

## ORIGINAL ARTICLE

# Global public awareness of venous thromboembolism

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**Abstract.** *Background:* Data on public awareness about thrombosis in general and venous thromboembolism (VTE) in particular are limited. We aimed to measure the global awareness of thrombosis to address this gap. *Methods:* With Ipsos-Reid, from 22 July to 5 August 2014, we surveyed 800 respondents in their native language from each of Argentina, Australia, Canada, Germany, Japan, Thailand, the Netherlands, the United Kingdom and the United States to measure general awareness about thrombosis, including deep vein thrombosis (DVT) and pulmonary embolism (PE). In each country, respondents were distributed among three age groups: 18–39 years, 40–64 years, and over 65 years of age. Proportions and 95% confidence intervals (CIs) were calculated. *Results:* Overall, the proportion of respondents that were aware of thrombosis, DVT and PE (68%, 44% and 54%, respectively) was lower than the proportion that was aware of other thrombotic disorders, such as heart attack and stroke (88% and 85%, respectively), and health conditions such as hypertension, breast cancer, prostate cancer and AIDS (90%, 85%, 82% and 87%, respectively). Although there was variation across countries, lower awareness was associated with younger age and being male. Only 45% (95% CI, 43.9–46.5) of respondents were aware that blood clots were preventable, and awareness of cancer, hospitalization and surgery as risk factors was low (16%, 25%, and 36%, respectively). *Conclusions:* On a global level, public awareness about thrombosis overall, and VTE in particular, is

low. Campaigns to increase public awareness about VTE are needed to reduce the burden from this largely preventable thrombotic disorder.

**Keywords:** awareness; prevention; public health; risk factors; thrombosis; venous thromboembolism.

## Introduction

Thrombosis is a major contributor to the global disease burden and a leading cause of mortality [1,2], being responsible for about one in four deaths worldwide [1,2]. As countries develop, chronic diseases become more common causes of morbidity and mortality than infectious disorders. For example, since 1990 the numbers of deaths from ischemic heart disease and stroke worldwide have increased by 35% and 25%, respectively [1,3].

Venous thromboembolism (VTE) is also a major contributor to the global disease burden [1], and hospital-associated VTE is a leading cause of death and disability in low-, middle- and high-income countries [4]. Although VTE-related mortality and disability are largely preventable, global audits reveal systemic under-use of thromboprophylaxis in patients at moderate and high risk of VTE [5,6]. These missed opportunities have prompted multiple calls to action to increase public awareness about VTE [7–9].

To increase global awareness of the thrombosis-related disease burden, starting in 2014, the International Society on Thrombosis and Haemostasis (ISTH) declared 13 October as World Thrombosis Day. As public awareness campaigns focusing on heart disease and stroke were already established through World Heart Day and World Stroke Day, a strategic decision was made to concentrate initial plans for World Thrombosis Day on VTE. One of the key activities of World Thrombosis Day was to conduct a global survey to quantify baseline global public awareness about thrombosis in general and VTE in particular so that the success of the program could be assessed through follow-up surveys. This survey was

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designed to assess the degree of awareness about VTE relative to other common thrombotic and non-thrombotic disorders, the extent of recognition of the symptoms and signs of deep vein thrombosis (DVT) and pulmonary embolism (PE), and knowledge about the key risk factors for VTE. The survey was conducted in nine representative countries and included respondents of different ages to assess the generational differences in awareness. The goal is to use this baseline information to inform future World Thrombosis Day campaigns to enhance awareness about VTE among the general public and enable patients to engage their physicians, surgeons and healthcare providers in discussion about their individual risk of VTE and their need for thromboprophylaxis when they are in at-risk situations.

## Methods

In collaboration with Ipsos-Reid, a global social and media research firm, we developed an Internet-based quantitative survey to assess awareness among the general public about VTE, which includes DVT and PE, relative to other thrombotic disorders (heart attack and stroke) and common non-thrombotic disorders (prostate cancer, breast cancer, AIDS and high blood pressure). Closed-ended questions were asked about awareness of the risk factors for VTE and the specific symptoms and signs of DVT and PE (see Appendix). Among the response options listed, both correct and incorrect options were offered. The survey was conducted between 22 July and 5 August 2014 in the following nine countries: Argentina, Australia, Canada, Germany, Japan, Thailand, the Netherlands, the United Kingdom (UK) and the United States (US). Surveys were translated into Spanish, German, Japanese, Thai, Dutch, and French and back-translated into English. In addition, surveys were available in North American English, UK English and Australian English in their respective countries.

The research was conducted according to guidelines established by the Council of American Survey Research Associations [10]. Ipsos contracts with Survey Sampling International (SSI) to administer surveys to participants aged  $\geq 18$  years who were previously recruited on Internet panels who had opted-in to do online research. SSI has 62 proprietary panels across the globe and improves the quality and representativeness of its online sample by incorporating participants from affiliate panels and trusted online communities. Participants come from sources with which SSI has a relationship and access to detailed information about the source, including rigorous quality controls within the SSI Dynamix sampling platform before being included in any sample. The panels used a points-based system to incentivize the respondents; the redemption and valuation system of the points is between the vendors and the participants.

Demographic information collected on the respondents included age, gender, country of residence, and relative

size of the city in which they resided (in or near a major city, in or near a small city, and far away from a city of any size). Only women were asked questions about breast cancer and estrogen-based medications and only men were asked questions about prostate cancer. The survey required approximately 5 min to complete and the survey questions are provided in the Appendix.

We aimed to collect 800 participants from each country for a total sample size of 7200. Respondents were selected by age group, 20% aged 18–39 years, 40% aged 40–64 years and 40% aged 65 years or older. Because the risk of VTE increases with age, we weighted the population sampling to include a greater proportion of participants in the higher risk categories of 40–64 years and 65 years and older. This sample size was chosen to provide a 95% confidence interval (CI) of  $\pm 3\%$  for the response to each question. The target number of responses by age was achieved in all countries except Thailand and Japan, where the 40–64 years and 65 years and older age categories were combined such that 80% of the respondents were aged 40 years or older (resulting in a larger proportion of those aged 40–64 years in these countries). Once participation quotas were reached in each country, the survey closed without any additional solicitation.

## Statistical analysis

The data were weighted according to the population size using the most recently available county-specific census data. For each five-scale question, the top two response options were combined as affirmative responses, the third response option was interpreted as a neutral response option, and the bottom two response options were combined as dissenting response options. Descriptive statistics were generated using SurveyFreq in SAS 9.3 (Cary, NC, USA) to summarize the findings and calculate Rao-Scott  $\chi^2$  tests with an  $\alpha = 0.05$  to compare differences across categories. Proportions and their corresponding 95% CIs were also calculated. Prevalence proportion ratios (PPRs) and 95% CIs were calculated to measure the association between a respondent's awareness across similar questions (e.g. awareness of what a DVT would feel like and what a PE would feel like).

## Results

Age group- and country-specific participation quotas were reached as described in the Methods above. A total of 7233 participants responded to the survey, ranging from 800 to 810 in each country.

### *Awareness of and concern over VTE as a medical condition*

Among the health conditions listed for the 7233 respondents, awareness was lowest for thrombosis (68%,

$n = 4895$ ), DVT (44%,  $n = 3159$ ) and PE (54%,  $n = 3881$ ). In contrast, awareness of prostate cancer, breast cancer, stroke, AIDS, heart attack and high blood pressure ranged from 82% ( $n = 5937$ ) to 90% ( $n = 6480$ ) (listed in ascending order of awareness, see Table 1 and Fig. 1). Older age and being female were significantly associated with increased awareness about thrombosis, DVT and PE (Table 1;  $P < 0.001$  for all). In contrast, the population density of the respondent's residence (i.e. living in a major city, a minor city or a rural area) was not significantly associated with awareness of thrombosis and related conditions (thrombosis,  $P = 0.788$ ; DVT,  $P = 0.634$ ; PE,  $P = 0.618$ ).

The overall awareness of the nine selected health conditions across countries, and the awareness of thrombosis generally, and of DVT and PE in particular, are shown in Table 1. In an effort to better understand consistency of awareness trends within each country, we compared the difference in awareness of DVT and PE by country. There were marked differences in that there was greater awareness of PE relative to DVT in the Netherlands (72% [582/805] and 20% [163/805], respectively), Argentina (66% [532/803] and 33% [266/803], respectively), and Canada (63% [506/802] and 41% [330/802], respectively), whereas the opposite was true in Australia (57% [455/800] and 80% [644/800], respectively).

In addition to limited awareness about VTE, there was also low concern over experiencing a thrombosis-related event among those who indicated they were aware of the condition. Specifically, only 28% (1394/4895) of respondents were concerned about thrombosis, 28% (1080/3881) were concerned about a PE, and 27% (858/3159) were concerned about a DVT. The only condition respondents were less concerned about than thrombosis-related conditions was AIDS (20%, 1259/6279). In contrast, at least 10% more respondents were concerned about prostate cancer, high blood pressure, heart attack, stroke and breast cancer (42% [1204/2888], 43% [2769/6480], 44% [2814/6353], 44% [2717/6156] and 49% [1585/3248], respectively).

#### Recognition of symptoms and signs of VTE

Overall awareness of what a VTE-related condition would feel like was low among the 7233 respondents; for DVT, awareness was 28% ( $n = 2002$ ) (range by country, 15% [124/805] to 51% [409/800]), and for PE awareness was 19% ( $n = 1378$ ) (range by country, 12% [98/800] to 44% [352/800]). Although the association between respondents knowing what a DVT felt like and knowing what a PE would feel like was strong (PPR, 8.4; 95% CI, 7.4–9.6), the association between being aware of DVT as a health condition and knowing what one would feel like was weaker (PPR, 1.7; 95% CI, 1.6–1.9). The association of being aware of PE as a health condition and knowing what a PE would feel like was similar (PPR, 1.8; 95% CI, 1.6–2.0).

When asked about the recognition of specific symptoms and signs of DVT, among the 2002 people who indicated they would know what a DVT would feel like (Table 2), the most commonly identified symptoms were pain or tenderness of the leg (78%,  $n = 1569$ ), followed by leg swelling (74%,  $n = 1484$ ), skin color change (61%,  $n = 1225$ ) and leg feels warm (40%,  $n = 800$ ). In an attempt to validate these measures of awareness, incorrect symptoms and signs were available for selection. Leg paralysis and itching of the leg were selected as symptoms believed to be indications of DVT by 35% ( $n = 702$ ) and 22% ( $n = 435$ ) of respondents, respectively.

Likewise for the 1378 who indicated they knew what a PE would feel like, when asked about the recognition of specific symptoms and signs, the most commonly identified were shortness of breath (76%,  $n = 1041$ ), followed by chest pain (71%,  $n = 979$ ), rapid heart rate (47%,  $n = 653$ ), light headedness (37%,  $n = 514$ ) and coughing up blood (35%,  $n = 484$ ). The responses for the incorrect symptoms used for validation were slow shallow breathing (50%,  $n = 692$ ), pain radiating down the arm (24%,  $n = 326$ ) and frequent headaches (17%,  $n = 232$ ). The incorrect identification of slow shallow breathing as a symptom of PE was significantly higher than the correct symptoms of light headedness and coughing up blood.

#### Underlying causes of DVT and prevention

Awareness of the underlying causes of DVT was moderately high among the 7233 respondents with 61% ( $n = 4426$ , 95% CI, 59.9%–62.5%) of respondents aware that a clot in the vein was the underlying cause. However, only 45% ( $n = 3272$ , 95% CI, 43.9–46.5) of respondents were aware that many blood clots can be prevented.

#### Risk factors for VTE

Awareness of risk factors for VTE is shown in Fig. 2. While there was awareness among the 7233 respondents about immobility, family history and older age being risk factors (63% [ $n = 4570$ ], 53% [ $n = 3857$ ] and 47% [3422], respectively), 52% ( $n = 3789$ ) and 45% ( $n = 3275$ ) of respondents, respectively, incorrectly thought that high blood cholesterol and high blood pressure also were risk factors. The least recognized risk factors were cancer (16%,  $n = 1159$ ), pregnancy (23%,  $n = 1637$ ), using estrogen-based medications (24%,  $n = 1772$ ), being hospitalized (25%,  $n = 1783$ ) and surgery (36%,  $n = 2598$ ), all of which were recognized significantly less frequently than the incorrect risk factors of high blood cholesterol and high blood pressure.

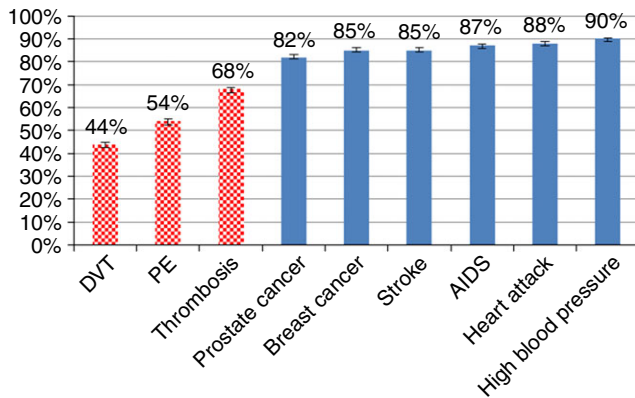
#### Agreement with blood clot-related statements

Respondents were asked to agree or disagree with five statements regarding the treatment, prevention and urgency of blood clots (Table 3). Respondents were more

**Table 1** Overall awareness and 95% confidence intervals (CIs) of selected health conditions stratified by age group, gender, population density of place of residence, and country

Demographic characteristic	Thrombosis		DVT		PE		Prostate cancer		Breast cancer		Stroke		AIDS		Heart attack		High blood pressure			
	%	95% CI	%	95% CI	%	95% CI	%	95% CI	%	95% CI	%	95% CI	%	95% CI	%	95% CI	%	95% CI		
Overall (n = 7233)	68	66.5, 68.9	44	42.5, 44.8	54	52.4, 54.9	82	81.1, 83.1	85	84.4, 86.3	85	84.2, 86.1	87	85.9, 87.7	88	87.0, 88.7	90	88.8, 90.4		
Age (years)																				
18–39	58	55.2, 60.2	38	35.7, 40.3	49	46.2, 51.2	79	77.1, 81.2	84	82.0, 85.7	82	80.3, 84.3	87	85.1, 88.5	87	85.1, 88.5	86	84.4, 88.0		
40–64	71	69.9, 72.9	46	44.4, 47.3	56	54.3, 57.5	83	82.3, 84.7	86	84.8, 87.1	86	85.2, 87.5	87	86.3, 88.5	88	87.2, 89.4	88	87.2, 89.4	91	90.0, 92.0
65+	79	76.8, 80.8	50	47.8, 52.2	58	56.1, 60.8	85	82.9, 86.5	87	85.4, 88.7	88	86.3, 89.4	88	86.3, 89.4	85	83.8, 87.2	89	87.2, 90.4	93	91.8, 94.5
Gender																				
Male	64	61.9, 65.5	40	37.8, 41.2	50	48.1, 51.7	81	79.7, 82.5	82	80.8, 83.6	83	81.8, 84.6	83	81.8, 84.6	85	84.2, 86.7	86	85.2, 87.7	89	87.6, 90.0
Female	72	69.8, 73.2	48	45.9, 49.5	57	55.5, 59.1	83	81.6, 84.4	88	87.2, 89.6	87	85.7, 88.2	87	85.7, 88.2	88	86.9, 89.3	89	88.0, 90.3	90	89.2, 91.5
Density of place of residence																				
Major city	68	66.0, 69.2	43	41.6, 44.8	53	51.6, 54.9	83	81.7, 84.2	85	84.1, 86.5	85	84.0, 86.4	85	84.0, 86.4	88	86.5, 88.7	88	87.2, 89.3	90	88.8, 91.0
Minor city	68	65.9, 70.2	44	41.6, 46.6	54	51.9, 56.3	81	83.9, 87.1	86	83.9, 87.1	85	83.7, 87.0	85	83.7, 87.0	86	84.3, 87.5	87	85.9, 89.0	89	87.8, 90.8
Rural	66	61.7, 70.8	44	39.7, 49.0	55	50.8, 60.2	81	77.3, 84.7	85	81.7, 88.4	83	79.8, 87.0	83	79.8, 87.0	84	80.9, 87.6	86	82.8, 89.3	88	85.1, 91.4
Country*																				
Argentina	70	66.0, 74.1	33	29.2, 37.0	66	62.2, 70.5	89	86.6, 92.1	95	92.8, 96.5	90	86.8, 92.5	94	92.1, 95.8	95	93.3, 96.8	94	91.9, 96.4		
Australia	68	64.7, 71.9	80	77.2, 83.8	57	53.0, 60.6	91	88.5, 93.4	92	89.3, 94.0	91	88.8, 93.6	93	90.5, 94.9	93	90.9, 95.2	93	90.8, 95.2		
Canada	52	48.1, 55.6	41	37.4, 44.8	63	59.3, 66.8	87	84.6, 89.9	89	86.2, 91.2	86	83.6, 89.1	89	86.4, 91.2	90	87.2, 92.0	88	85.8, 90.9		
Germany	82	78.7, 84.5	38	34.8, 41.9	23	20.1, 26.3	60	56.4, 63.6	81	77.9, 83.8	82	79.6, 85.3	81	78.2, 84.0	84	81.0, 86.5	87	84.5, 89.6		
Japan	59	55.0, 62.9	13	10.7, 16.2	31	26.9, 34.4	72	68.8, 76.0	78	74.5, 81.1	80	76.5, 83.0	79	75.5, 82.1	79	75.3, 81.9	82	79.4, 85.6		
The Netherlands	77	74.1, 80.3	20	17.2, 23.3	72	68.9, 75.6	78	75.3, 81.4	81	77.9, 83.7	80	76.9, 82.8	80	76.9, 82.8	77	74.3, 80.4	81	78.4, 84.2	86	83.1, 88.4
Thailand	69	65.0, 72.8	24	20.1, 27.0	30	25.6, 33.0	82	78.5, 84.9	74	70.4, 77.6	77	73.1, 80.0	77	73.1, 80.0	89	86.0, 90.9	87	84.5, 89.9	90	87.0, 92.2
United Kingdom	80	77.1, 83.5	86	83.4, 89.0	72	68.0, 75.0	91	88.4, 93.1	91	88.6, 93.3	91	89.1, 93.6	91	89.1, 93.6	92	89.4, 93.8	92	89.4, 93.9	94	91.5, 95.5
United States	52	47.7, 55.7	57	52.7, 60.6	70	65.9, 73.4	88	85.3, 90.9	89	86.2, 91.6	89	86.0, 91.6	89	86.0, 91.6	89	85.8, 91.3	90	87.9, 92.9	93	90.2, 94.9

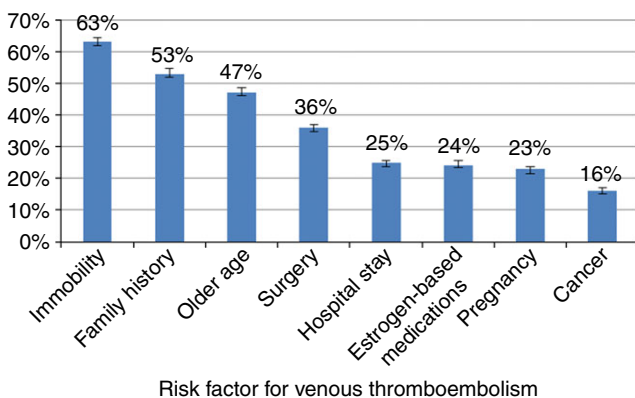
\*Sample size for each country ranged from 800 to 810.



**Fig. 1.** Average overall awareness (and 95% confidence intervals) of selected health conditions. Thrombosis-related health conditions in red checks and other health conditions in solid blue.

**Table 2** Per cent awareness and 95% confidence intervals (CIs) of correct and incorrect signs and symptoms of deep vein thrombosis (DVT) and pulmonary embolism (PE)

Signs and symptoms	%	95% CI
<b>DVT</b>		
Correct signs and symptoms		
Pain or tenderness in leg	78	76.2, 80.5
Swelling of leg	74	71.9, 76.4
Skin color change	61	58.7, 63.6
Leg feels warm	40	37.6, 42.4
Incorrect signs and symptoms		
Leg paralysis	35	32.7, 37.4
Itching of leg	22	19.6, 23.8
<b>PE</b>		
Correct signs and symptoms		
Shortness of breath	76	72.9, 78.2
Chest pain	71	68.1, 73.8
Rapid heart rate	47	44.3, 50.4
Light headedness	37	34.3, 40.3
Coughing up blood	35	32.1, 38.1
Incorrect signs and symptoms		
Slow, shallow breathing	50	47.1, 53.3
Pain radiating down arm	24	21.0, 26.3
Frequent headaches	17	14.4, 19.2



**Fig. 2.** Distribution (and 95% confidence intervals) of awareness of risk factors for venous thromboembolism.

likely to agree with statements regarding the urgency and severity of blood clots, but less likely to agree with statements regarding the prevention of blood clots. Specifically, 82.6% (5971/7233) of respondents agreed with the statement that 'blood clots can cause death', but only 45.2% (3272/7233) agreed with the statement that 'most blood clots can be prevented'.

## Discussion

The findings from this global survey highlight a relative lack of public awareness about thrombosis overall, and DVT and PE in particular. Similarly, there is poor awareness about the symptoms and signs of DVT and PE, the major risk factors for VTE (i.e. hospitalization, surgery, and cancer), and that VTE is largely preventable. There was also low awareness that estrogen-containing medications are a risk factor for VTE. Not surprisingly, there is a corresponding lack of concern over these conditions as well.

The lack of awareness found in this global survey is consistent with the results of previous country-specific studies done in Australia, Italy and the US; in these countries, awareness about VTE was low among patients and the general public [7,11–14]. However, to our knowledge, ours is the first international study to assess awareness about thrombosis. Although the differences across the countries surveyed in terms of culture, language and access to the Internet are inherent limitations of this study, the use of consistent methodology in this international context provides a unique dataset that enables a greater understanding of differences in awareness about thrombosis across countries and cultures.

A challenging aspect of conducting this study is the potentially leading nature of the closed-ended questions used in the survey. Two proxy methods were used to assess the extent to which awareness may be artificially inflated with this methodology. First, we included incorrect options for many of the questions. Second, we measured the association between the overall awareness of DVT and PE and knowledge about what those conditions might feel like if the respondent were to suffer from the condition. Given that incorrect options were selected by up to 50% of respondents and the relatively weak association between awareness of VTE-related questions, we expect these findings to over-estimate the true awareness of these conditions.

Although we aimed to make these results representative of the general population, because the survey was conducted online, those without Internet access were not included. For example, limited Internet access in those 65 years of age and older in Japan and Thailand necessitated collapsing of the age groups of 40–64 years and 65 years of age and older into a single age category of 40 years and older in these two countries. Also, if Internet access is associated with a higher level of education and economic advantage, our results are likely to over-estimate the extent of awareness about VTE.

**Table 3** The distribution (per cent and 95% confidence intervals [CIs]) of those who agree or disagree with and were neutral to statements regarding blood clots

Statement regarding blood clots	% Agree	95% CI	% Neutral	95% CI	% Disagree	95% CI
People under 40 years old have to worry about blood clots	72.1	70.9, 73.3	19.7	18.6, 20.8	8.2	7.5, 9.0
Most blood clots can be prevented	45.2	43.9, 46.5	37.6	36.3, 38.8	17.2	16.2, 18.2
It is likely that a blood clot in the leg left untreated can travel to your lungs	55.9	54.7, 57.2	28.3	27.1, 29.5	15.8	14.8, 16.8
Having a blood clot is considered a medical emergency	68.7	67.5, 69.9	20.0	18.9, 21.1	11.3	10.4, 12.2
Blood clots can cause death	82.6	81.5, 83.6	11.0	10.1, 11.8	6.5	5.8, 7.1

This study used a unified methodology to measure the public awareness of thrombosis overall and VTE specifically in nine countries on five continents. The awareness of VTE as an important health concern was found to be low relative to heart attack and stroke, the major burden caused by arterial thrombosis. Awareness of VTE was also low relative to AIDS, prostate cancer and breast cancer. A common feature of all of these conditions with greater awareness than VTE is major public educational campaigns. Campaigns similar to those undertaken in the UK by Lifeblood: The Thrombosis Charity for the last 12 years are needed for VTE (the UK showed the highest awareness of thrombosis, DVT and PE). This highlights the importance of World Thrombosis Day and rationalizes its initial focus on VTE. Among the key public health messages are that VTE is largely preventable and that hospitalization and surgery are major risk factors. As 60% of the disease burden can be attributed to hospital-associated VTE, increasing awareness about hospital-associated VTE will be a major focus of World Thrombosis Day 2015.

#### Addendum

A. M. Wendelboe played a significant role in the conception of the study, writing the manuscript, guiding the analyses and interpreting the data. M. McCumber was responsible for the statistical analyses and submission of the manuscript and contributed to data interpretation and manuscript formatting. E. M. Hylek, H. Buller and J. I. Weitz contributed to the conception of the study and significant revision of the manuscript. G. E. Raskob contributed to the conception of the study, interpretation of the data and significant revision of the manuscript. All authors read and approved the final manuscript.

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#### Disclosure of Conflict of Interests

A. Kakkar reports personal fees from Armetheon Inc., Aspen Pharmacare, Boehringer Ingelheim, Daiichi Sankyo and Sanofi, and grants from Bayer Healthcare, out-

side the submitted work. J. I. Weitz reports personal fees from Boehringer-Ingelheim, Daiichi Sankyo, Bayer Healthcare, Bristol-Myers Squibb, Pfizer, Portola, Janssen and ISIS Pharmaceuticals, outside the submitted work. G. E. Raskob reports personal fees from Bayer Healthcare, Bristol-Myers Squibb, Daiichi Sankyo, Boehringer Ingelheim, Janssen/Johnson and Johnson, Pfizer and Portola, outside the submitted work. E. Hylek reports personal fees from Bayer Healthcare, Boehringer Ingelheim, Bristol-Myers Squibb, Daiichi Sankyo, Janssen and Pfizer, outside the submitted work.

#### Appendix

##### The members of the ISTH Steering Committee for World Thrombosis Day

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