed with both cancer and VTE has remained relatively constant over the previous three years; averaging around 1.7% across England and Wales.

Incidence and Variation

The South of England region has an incidence rate of 2% and Wales is significantly higher at 3.6%.

Mortality

Of the patients who died of cancer in the previous three years, 2.6% also had VTE listed on their death certificate as a cause of death. This accounts for an average of 3988 deaths per year, which is likely to be an underestimate of the true scale.

High Risk Cancers

Death rates for patients who died of brain, lung and bladder cancers - where VTE was also implicated – were particularly high, recorded at 2.6%, 2.5% and 2.3% respectively (in 2014).

Patient Information

Across all regions just under half of Trusts are providing patients with both written and verbal information about the risk of developing VTE during chemotherapy, what symptoms to look out for and what action they should take if they suspect a Deep Vein Thrombosis or Pulmonary Embolism.

VTE Cancer Policies

Only 41% of Trusts have a dedicated policy or pathway for the management of suspected VTE in patients receiving chemotherapy.

AIMS AND OBJECTIVES

This report seeks to further establish the known link between the treatment of cancer patients and the increased risk of venous thromboembolism (VTE). It aims to identify both individual hospitals where death rates for patients with cancer and VTE are particularly high, and to paint an overall national picture. Furthermore, it is hoped that it will reveal a breakdown of which cancers (and their treatments) are associated with particularly high rates of VTE. Finally, it will identify if hospitals provide advice (both verbal and written) to cancer patients about the risks of VTE; and if appropriate pathways are followed to treat affected patients.

Outcomes

The findings of this report will be used to:

- launch a research and awareness campaign: “Three Cs” (Cancer, Chemo and Clots);
- campaign for VTE and cancer to become prominent on the VTE Board agenda;
- campaign for a VTE question in the Cancer Patient Experience Survey;

Background

Venous thromboembolism (VTE) is a condition in which a thrombus – a blood clot – forms in a vein. Usually, this occurs in the deep veins of the legs and pelvis and is known as deep vein thrombosis (DVT). The thrombus or its part can break off, travel in the blood system and eventually block an artery in the lung. This is known as a pulmonary embolism (PE). VTE is a collective term for both DVT and PE.

The links between VTE and patients with cancer have been well established, and represent a major cause of morbidity and mortality in such patients. VTE is the second most common cause of death in patients with cancer. Population-based case–control studies have shown that the 2-year cumulative incidence of VTE is between 0.8 and 8% (Chew HK, 2006).

Patients with the highest 1-year incidence rate of VTE are those with advanced disease of the brain, lung, uterus, bladder, pancreas, stomach and kidney. In these cancers, the rate of VTE is 4–13 times higher among patients with metastatic disease as compared with those with localized disease. Despite an increasing body of knowledge to support the link between cancer treatment and VTE, it is believed that many hospitals in England and Wales do not take suitable precautions to avoid the risks (Mandala M, 2011).

For the general population, the standard treatment for acute VTE consists of initial therapy with a low-molecular-weight heparin (LMWH) followed by longer-term treatment (3–6 months) with an oral vitamin K antagonist (VKA). Although this approach can be effective for many patients, cancer patients have a substantial risk of recurrent VTE (Lee et al., 2013).

The National Institute for Health and Care Excellence pathway ‘*Venous thromboembolism: patients with cancer*’ recommends pharmacological prophylaxis for ambulant patients receiving oncological treatment who are at increased risk of VTE (NICE, 2011).

Methodology

Freedom of Information requests were sent to 150 Hospital Trusts in England and 7 Hospital Trusts in Wales by email in August 2015. A copy of the questionnaire can be found in the appendix. Trusts that do not treat patients with cancer were excluded, although children's hospitals were included.

In addition, a request was made to the Office for National Statistics to establish if the data provided by the individual hospital Trusts painted a similar picture to that nationally.

The following two questions were asked:

In England and Wales, in the years 2012, 2013 and 2014:

1. How many people had cancer listed as a cause of death on their death certificate?
 2. How many people had cancer **and** Venous thromboembolism (VTE) listed as a cause of death on their death certificate?
-

RESULTS

We grouped the responses received according to the 4 NHS England regions: North of England, Midlands and East of England, London and the South of England, and Wales. The maps below from NHS England's regional teams' web pages show the area boundaries.

North of England



1. Cumbria, Northumberland, Tyne & Wear
2. Durham, Darlington and Tees
3. North Yorkshire and Humber
4. Lancashire
5. West Yorkshire
6. Merseyside
7. Cheshire, Warrington and Wirral
8. Greater Manchester
9. South Yorkshire and Bassetlaw

Midlands and East of England



1. Shropshire and Staffordshire
2. Derbyshire and Nottinghamshire
3. Leicestershire and Lincolnshire
4. Birmingham and the Black Country
5. Arden, Herefordshire Worcestershire
6. Hertfordshire and South Midlands
7. East Anglia
8. Essex

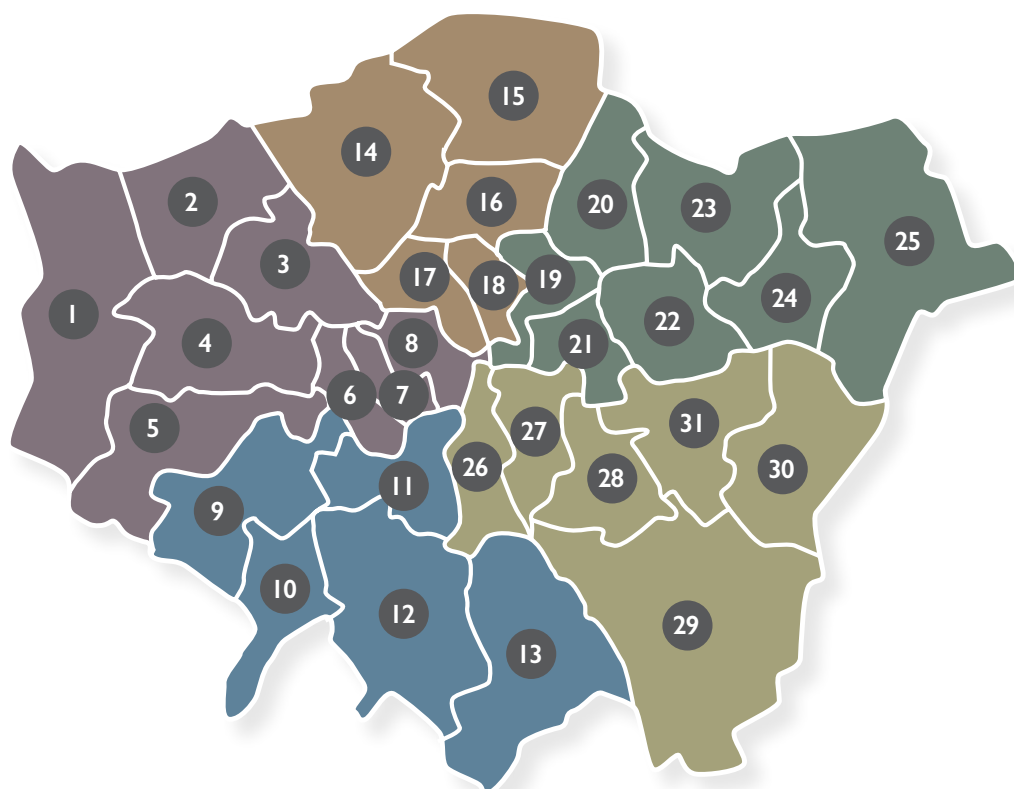
South of England



1. Devon, Cornwall and Isles of Scilly
2. Bristol, North Somerset, Somerset and South Gloucestershire
3. Wessex
4. Bath, Gloucestershire, Swindon and Wiltshire
5. Thames Valley
6. Surrey and Sussex
7. Kent and Medway

London

1. Hillingdon
2. Harrow
3. Brent
4. Ealing
5. Hounslow
6. Hammersmith & Fulham
7. Kensington & Chelsea
8. Westminster
9. Richmond & Twickenham
10. Kingston
11. Wandsworth
12. Sutton & Merton
13. Croydon
14. Barnet
15. Enfield
16. Haringey
17. Camden
18. Islington
19. City & Hackney
20. Waltham Forest
21. Tower Hamlets
22. Newham
23. Redbridge
24. Barking & Dagenham
25. Havering
26. Lambeth
27. Southwark
28. Lewisham
29. Bromley
30. Bexley
31. Greenwich



RESULTS

Response rate to the FOI survey

	North of England	South of England	Midlands and East of England	London	Wales	England and Wales
Number of requests sent	48	37	43	22	7	157
Number of responses received	28	21	25	13	5	92
Percentage response rate	58.3%	56.8%	58.1%	59.1%	71.4%	58.6%

Incidence rates of cancer and VTE

Proportion of patients diagnosed with cancer and VTE in England and Wales

Year	Number of patients treated for cancer	Number of cancer patients also diagnosed with VTE	Percentage of cancer patients also diagnosed with VTE
2014	363,692	6301	1.7%
2013	353,614	6506	1.8%
2012	339,125	5716	1.7%

Proportion of patients diagnosed with cancer and VTE - London

Year	Number of patients treated for cancer	Number of cancer patients also diagnosed with VTE	Percentage of cancer patients also diagnosed with VTE
2014	44,696	564	1.3%
2013	43,202	640	1.5%
2012	37,923	579	1.5%

Proportion of patients diagnosed with cancer and VTE - Midlands and East of England

Year	Number of patients treated for cancer	Number of cancer patients also diagnosed with VTE	Percentage of cancer patients also diagnosed with VTE
2014	108,891	1742	1.6%
2013	105,541	1542	1.5%
2012	105,717	1320	1.2%

Proportion of patients diagnosed with cancer and VTE - South of England

Year	Number of patients treated for cancer	Number of cancer patients also diagnosed with VTE	Percentage of cancer patients also diagnosed with VTE
2014	84,431	1571	1.9%
2013	82,367	1733	2.1%
2012	77,500	1476	1.9%

Proportion of patients diagnosed with cancer and VTE - North of England

Year	Number of patients treated for cancer	Number of cancer patients also diagnosed with VTE	Percentage of cancer patients also diagnosed with VTE
2014	108,146	1968	1.8%
2013	105,074	1905	1.8%
2012	101,195	1631	1.6%

Proportion of patients diagnosed with cancer and VTE - Wales

Year	Number of patients treated for cancer	Number of cancer patients also diagnosed with VTE	Percentage of cancer patients also diagnosed with VTE
2014	17,528	456	2.6%
2013	17,430	686	3.9%
2012	16,790	710	4.2%

Mortality rates involving cancer and VTE in England and Wales

Cancer deaths

Year	Lung Cancer	Brain Cancer	Bladder Cancer	All Cancers
2014	33,026	3793	6228	159,187
2013	32,724	3721	6059	157,848
2012	32,437	3782	6110	157,293

Cancer deaths where VTE is also listed as a cause of death on death certificate

Year	Lung Cancer	Brain Cancer	Bladder Cancer	All Cancers
2014	840	98	145	4088
2013	850	81	154	4028
2012	775	78	146	3848

(Data provided by the Office for National Statistics, September 2015)

RESULTS

Trends over three years

2014	2.6% of patients who died of cancer also had VTE present (4088 patients)
2013	2.6% of patients who died of cancer also had VTE present (4028 patients)
2012	2.5% of patients who died of cancer also had VTE present (3848 patients)

2014

2014	2.6% of patients who died from brain cancer also had VTE present (98 patients)
2014	2.5% of patients who died from lung cancer also had VTE present (840 patients)
2014	2.3% of patients who died from bladder cancer also had VTE present (145 patients)

Advice given to patients

Are patients who receive chemotherapy provided with written and verbal information about the risk of developing VTE during chemotherapy?

Written and Verbal	54 Trusts (58.7%)
Written only	5
Verbal only	4

Are patients who receive chemotherapy provided with written and verbal information which outlines the symptoms suggestive of VTE?

Written and Verbal	44 Trusts (47.8%)
Written only	7
Verbal only	8

Are patients who receive chemotherapy provided with written and verbal information regarding what action they should take if they suspect a Deep Vein Thrombosis (DVT) or Pulmonary Embolism (PE)?

Written and Verbal	50 Trusts (54.3%)
Written only	2
Verbal only	6

Does your Trust have a policy or pathway for the management of suspected VTE in patients receiving chemotherapy?

Yes	38 Trusts (41.3%)
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DISCUSSION AND OBSERVATIONS

Of the 157 hospital Trusts who were sent the Freedom of Information questionnaire, just under 60% returned their data (despite a 7 working day extension of the 20 day deadline). A further 13 Trusts returned their data after the extended deadline passed and therefore could not be included in the analysis.

Each region had a very similar response rate and this enabled good comparisons to be made between regions. The only exception being Wales, which had a response rate of 71% - though there are only 7 health boards in the region (one of which stated that the survey was not applicable to them).

It became apparent that many hospitals were unable to provide mortality figures due to the unavailability of this information held at Trust level. This had been anticipated and the mortality analysis is based upon figures obtained from the Office for National Statistics; which we deemed to be of the highest level of accuracy that could reasonably be obtained. However, as the response rate relating to patients who were receiving chemotherapy for specific cancers - who had then died of cancer and VTE - were so low, no meaningful conclusions could be drawn.

The number of patients diagnosed with both cancer and VTE has remained relatively constant over the previous three years; averaging around 1.7% across England and Wales. The South of England region has an incidence rate of 2% and Wales is significantly higher at 3.6%. This could be due to recording and reporting inaccuracies, or population bias (in the case of Wales, this data is only available for 5 out of 6 potential Trusts).

Of the patients who died of cancer in the previous three years, 2.6% also had VTE listed on their death certificate as a cause of death. This accounts for an average of 3988 deaths per year.

Previous research has shown that brain, lung and bladder cancers have a particularly high association with death involving VTE; and the data reveals that in 2014 the incidences were 2.6%, 2.5% and 2.3% respectively.

Across all regions, just under half of Trusts are providing patients with both written and verbal information about the risk of developing VTE during chemotherapy, what symptoms to look out for and what action they should take if they suspect a Deep Vein Thrombosis or Pulmonary Embolism. Only 41% of Trusts have a dedicated policy or pathway for the management of suspected VTE in patients receiving chemotherapy.

It is well known that the recording and reporting of death statistics in hospitals is poor, and undoubtedly under-reported. Of the 92 Trusts who returned data, only 32 were able to provide basic statistics on how many cancer patients had died. Only 31 Trusts were able to provide information on how many cancer patients who had died also had VTE listed as a cause of death. Even fewer were able to report how many patients who had received chemotherapy had died (16 Trusts).

CONCLUSIONS AND APPTG RECOMMENDATIONS

It is clear from the data obtained that there is a credible link between patients who have been diagnosed with cancer and incidence of VTE. Whilst the rates of such a link have remained relatively stable over the last three years, the risks posed to patients are still significant and unacceptable, with almost 4000 deaths occurring each year. Despite this, less than half of all hospital Trusts have a specific policy or pathway in place for the management of suspected VTE in patients receiving chemotherapy.

The poor recording and reporting of mortality figures (including causes of mortality) are of concern. In order for trends to be monitored, it is essential that this data is routinely recorded and monitored at Trust level.

The findings of this report paint a worrying picture across the whole of England and Wales for cancer patients. It is clear that potentially avoidable deaths from VTE are occurring in hospitals; a risk that could be alleviated by increasing clinical awareness and by providing patients with basic information. Policy in the NHS should be driven by favourable patient outcomes and increased patient safety. The evidence emerging is that lives are unnecessarily being put at risk and much more needs to be done to address these urgent needs.

Based upon the findings of this report, the All-Party Parliamentary Thrombosis Group recommends the following:

- The risks between VTE and cancer should become more prominent on VTE Board agendas.
- There should be specific recognition of VTE cancer risk in chemotherapy Clinical Reference Group (CRG) service specifications for high risk cancers, with a recommendation for mandatory risk assessment to be undertaken.
- There is a need for a VTE question in the Cancer Patient Experience Survey.
- There is a need for standardized NHS information on managing VTE in cancer patients.

The data obtained for this report collated information from patients who were treated in both an inpatient and outpatient setting. Anecdotal evidence suggests that even when patients are informed of the risk of developing a clot when being treated for cancer; this is only happening at an inpatient level. The APPTG is planning future work to obtain data to study this in more detail.

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<http://pathways.nice.org.uk/pathways/venous-thromboembolism/venous-thromboembolism-patients-with-cancer#content=view-node%3Anodes-pharmacological-prophylaxis>

NHS England (2014, 2015)

NHS England regional teams
<https://www.england.nhs.uk/about/regional-area-teams/>

APPENDIX

Part I: Incidence

Question 1:

How many patients has your Trust treated for cancer (of all types) in each of the past three years?

- a) 2014
- b) 2013
- c) 2012

Question 2:

Of the patients treated for cancer, how many also had a diagnosis of venous thromboembolism (VTE) {VTE is defined by the following ICD 10 codes: I80.0-I80.3, I80.8-I80.9, I82.9, O22.2 – O22.3, O87.0 – O87.1, I26.0, and I26.9} in each of the past three years?

- a) 2014
- b) 2013
- c) 2012

Question 3:

Of the patients treated for cancer who also had a diagnosis of VTE in each of the past three years, how many:

	2014	2013	2012
Were receiving chemotherapy?			
Had metastatic disease?			
Had localised disease?			
Were treated for brain cancer?			
Were treated for lung cancer?			
Were treated for uterine cancer?			
Were treated for bladder cancer?			
Were treated for pancreatic cancer?			
Were treated for stomach cancer?			
Were treated for kidney cancer?			

Part 2: Mortality

Question 4:

In how many patient deaths within your Trust was cancer (of any type) listed as the primary cause of death in each of the past three years:

- a) 2014
- b) 2013
- c) 2012

Question 5:

Of the patients who died within your Trust, in how many was VTE **as well** as cancer listed as a cause of death in each of the past three years:

- a) 2014
- b) 2013
- c) 2012

Question 6:

Of the patients who died in your Trust who had both VTE **and** cancer listed as a cause of death, how many:

	2014	2013	2012
Were receiving chemotherapy?			
Were treated for brain cancer?			
Were treated for lung cancer?			
Were treated for uterine cancer?			
Were treated for bladder cancer?			
Were treated for pancreatic cancer?			
Were treated for stomach cancer?			
Were treated for kidney cancer?			

APPENDIX

Part 3: Advice given to patients

Question 7:

Are patients who receive chemotherapy provided with written and verbal information about the risk of developing VTE during chemotherapy?

Question 8:

Are patients who receive chemotherapy provided with written and verbal information which outlines the symptoms suggestive of VTE?

Question 9:

Are patients who receive chemotherapy provided with written and verbal information regarding what action they should take if they suspect a Deep Vein Thrombosis (DVT) or Pulmonary Embolism (PE)?

Question 10:

Does your Trust have a policy or pathway for the management of suspected VTE in patients receiving chemotherapy?

CONTACT DETAILS

All-Party Parliamentary Thrombosis Group Officers:

Andrew Gwynne MP (Chair)
Sir David Amess MP (Vice Chair)
Lyn Brown MP (Vice Chair)
Baroness Masham of Ilton (Vice Chair)
Lord Haworth (Secretary)

All-Party Parliamentary Thrombosis Group Contact:

All-Party Parliamentary Thrombosis Group Secretariat
c/o Insight Consulting Group,
52 Grosvenor Gardens,
London, SW1W 0AU

T: 020 7054 9966

E: neal.suchak@weareicg.com

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