



EUROPEAN
CANCER
PATIENT
COALITION

Cancer-associated thrombosis awareness survey

Results report

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European Cancer Patient Coalition

With support from LEO Pharma

Carried out by Quality Health Limited



Quality
Health

Contributors

Stakeholders

The European Cancer Patient Coalition (ECPC)

ECPC works for a **Europe of equality**, where all European cancer patients have timely and **affordable access** to the **best treatment and care available**, throughout their life. ECPC believes that cancer patients are the most important partners in the fight against cancer and against all the cancer-related issues affecting our society. Policy makers, researchers, doctors and industry should recognise cancer patients as co-creators of their own health. ECPC has over 400 member organisations from within the European Union, and as such is the largest European cancer patients community, covering almost all cancer types, from the most common to the very rare. ECPC's members are non-profit organisations whose main objectives are the advocacy, support and care of cancer patients and their carers.

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Quality Health is a UK-based specialist health and social care survey organisation, working for public, private and not-for-profit sectors, in the UK and overseas.

Quality Health has been measuring and interpreting staff and patient experience in healthcare for over 30 years - the largest provider of patient and employee surveys and related consultancy to the NHS in the UK, with significant experience in other sectors and other countries.

Quality Health is a world-leading expert in measuring, analysing and interpreting experience data from patients at all stages of the cancer diagnosis and treatment pathway. Quality Health has developed cancer patient experience survey methodologies on behalf of government, academic, private and voluntary sector clients for well over a decade, and has significant experience in a vast range of cancer-specific qualitative and quantitative research.

LEO Pharma

LEO Pharma is a global healthcare company that offers care solutions within dermatology and thrombosis to patients in more than 100 countries around the world. Founded in 1908 and owned by the LEO Foundation, LEO Pharma has devoted decades of research and development to delivering products and solutions to people with skin conditions and thrombosis. LEO Pharma is headquartered in Denmark and employs around 5,000 people worldwide.

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Key findings

- The survey illustrated a very low level of awareness about cancer associated thrombosis. A vast majority (**72%**) of respondents said that, before taking part in the survey, they were unaware that people with cancer have a higher than normal risk of developing thrombosis. The other **28%** of respondents were previously aware.
- Among the **28%** that were aware of the increased risk of thrombosis for cancer patients, the level of understanding was nevertheless reported to be low. Asked to rate their overall understanding of cancer-associated thrombosis on a scale of 1 (low) to 10 (high), over half of respondents (**55%**) gave a rating of 4 or below, whilst only **21%** of respondents gave a rating of 7 or above. The average (mean) rating was **4.1** out of **10**; the median was **4** out of **10**.
- **26%** of the patients previously aware of the increased risk of thrombosis for cancer patients only became aware of this risk when suffering from a blood clot themselves.
- Asked how they got information about cancer-associated thrombosis, most received this verbally, usually from their hospital doctor (**12%**) or GP (**5%**). Nearly as many respondents (**10%**) said that they found out about it from their own research, usually online. Relatively few respondents said that they had got information in writing. Most respondents said that they first became aware of cancer-associated thrombosis when they suffered a blood clot (**26%**); or that they already knew about it before they were diagnosed with cancer (**19%**).
- Awareness of the risk factors related to cancer-associated thrombosis varies a great deal. For example, virtually all respondents (**90%**) said that they were aware of the risks related to inactivity; but less than half (**46%**) said that they were aware of the risks related to radiotherapy.
- Some of the symptoms of cancer-associated thrombosis are relatively well known: e.g. **73%** of respondents said they were aware that swelling in the foot, ankle or leg could be a sign of deep vein thrombosis; and **71%** that unexplained shortness of breath could be a sign of pulmonary embolism. But other symptoms are much less well known: e.g. only just over a half (**57%**) said that they were aware that pain, cramping or tenderness, often in the calf, could be a sign of deep vein thrombosis; and under a third (**33%**) that an irregular heartbeat could be a sign of pulmonary embolism.
- Nearly half of respondents said they did not know that an ultrasound scan (**40%**) or CT scan (**45%**) could be used to diagnose thrombosis.
- Awareness of actions that patients can take to reduce their risk of thrombosis varies a great deal: from **87%** of respondents saying they were aware that taking a walk could reduce their risk; to only just over half (**55%**) saying they were aware that stretching their legs could reduce their risk.
- Just over a third of respondents said that they were currently using anticoagulants, although virtually all (**96%**) knew that they could be used to effectively treat thrombosis. Only **41%** of those using anticoagulants said they had been told about any possible side effects; and **22%** had suffered some of these themselves.

As set out in the detail of the report that follows, many of these findings vary by country, and by cancer type.

Conclusions and recommendations

Nearly three-quarters of respondents (**72%**) said that, before taking part in the survey, they were not aware that people with cancer have a higher than normal risk of developing thrombosis; and overall, amongst all respondents, the average (mean) rating of their understanding of cancer-associated thrombosis is only **4.1** out of **10** (the median is **4** out of **10**).

Recommendation

More needs to be done by clinicians and patient organisations, at every stage of the cancer journey, to ensure that the risks of cancer-associated thrombosis are better known. Health professionals should provide more information for patients at the time of the cancer diagnosis, and also at follow-up appointments. An informative patient brochure (such as ecpc.org/edu/thrombosis) should be distributed by pharmacists, nurses, doctors, and patient organisations.

Amongst those respondents who were already aware of cancer-associated thrombosis, awareness of individual risk factors varies greatly.

Recommendation

When patients are given information about cancer-associated thrombosis, more information needs to be shared by health professionals about some of the lesser known risk factors, including the risks associated with: cancer surgery; advanced stage cancers; the use of a central line; chemotherapy; and radiotherapy. This information should be shared at the time of diagnosis, when treatment commences, and during follow-up consultations.

Similarly, amongst those respondents who were already aware of cancer-associated thrombosis, awareness of individual symptoms varies greatly.

Recommendation

More information needs to be shared by health professionals with cancer patients about some of the lesser known symptoms of cancer-associated thrombosis. For deep vein thrombosis, this includes: a warm or heavy sensation in the leg; and pain, cramping or tenderness, often in the calf. For pulmonary embolism, this includes: coughing up blood; light-headedness/dizziness; and an irregular heartbeat. This information should be shared at the time of diagnosis, when treatment commences, and during follow-up consultations.

There is a wide range of different sources of information about cancer-associated thrombosis. Most respondents received this information verbally from their hospital doctor (12%) or their GP (5%); but almost as many respondents (10%) had to find out about cancer-associated thrombosis from their own research, usually online.

Recommendation

As well as providing information about cancer-associated thrombosis verbally, doctors and nurses need to provide written information or provide information about credible resources on-line to cancer patients that they can access and refer to. Given that cancer patients often need, or choose, to seek information about cancer-associated thrombosis on-line, healthcare providers and patient organisations need to do more to ensure that such information is available, clear and consistent.

Most cancer patients who are aware of cancer-associated thrombosis are also aware of many of the actions they can take to reduce their risk. For example, 87% said they are aware that taking a walk could reduce their risk; and 75% said they are aware that stopping smoking could reduce their risk. However, other preventative actions are much less known.

Recommendation

More information needs to be shared with cancer patients about some of the lesser known actions they can take to reduce their risk of cancer-associated thrombosis, in particular those that are relatively easy and low cost to implement. These actions include: moving their feet; keeping hydrated; and stretching their legs. Throughout diagnosis and treatment journey, health professionals should inform cancer patients about the signs of cancer-associated thrombosis, and closely monitor all patients, especially those at increased risk.

Many respondents were already using anticoagulants; and virtually all (96%) said they knew that they could be used to effectively treat thrombosis. Only 41% of those using anticoagulants said that they had been told about any possible side effects of using anticoagulants; and whilst most of these patients had been told what to do if they experienced any of these side effects (contacting their doctors/nurse, or emergency services), a significant minority (9%) said that they had not been told what to do.

Recommendation

For those patients using anticoagulants to treat and/or prevent cancer-associated thrombosis, more information (preferably in writing) needs to be given about the side effects, and what to do if they experience any of these symptoms. Serious side-effects can include easy bleeding or bruising, anaemia, allergic reactions, and dark urine. Patients also need to be given clear information about the risks and benefits of long-term use of anticoagulants, especially in older people.

The European Cancer Patient Coalition, in collaboration with health professionals and industry, has produced a patient brochure on cancer-associated thrombosis.

This brochure is available to download for free at www.ecpc.org/edu/thrombosis in English, French, German, Greek, Italian, Portuguese, and Spanish.

Introduction

Cancer and its treatments (surgery, hospital admissions, chemotherapy, the presence of indwelling catheters, radiotherapy) are well recognised risk factors for venous thrombosis. **Thrombosis is a very common complication in cancer patients, but relatively little understood.** Approximately **4% to 20%** of cancer patients experience venous thrombosis – an incidence 4 to 5 times higher than in the general population^[1]. Venous thrombosis, and associated complications, have significant adverse impacts on quality of life for those who are suffering from it; and they are **the second leading cause of preventable death in cancer patients**^[2].

A recent roundtable of policy-makers, oncology nurses, medical oncologists, industry, and patient advocates concluded that with treatment options for cancer patients becoming increasingly complex, the multi-faceted care needs of people with cancer are growing. Several challenging themes emerged as needing further attention such as training of health professionals and improved communication throughout the entire cancer care pathway. There is a need to raise further awareness on cancer associated thrombosis, and collaborate with healthcare professionals to ensure further investment into primary and secondary prevention of these conditions^[3].

The European Cancer Patient Coalition, in collaboration with health professionals and industry, has produced a patient brochure on cancer-associated thrombosis. This brochure is available to download for free at www.ecpc.org/edu/thrombosis in English, French, German, Greek, Italian, Portuguese, and Spanish.

In the Roadmap of the Cancer-Associated Thrombosis White Paper^[4], one of the preferred actions of the cancer-associated thrombosis whitepaper expert group was to conduct a patient survey to measure awareness of cancer-associated thrombosis among cancer patients. More specifically, the Roadmap states that:

A patient survey should be undertaken to measure the level of awareness of cancer associated thrombosis among cancer patients, including a mapping of where patients get their information about cancer-associated thrombosis. This could be done in one or more countries in one/more parts of the world. Such a survey could be developed into a publication and published. This would give a baseline for the expert group's work and would also be a helpful tool to engage in conversation with stakeholders, especially patients and health professionals.

British chemotherapy patients have indicated that they have limited knowledge about cancer-associated thrombosis and received no information about the condition. Some of their symptoms suggestive of cancer-associated thrombosis were mis-attributed to chemotherapy or cancer, resulting in delayed diagnosis and treatment^[5].

If a patient requires anticoagulation treatment, it is important to offer cancer patients a choice in their treatment. This choice should be informed by a discussion with health professionals about the attributes of the various forms of treatment and the preferences of the patient. Attributes for anticoagulation treatment that are important to cancer patients include: the level of interference with their cancer treatment, the rate of thrombosis recurrence rate, the risk of major bleed, and the administration route^[6].

In order to further explore cancer patient awareness and treatment of cancer-associated thrombosis, ECPC collaborated with Quality Health – a UK based specialist health and social care survey organisation – to carry out a patient study about cancer-associated thrombosis.

Little – if any – work has been undertaken to understand cancer patients’ awareness of thrombosis, of these risk factors, of symptoms, or of possible treatments. **The aim of the European Cancer Patient Coalition (ECPC) cancer-associated thrombosis awareness study was to develop a new evidence set** through a patient survey that will establish:

- the level of awareness of cancer-associated thrombosis among cancer patients
- a mapping of where and when patients get their information about cancer-associated thrombosis
- the gaps of information and support during the patient pathway, and the spaces for improvement to raise awareness about cancer associated thrombosis among cancer patients.

A three-stage process was undertaken:

- the development and testing of a survey tool (an online questionnaire)
- patient survey fieldwork in Europe
- thorough analysis of the findings.

Further details on the methodology used can be found in [Appendix A](#).

This survey will be a tool to demonstrate towards policymakers and health professionals where more needs to be done to raise the awareness about cancer-associated thrombosis and supportive care among cancer patients and will be launched for World Thrombosis Day - 13 October 2018.

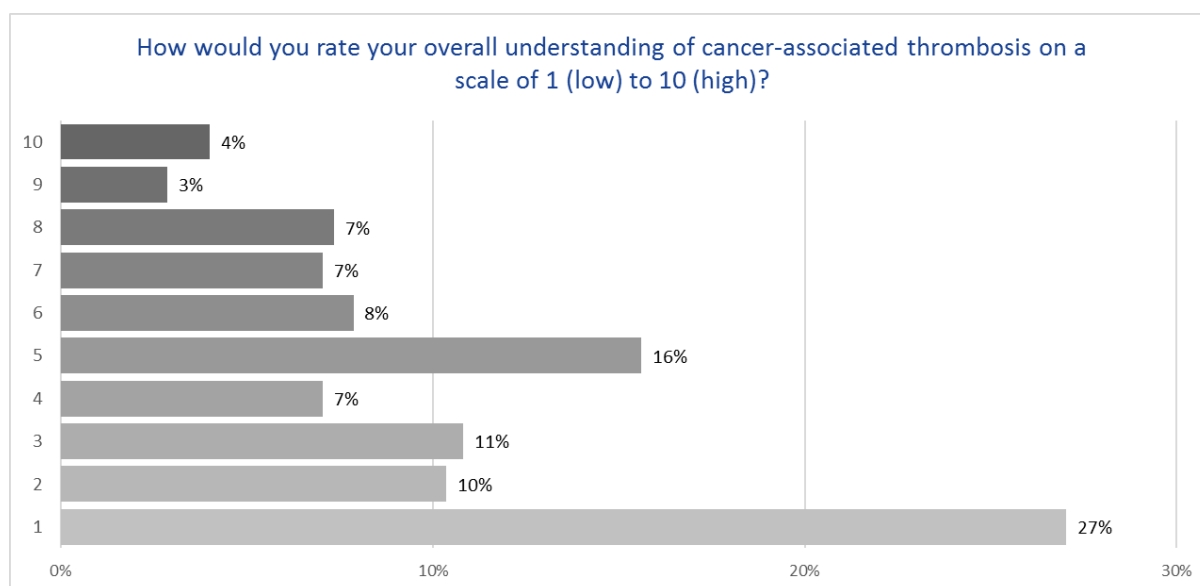
Detailed survey findings

All countries

Overall summary

72% of respondents said that, before taking part in the survey, they were unaware that people with cancer have a higher than normal risk of developing thrombosis. The other **28%** were already aware.

Asked to rate their overall understanding of cancer-associated thrombosis on a scale of 1 (low) to 10 (high), over half of respondents (**55%**) gave a rating of 4 or below, whilst only **21%** of respondents gave a rating of 7 or above. The average (mean) rating was **4.1** out of **10**; the median was **4** out of **10**.



Country analysis. This average rating is very similar in the different countries surveyed.

Analysis by cancer type. This average rating differs across different cancer types, with breast cancer patients giving a lower rating than patients with other cancer types.

The bulk of the questionnaire asked about respondents' understanding of the risks of cancer-associated thrombosis; their understanding of what to look out for; the diagnosis of cancer-associated thrombosis; preventing the risk of cancer-associated thrombosis; treating cancer-associated thrombosis; and how they know about cancer-associated thrombosis.¹

Understanding the risks of cancer-associated thrombosis

¹ Percentages of respondents **in all of these sections** refer only to those who said that, before taking part in the survey, they were aware that people with cancer have a higher than normal risk of developing thrombosis. Other respondents are excluded.

Summary. Awareness of the risk factors related to cancer-associated thrombosis varies a great deal. For example, virtually all respondents (**90%**) said that they were aware of the risks related to inactivity; but less than half (**46%**) said that they were aware of the risks related to radiotherapy.

78% of respondents said that they were aware that certain cancers (including cancers of the stomach, brain, kidney and ovaries) have a higher risk than others of cancer-associated thrombosis: **only 15% completely aware**, and **64%** to some extent.

59% of respondents said they knew that the risk of increases for people with cancer at an advanced stage: **only 22% completely aware**, and **37%** to some extent.

65% of respondents said they knew that cancer surgery can increase the risk of thrombosis: **only 35% completely aware**, and **31%** to some extent.

70% of respondents said they knew that chemotherapy can increase the risk of thrombosis: **only 33% completely aware**, and **37%** to some extent.

46% of respondents said they knew that radiotherapy can increase the risk of thrombosis: **only 17% completely aware**, and **29%** to some extent.

50% of respondents said they knew that having a central venous catheter (a central line) can increase the risk of thrombosis: **only 23% completely aware**, and **27%** to some extent.

90% of respondents said they knew that they were more likely to suffer from thrombosis if they were inactive for long periods of time (e.g. if they were in bed for 4 days or more): **65% completely aware**, and **25%** to some extent.

79% of respondents said they knew that they were more likely to suffer from thromboses if they had had them before: **only 46% completely aware**, and **32%** to some extent.

Risk factor for cancer-associated thrombosis	Percentage of respondents completely aware
Inactivity	65%
Previous thromboses	46%
Cancer surgery	35%
Chemotherapy	33%
Central line	23%
Advanced stage cancers	22%
Radiotherapy	17%
Certain cancer types	15%

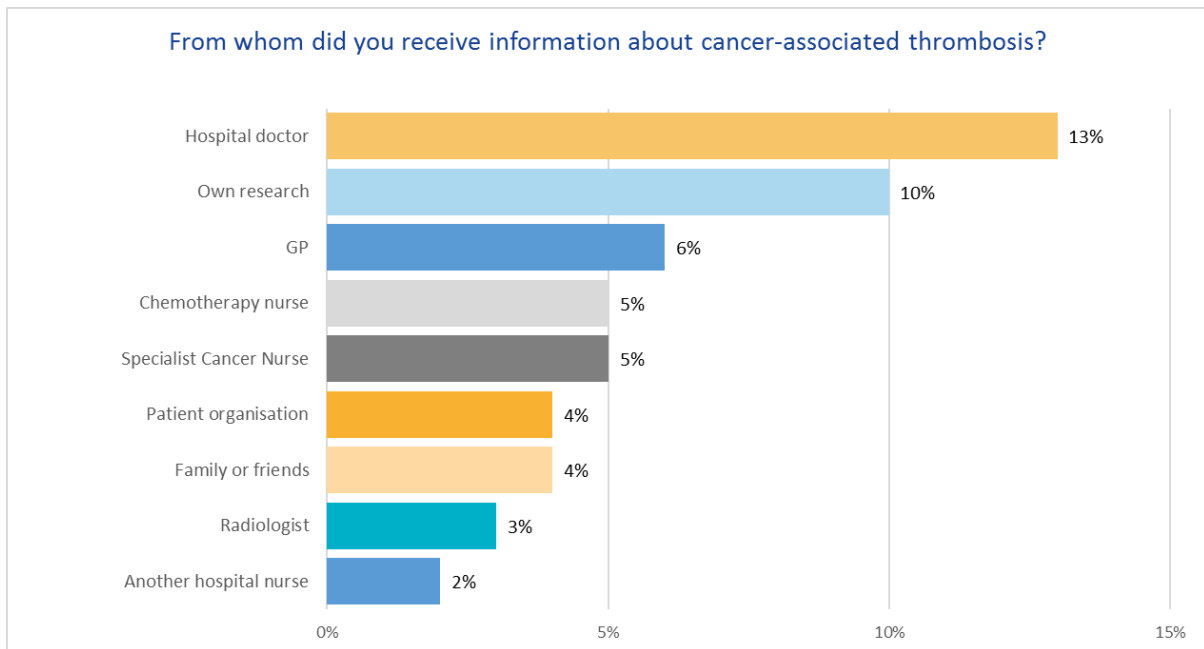
Country analysis. The results in this section are very similar in the different countries surveyed.

Analysis by cancer type. The results in this section differ across different cancer types, with haematological cancer patients reporting a better awareness on many risk factors than those with breast, colorectal/bowel or lung cancers. For example, **82%** of haematological cancer patients said that they were aware of the risks associated with chemotherapy; compared to **72%** for breast cancer patients, **80%** for colorectal/bowel cancer patients, and **64%** for lung cancer patients.

First information about cancer-associated thrombosis

Summary. Asked how they got information about cancer-associated thrombosis, most received this verbally, usually from their hospital doctor (**12%**) or GP (**5%**). Nearly as many respondents (**10%**) said that they found out about it from their own research, usually online. Relatively few respondents said that they had got information in writing. **Most respondents said that they first became aware of cancer-associated thrombosis when they suffered a blood clot (26%). 19%** already knew about it before they were diagnosed with cancer.

Respondents were asked in what form they had received information about cancer-associated thrombosis, and from whom. The chart overleaf summarises the results:



Most patients who said they received information from their hospital doctor (**12%** out of **13%**), or from their GP (**5%** out of **6%**), received this verbally. In contrast, most of those who said they used their own research (**6%** out of **10%**) found this out on-line.

Asked when they first became aware of cancer-associated thrombosis:

- **26%** of respondents said they became aware when they suffered a blood clot
- **19%** said they already knew about it before they were diagnosed with cancer
- **16%** said they were given information before/during chemotherapy
- **16%** said they were given information during their cancer diagnosis
- **11%** said they were given information following surgery
- **10%** said they were given information before surgery
- **2%** said they were given information before/during radiotherapy.

Country analysis. The results in this section are very similar in the different countries surveyed.

Analysis by cancer type. There are few reported differences between the four cancer types around *how* they first became aware of cancer-associated thrombosis; but there are some reported differences between cancer types around *when* they found out this information – with haematological cancer patients much more likely to know to receive information before diagnosis than those with other cancers.

Understanding symptoms and what to look out for

Summary. Some of the symptoms of cancer-associated thrombosis are relatively well known: e.g. **73%** of respondents said they were aware that swelling in the foot, ankle or leg could be a sign of deep vein thrombosis; and **71%** that unexplained shortness of breath could be a sign of pulmonary embolism. However, other symptoms are much less well known: e.g. only just over a half (**57%**) said that they were aware that pain, cramping or tenderness, often in the calf, could be a sign of deep vein thrombosis; and under a third (**33%**) that an irregular heartbeat could be a sign of pulmonary embolism

24% of respondents said that they had suffered from thrombosis associated with their cancer².

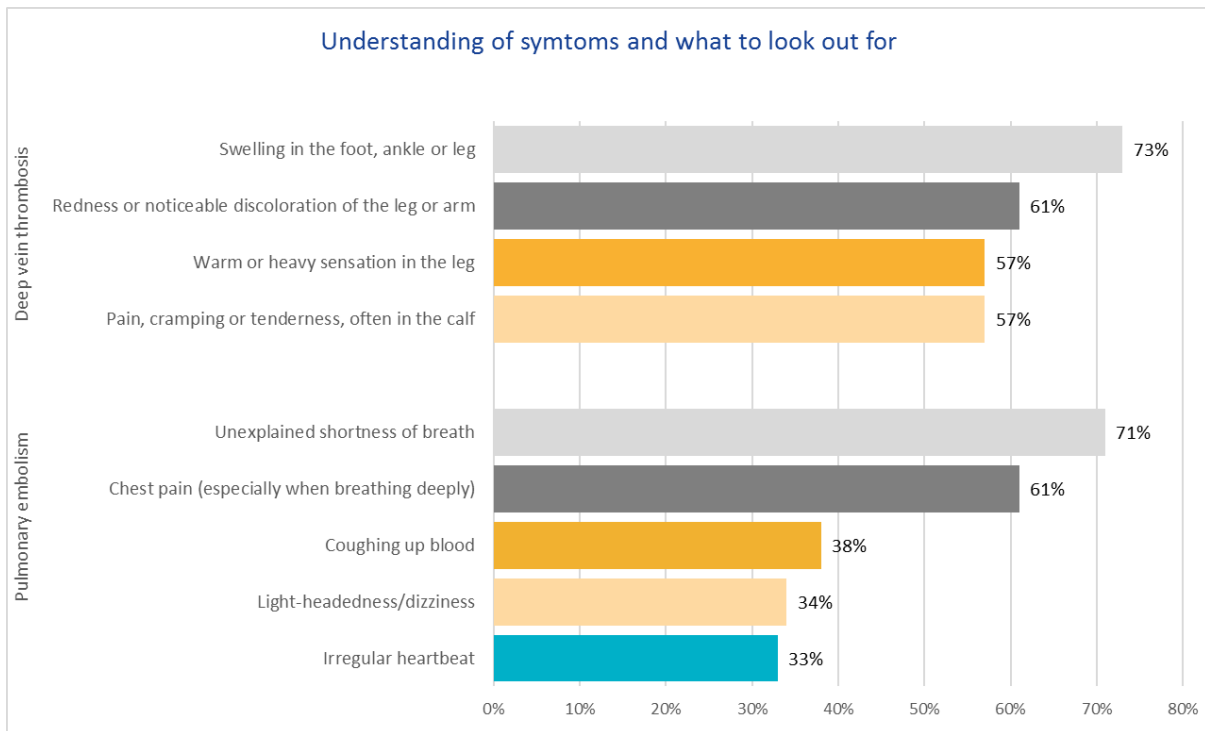
Asked about a range of signs of a blood clot in the arm/leg (deep vein thrombosis (DVT)):

- **73%** of respondents said they were aware that swelling in the foot, ankle or leg could be a sign
- **61%** said they were aware that redness or noticeable discoloration of the leg or arm could be a sign
- **57%** said they were aware that a warm or heavy sensation in the leg could be a sign
- **57%** said they were aware that pain, cramping or tenderness, often in the calf, could be a sign.

Asked about a range of signs of a blood clot in the lung (pulmonary embolism (PE)):

- **71%** of respondents said they were aware that unexplained shortness of breath could be a sign
- **61%** said they were aware that chest pain (especially when breathing deeply) could be a sign
- **38%** said they were aware that coughing up blood could be a sign
- **34%** said they were aware that light-headedness/dizziness could be a sign
- **33%** said they were aware that an irregular heartbeat could be a sign.

² Given the distribution methods for the survey (making use of social media platforms dedicated to certain types of cancer – and patient organisations for those with thrombosis) it is likely that these overall numbers are not representative of the overall cancer patient population, and that in reality fewer cancer patients than these are aware of cancer-associated thrombosis). See Appendix A for more details.



Country analysis. The results in this section vary between countries, across conditions and between different symptoms – there does not seem to be any overall pattern.

Analysis by cancer type. The results in this section differ across different cancer types, with haematological cancer patients reporting a better awareness of most symptoms than those with breast, colorectal/bowel or lung cancers. For example, **86%** of haematological cancer patients said they were aware that swelling in the foot, ankle or leg could be a sign of deep vein thrombosis; compared to **73%** of breast cancer patients, **57%** of colorectal/bowel cancer patients, and **30%** of lung cancer patients.

The diagnosis of cancer-associated thrombosis

Summary. Nearly half of respondents said they did not know that an ultrasound scan (**40%**) or CT scan (**45%**) could be used to diagnose thrombosis.

24% of respondents said that they had suffered from thrombosis associated with their cancer³.

³ Given the distribution methods for the survey (making use of social media platforms dedicated to certain types of cancer – and patient organisations for those with thrombosis) it is likely that these overall numbers are not representative of the overall cancer patient population, and that in reality fewer cancer patients than these are aware of cancer-associated thrombosis). See Appendix A for more details.

Asked about a range of tests that can be used to diagnose thrombosis:

- **60%** of respondents said they knew that an ultrasound scan could be used
- **55%** said they knew that a CT scan could be used.

Country analysis. The results in this section vary by country. For example, **79%** of respondents in Germany said they knew about the use of ultrasound scans, compared to **51%** in Italy.

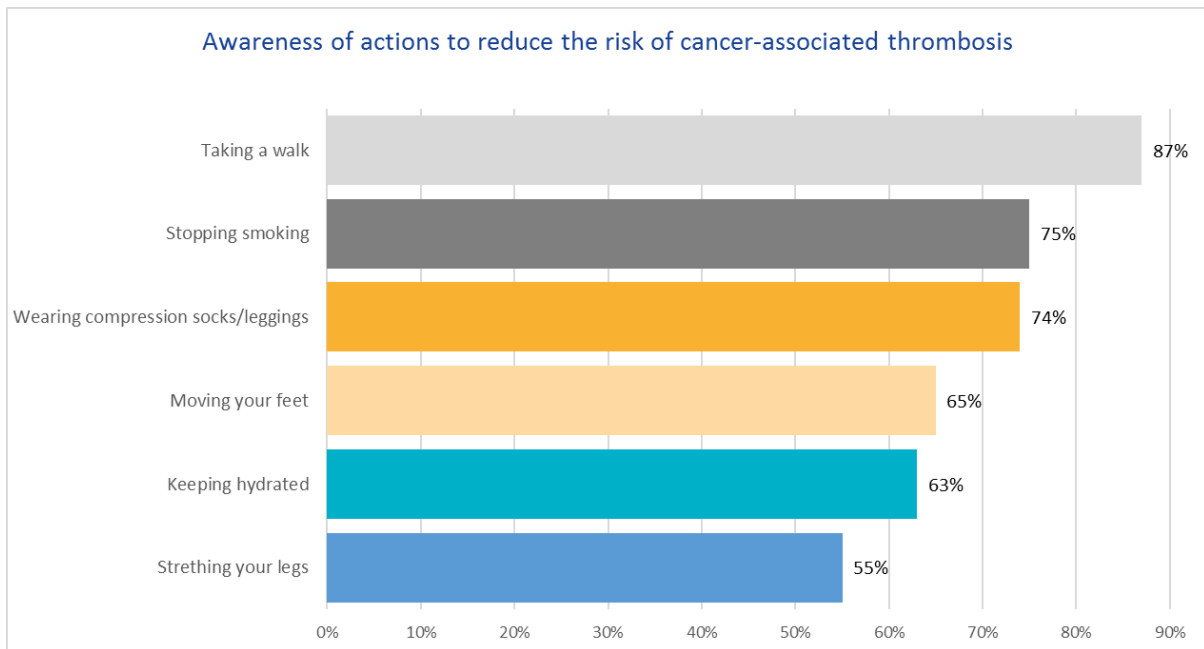
Analysis by cancer type. The results in this section differ across different cancer types. For example, **70%** of colorectal/bowel cancer patients said they knew about the use of CT scans, compared to only **52%** of lung cancer patients.

Preventing the risk of cancer-associated thrombosis

Summary. Awareness of actions they can take to reduce their risk of thrombosis varies a great deal: from **87%** of respondents saying they were aware that taking a walk could reduce their risk; to only just over half (**55%**) saying they were aware that stretching their legs could reduce their risk.

Asked about a range of actions that could reduce their risk of thrombosis:

- **87%** of respondents said they were aware that taking a walk could reduce their risk
- **75%** said they were aware that stopping smoking could reduce their risk
- **74%** said they were aware that wearing compression socks/stockings, if these were prescribed, could reduce their risk
- **65%** said they were aware that moving their feet could reduce their risk
- **63%** said they were aware that keeping hydrated could reduce their risk
- **55%** said they were aware that stretching their legs could reduce their risk.



Analysis by cancer type. The results in this section differ across different cancer types. For example, **82%** of haematological cancer patients said they knew that moving their feet could reduce their risk, compared to only **48%** of lung cancer patients.

Treating cancer-associated thrombosis

Summary. Just over a third of respondents said that they were currently using anticoagulants, although virtually all (**96%**) knew that they could be used to effectively treat thrombosis. Only **41%** of those using anticoagulants said they had been told about any possible side effects; and **22%** had suffered some of these themselves.

96% of respondents said they knew that thrombosis could be treated effectively using medicines known as anticoagulants (often referred to as “blood thinners”): **70%** completely, and **26%** to some extent.

37% of respondents said that they were currently using anticoagulants:

- **60%** of these as a treatment for an existing condition; and **31%** to reduce the risk of thrombosis in the future
- **40%** given orally; and **40%** using an injection.

41% of respondents said that they had been told about any possible side effects of anticoagulants/blood thinners.

These respondents were asked if they had been told what to do if they were affected by any of these side effects:

- **48%** said that they were told to speak to their doctor or nurse
- **39%** said that they were told to contact emergency services
- **9%** said that they had not been told what to do.

22% of respondents said that they had suffered from any of these possible side effects of anticoagulants/blood thinners.

Country analysis. Some of the results in this section differ by country. For example, the majority of respondents in Spain (**54%**) said that they were told to contact emergency services if they suffered any side effects of anticoagulants; whereas in Germany, the majority (**67%**) were told to speak to their doctor or nurse.

Analysis by cancer type. The results in this section differ between different cancer types. For example, **89%** of haematological cancer patients said that they knew about the use of anticoagulants to treat thrombosis, compared to only 68% of breast cancer patients.

Germany

Overall summary

Only **21%** of respondents said that, before taking part in the survey, they were aware that people with cancer have a higher than normal risk of developing thrombosis. The other **79% were not aware**.

Asked to rate their overall understanding of cancer-associated thrombosis on a scale of 1 (low) to 10 (high), nearly half of respondents (**48%**) gave a rating of 4 or below, whilst only **23%** of respondents gave a rating of 7 or above. The average (mean) rating was **4.5** out of **10**; the median was **5** out of **10**.

30% of respondents said that they had suffered from thrombosis associated with their cancer.

The bulk of the questionnaire asked about respondents' understanding of the risks of cancer-associated thrombosis; their understanding of what to look out for; the diagnosis of cancer-associated thrombosis; preventing the risk of cancer-associated thrombosis; treating cancer-associated thrombosis; and how they know about cancer-associated thrombosis.

Understanding the risks of cancer-associated thrombosis

Summary. Awareness of the risk factors related to cancer-associated thrombosis varies a great deal. For example, virtually all respondents (**94%**) said that they were aware of the risks related to inactivity; but less than half (**47%**) said that they were aware of the risks related to radiotherapy.

78% of respondents said that they were aware that certain cancers (including cancers of the stomach, brain, kidney and ovaries) have a higher risk than others of cancer-associated thrombosis: **only 33% completely aware**, and **44%** to some extent.

61% of respondents said they knew that the risk of increases for people with cancer at an advanced stage: **only 36% completely aware**, and **25%** to some extent.

67% of respondents said they knew that cancer surgery can increase the risk of thrombosis: **58% completely aware**, and **8%** to some extent.

64% of respondents said they knew that chemotherapy can increase the risk of thrombosis: **53% completely aware**, and **11%** to some extent.

47% of respondents said they knew that radiotherapy can increase the risk of thrombosis: **only 33% completely aware**, and **14%** to some extent.

56% of respondents said they knew that having a central venous catheter (a central line) can increase the risk of thrombosis: **only 31% completely aware**, and **25%** to some extent.

94% of respondents said they knew that they were more likely to suffer from thrombosis if they were inactive for long periods of time (e.g. if they were in bed for 4 days or more): 89% completely aware, and 6% to some extent.

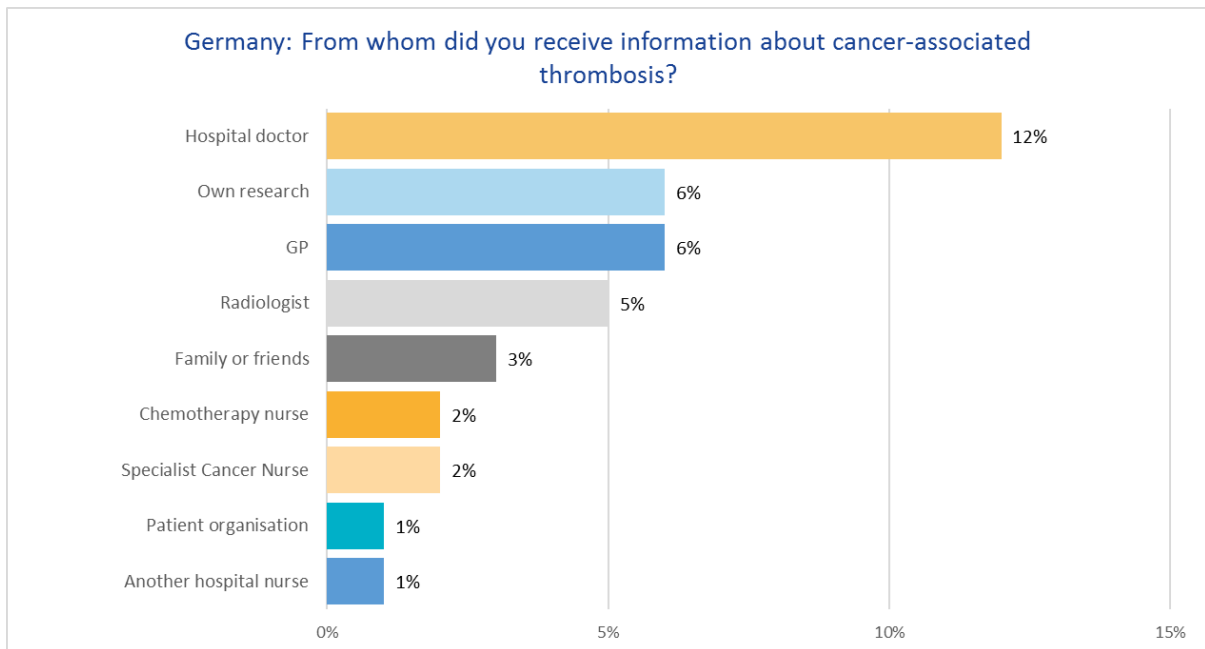
78% of respondents said they knew that they were more likely to suffer from thromboses if they had had them before: 67% completely aware, and 11% to some extent.

Risk factor for cancer-associated thrombosis	Percentage of respondents completely aware
Inactivity	89%
Previous thromboses	67%
Cancer surgery	58%
Chemotherapy	53%
Advanced stage cancers	36%
Certain cancer types	33%
Radiotherapy	33%
Central line	31%

First information about cancer-associated thrombosis

Summary. Asked how they got information about cancer-associated thrombosis, most received this verbally, usually from their hospital doctor (12%) or GP (6%). Many respondents (6%) said that they found out about it from their own research, usually online. Relatively few respondents said that they had got information in writing. **Most respondents said that they already knew about cancer-associated thrombosis before they were diagnosed with cancer (24%);** or that they first became aware of when they suffered a blood clot (21%).

Respondents were asked in what form they had received information about cancer-associated thrombosis, and from whom. The chart overleaf summarises the results:



Most patients who said they received information from their hospital doctor (**10%** out of **12%**), or from their GP (**5%** out of **6%**), received this verbally. In contrast, half of those who said they used their own research (**3%** out of **6%**) found this out on-line.

Asked when they first became aware of cancer-associated thrombosis:

- **24%** said they already knew about it before they were diagnosed with cancer
- **21%** of respondents said they became aware when they suffered a blood clot
- **21%** said they were given information during their cancer diagnosis
- **12%** said they were given information before/during chemotherapy
- **9%** said they were given information following surgery
- **12%** said they were given information before surgery
- **0%** said they were given information before/during radiotherapy.

Understanding symptoms and what to look out for

Summary. Some of the symptoms of cancer-associated thrombosis are relatively well known: e.g. **79%** of respondents said they were aware that redness or noticeable discoloration of the leg or arm could be a sign of deep vein thrombosis; and **91%** that unexplained shortness of breath could be a sign of pulmonary embolism. However, other symptoms are much less well known: e.g. only just over a half (**59%**) said that they were aware that a warm or heavy sensation in the leg could be a sign of deep vein thrombosis; and only a third (**33%**) that coughing up blood could be a sign of pulmonary embolism.

Asked about a range of signs of a blood clot in the arm/leg (deep vein thrombosis (DVT)):

- **79%** said they were aware that redness or noticeable discoloration of the leg or arm could be a sign
- **69%** of respondents said they were aware that swelling in the foot, ankle or leg could be a sign
- **65%** said they were aware that pain, cramping or tenderness, often in the calf, could be a sign
- **59%** said they were aware that a warm or heavy sensation in the leg could be a sign.

Asked about a range of signs of a blood clot in the lung (pulmonary embolism (PE)):

- **91%** of respondents said they were aware that unexplained shortness of breath could be a sign
- **73%** said they were aware that chest pain (especially when breathing deeply) could be a sign
- **52%** said they were aware that light-headedness/dizziness could be a sign
- **47%** said they were aware that an irregular heartbeat could be a sign
- **33%** said they were aware that coughing up blood could be a sign.

The diagnosis of cancer-associated thrombosis

Summary. Most respondents said they knew that an ultrasound scan (**79%**) could be used to diagnose thrombosis; but far fewer said they knew that a CT scan could be used (**55%**).

Asked about a range of tests that can be used to diagnose thrombosis:

- **79%** of respondents said they knew that an ultrasound scan could be used
- **55%** said they knew that a CT scan could be used.

Preventing the risk of cancer-associated thrombosis

Summary. Awareness of actions they can take to reduce their risk of thrombosis was very high, with awareness above **90%** for four out of the six.

Asked about a range of actions that could reduce their risk of thrombosis:

- **97%** said they were aware that stopping smoking could reduce their risk
- **94%** of respondents said they were aware that taking a walk could reduce their risk
- **94%** said they were aware that wearing compression socks/stockings, if these were prescribed, could reduce their risk
- **91%** said they were aware that keeping hydrated could reduce their risk
- **79%** said they were aware that moving their feet could reduce their risk
- **67%** said they were aware that stretching their legs could reduce their risk.

Treating cancer-associated thrombosis

Summary. Nearly half of respondents said that they were currently using anticoagulants, although virtually all (**94%**) knew that they could be used to effectively treat thrombosis. Only **34%** of those using anticoagulants said they had been told about any possible side effects; and **55%** had suffered some of these themselves.

94% of respondents said they knew that thrombosis could be treated effectively using medicines known as anticoagulants (often referred to as “blood thinners”): **81%** completely, and **14%** to some extent.

47% of respondents said that they were currently using anticoagulants:

- **29%** of these as a treatment for an existing condition; and **59%** to reduce the risk of thrombosis in the future
- **76%** given orally; and **24%** using an injection.

34% of respondents said that they had been told about any possible side effects of anticoagulants/blood thinners. These respondents were asked if they had been told what to do if they were affected by any of these side effects:

- **67%** said that they were told to speak to their doctor or nurse
- **11%** said that they were told to contact emergency services
- **11%** said that they had not been told what to do.

55% of respondents said that they had suffered from any of these possible side effects of anticoagulants/blood thinners.

Greece

Overall summary

Only **29%** of respondents said that, before taking part in the survey, they were aware that people with cancer have a higher than normal risk of developing thrombosis. The other **71% were not aware**.

Asked to rate their overall understanding of cancer-associated thrombosis on a scale of 1 (low) to 10 (high), nearly half of respondents (**49%**) gave a rating of 4 or below, whilst only **25%** of respondents gave a rating of 7 or above. The average (mean) rating was **4.5** out of **10**; the median was **5** out of **10**.

16% of respondents said that they had suffered from thrombosis associated with their cancer.

The bulk of the questionnaire asked about respondents' understanding of the risks of cancer-associated thrombosis; their understanding of what to look out for; the diagnosis of cancer-associated thrombosis; preventing the risk of cancer-associated thrombosis; treating cancer-associated thrombosis; and how they know about cancer-associated thrombosis.

Understanding the risks of cancer-associated thrombosis

Summary. Awareness of the risk factors related to cancer-associated thrombosis varies a great deal. For example, the majority of respondents (**80%**) said that they were aware of the risks related to inactivity; but less than half (**45%**) said that they were aware of the risks related to radiotherapy.

72% of respondents said that they were aware that certain cancers (including cancers of the stomach, brain, kidney and ovaries) have a higher risk than others of cancer-associated thrombosis: **only 14% completely aware**, and **58%** to some extent.

65% of respondents said they knew that the risk of increases for people with cancer at an advanced stage: **only 21% completely aware**, and **44%** to some extent.

67% of respondents said they knew that cancer surgery can increase the risk of thrombosis: **only 24% completely aware**, and **43%** to some extent.

64% of respondents said they knew that chemotherapy can increase the risk of thrombosis: **only 26% completely aware**, and **39%** to some extent.

45% of respondents said they knew that radiotherapy can increase the risk of thrombosis: **only 13% completely aware**, and **31%** to some extent.

49% of respondents said they knew that having a central venous catheter (a central line) can increase the risk of thrombosis: **only 16% completely aware**, and **33%** to some extent.

80% of respondents said they knew that they were more likely to suffer from thrombosis if they were inactive for long periods of time (e.g. if they were in bed for 4 days or more): **only 47% completely aware**, and **32%** to some extent.

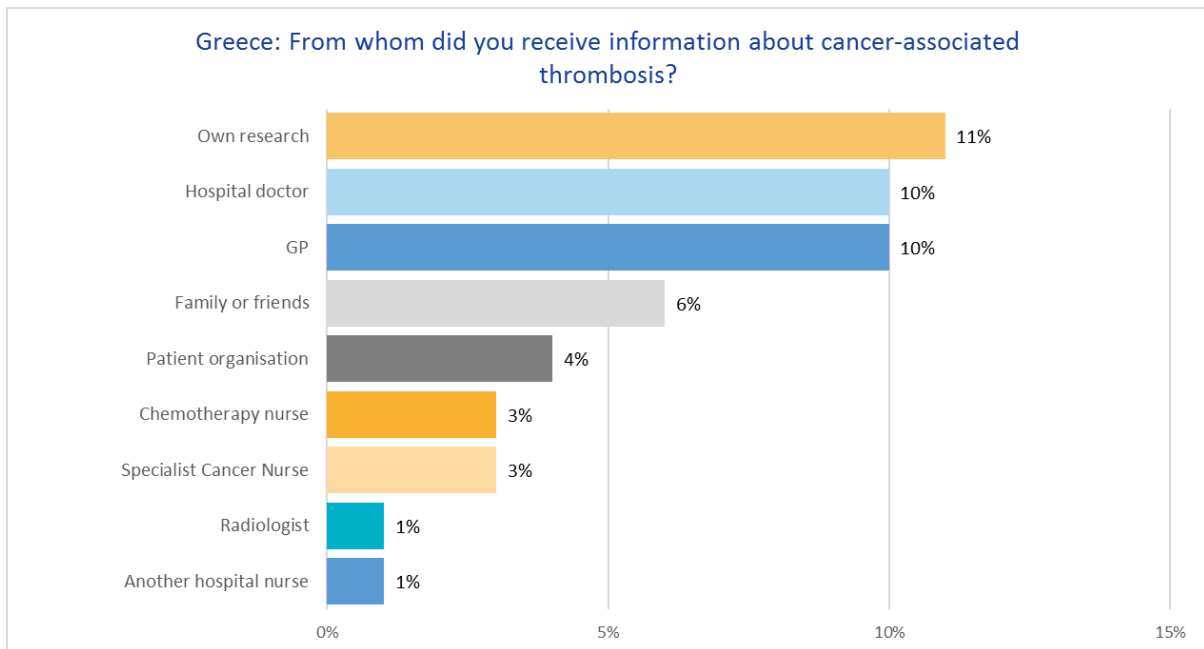
74% of respondents said they knew that they were more likely to suffer from thromboses if they had had them before: **only 44% completely aware**, and 30% to some extent.

Risk factor for cancer-associated thrombosis	Percentage of respondents completely aware
Inactivity	47%
Previous thromboses	44%
Chemotherapy	26%
Cancer surgery	24%
Advanced stage cancers	21%
Central line	16%
Certain cancer types	14%
Radiotherapy	13%

First information about cancer-associated thrombosis

Summary. Asked how they got information about cancer-associated thrombosis, most received this verbally, usually from their hospital doctor (**10%**) or GP (**10%**). Many respondents (**11%**) said that they found out about it from their own research, usually online. Relatively few respondents said that they had got information in writing. **Most respondents said that they first became aware of cancer-associated thrombosis when they suffered a blood clot (23%);** or that they already knew about it before they were diagnosed with cancer (**23%**).

Respondents were asked in what form they had received information about cancer-associated thrombosis, and from whom. The chart overleaf summarises the results:



All but one patient who said they received information from their hospital doctor (**10%**), received this verbally; as did the majority who said they received this from their GP (**9%** out of **10%**). In contrast, most of those who said they used their own research (**8%** out of **11%**) found this out on-line.

Asked when they first became aware of cancer-associated thrombosis:

- **23%** of respondents said they became aware when they suffered a blood clot
- **23%** said they already knew about it before they were diagnosed with cancer
- **19%** said they were given information following surgery
- **15%** said they were given information before/during chemotherapy
- **10%** said they were given information during their cancer diagnosis
- **10%** said they were given information before surgery
- **0%** said they were given information before/during radiotherapy.

Understanding symptoms and what to look out for

Summary. Some of the symptoms of cancer-associated thrombosis are relatively well known: e.g. **77%** of respondents said they were aware that swelling in the foot, ankle or leg could be a sign of deep vein thrombosis; and **62%** that unexplained shortness of breath could be a sign of pulmonary embolism. However, other symptoms are much less well known: e.g. less than half (**41%**) said that they were aware that pain, cramping or tenderness, often in the calf, could be a sign of DVT; and only a fifth (**21%**) that light-headedness/dizziness could be a sign of PE.

Asked about a range of signs of a blood clot in the arm/leg (deep vein thrombosis (DVT)):

- **67%** of respondents said they were aware that swelling in the foot, ankle or leg could be a sign
- **54%** said they were aware that redness or noticeable discoloration of the leg or arm could be a sign
- **47%** said they were aware that a warm or heavy sensation in the leg could be a sign
- **41%** said they were aware that pain, cramping or tenderness, often in the calf, could be a sign.

Asked about a range of signs of a blood clot in the lung (pulmonary embolism (PE)):

- **62%** of respondents said they were aware that unexplained shortness of breath could be a sign
- **61%** said they were aware that chest pain (especially when breathing deeply) could be a sign
- **32%** said they were aware that an irregular heartbeat could be a sign
- **22%** said they were aware that coughing up blood could be a sign
- **21%** said they were aware that light-headedness/dizziness could be a sign.

The diagnosis of cancer-associated thrombosis

Summary. Nearly half of respondents said they did not know that an ultrasound scan (**49%**) or CT scan (**41%**) could be used to diagnose thrombosis.

Asked about a range of tests that can be used to diagnose thrombosis:

- **51%** of respondents said they knew that an ultrasound scan could be used
- **59%** said they knew that a CT scan could be used.

Preventing the risk of cancer-associated thrombosis

Summary. Awareness of actions they can take to reduce their risk of thrombosis varied, with over three quarters of respondents (**78%**) saying they were aware that stopping smoking could reduce their risk; but only a third (**33%**) that stretching their legs could reduce their risk.

Asked about a range of actions that could reduce their risk of thrombosis:

- **78%** said they were aware that stopping smoking could reduce their risk
- **75%** of respondents said they were aware that taking a walk could reduce their risk
- **71%** said they were aware that wearing compression socks/stockings, if these were prescribed, could reduce their risk
- **57%** said they were aware that keeping hydrated could reduce their risk
- **54%** said they were aware that moving their feet could reduce their risk
- **33%** said they were aware that stretching their legs could reduce their risk.

Treating cancer-associated thrombosis

Summary. Just over a quarter of respondents said that they were currently using anticoagulants, although virtually all (**95%**) knew that they could be used to effectively treat thrombosis. Only **36%** of those using anticoagulants said they had been told about any possible side effects; and **14%** had suffered some of these themselves.

95% of respondents said they knew that thrombosis could be treated effectively using medicines known as anticoagulants (often referred to as “blood thinners”): **53%** completely, and **42%** to some extent.

26% of respondents said that they were currently using anticoagulants:

- **74%** of these as a treatment for an existing condition; and **21%** to reduce the risk of thrombosis in the future

- **74%** given orally; and **26%** using an injection.

36% of respondents said that they had been told about any possible side effects of anticoagulants/blood thinners. These respondents were asked if they had been told what to do if they were affected by any of these side effects:

- **58%** said that they were told to speak to their doctor or nurse
- **33%** said that they were told to contact emergency services
- **4%** said that they had not been told what to do.

14% of respondents said that they had suffered from any of these possible side effects of anticoagulants/blood thinners.

Italy

Overall summary

Only **27%** of respondents said that, before taking part in the survey, they were aware that people with cancer have a higher than normal risk of developing thrombosis. The other **73% were not aware**.

Asked to rate their overall understanding of cancer-associated thrombosis on a scale of 1 (low) to 10 (high), two thirds of respondents (**66%**) gave a rating of 4 or below, whilst only **15%** of respondents gave a rating of 7 or above. The average (mean) rating was **3.3** out of **10**; the median was **2** out of **10**.

27% of respondents said that they had suffered from thrombosis associated with their cancer.

The bulk of the questionnaire asked about respondents' understanding of the risks of cancer-associated thrombosis; their understanding of what to look out for; the diagnosis of cancer-associated thrombosis; preventing the risk of cancer-associated thrombosis; treating cancer-associated thrombosis; and how they know about cancer-associated thrombosis.

Understanding the risks of cancer-associated thrombosis

Summary. Awareness of the risk factors related to cancer-associated thrombosis varies a great deal. For example, the majority of respondents (**89%**) said that they were aware of the risks related to inactivity; but only just over half (**52%**) said that they were aware of the risks related to radiotherapy.

85% of respondents said that they were aware that certain cancers (including cancers of the stomach, brain, kidney and ovaries) have a higher risk than others of cancer-associated thrombosis: **only 20% completely aware**, and **64%** to some extent.

62% of respondents said they knew that the risk of increases for people with cancer at an advanced stage: **only 29% completely aware**, and **33%** to some extent.

75% of respondents said they knew that cancer surgery can increase the risk of thrombosis: **only 42% completely aware**, and **33%** to some extent.

75% of respondents said they knew that chemotherapy can increase the risk of thrombosis: **only 41% completely aware**, and **34%** to some extent.

52% of respondents said they knew that radiotherapy can increase the risk of thrombosis: **only 23% completely aware**, and **28%** to some extent.

56% of respondents said they knew that having a central venous catheter (a central line) can increase the risk of thrombosis: **only 31% completely aware**, and **26%** to some extent.

89% of respondents said they knew that they were more likely to suffer from thrombosis if they were inactive for long periods of time (e.g. if they were in bed for 4 days or more): 59% completely aware, and 30% to some extent.

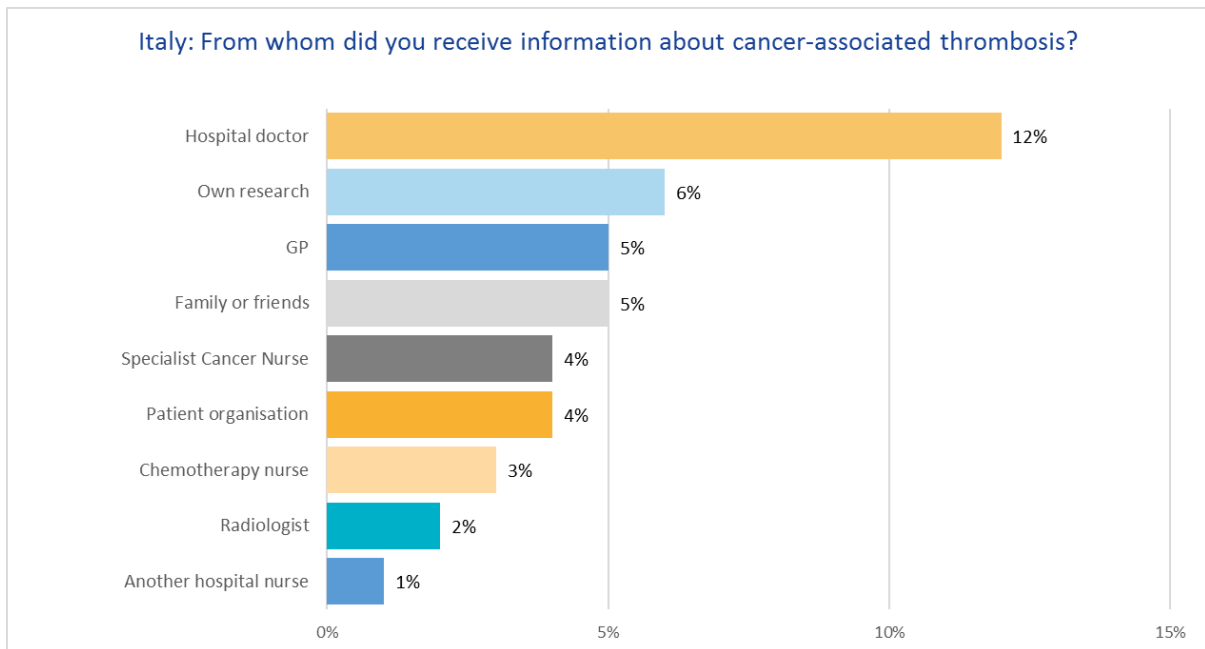
83% of respondents said they knew that they were more likely to suffer from thromboses if they had had them before: only 43% completely aware, and 40% to some extent.

Risk factor for cancer-associated thrombosis	Percentage of respondents completely aware
Inactivity	59%
Previous thromboses	43%
Cancer surgery	42%
Chemotherapy	41%
Central line	31%
Advanced stage cancers	29%
Radiotherapy	23%
Certain cancer types	20%

First information about cancer-associated thrombosis

Summary. Asked how they got information about cancer-associated thrombosis, most received this verbally, usually from their hospital doctor (11%). Some respondents (6%) said that they found out about it from their own research, usually online. Relatively few respondents said that they had got information in writing. **Most respondents said that they first became aware of cancer-associated thrombosis when they suffered a blood clot (24%);** or that they already knew about it before they were diagnosed with cancer (30%).

Respondents were asked in what form they had received information about cancer-associated thrombosis, and from whom. The chart overleaf summarises the results:



Most patients who said they received information from their hospital doctor (**11%** out of **12%**), or from their GP (**4%** out of **5%**), received this verbally. In contrast, most of those who said they used their own research (**4%** out of **6%**) found this out on-line.

Asked when they first became aware of cancer-associated thrombosis:

- **30%** said they already knew about it before they were diagnosed with cancer
- **24%** of respondents said they became aware when they suffered a blood clot
- **13%** said they were given information during their cancer diagnosis
- **11%** said they were given information before surgery
- **9%** said they were given information before/during chemotherapy
- **7%** said they were given information following surgery
- **6%** said they were given information before/during radiotherapy.

Understanding symptoms and what to look out for

Summary. Some of the symptoms of cancer-associated thrombosis are relatively well known: e.g. **58%** of respondents said they were aware that swelling in the foot, ankle or leg could be a sign of deep vein thrombosis; and **58%** that unexplained shortness of breath could be a sign of pulmonary embolism. However, other symptoms are much less well known: e.g. less than half (**46%**) said that they were aware that pain, cramping or tenderness, often in the calf, could be a sign of DVT; and only just over a quarter (**26%**) that coughing up blood could be a sign of PE.

Asked about a range of signs of a blood clot in the arm/leg (deep vein thrombosis (DVT)):

- **58%** of respondents said they were aware that swelling in the foot, ankle or leg could be a sign
- **58%** said they were aware that a warm or heavy sensation in the leg could be a sign
- **51%** said they were aware that redness or noticeable discoloration of the leg or arm could be a sign
- **46%** said they were aware that pain, cramping or tenderness, often in the calf, could be a sign.

Asked about a range of signs of a blood clot in the lung (pulmonary embolism (PE)):

- **58%** of respondents said they were aware that unexplained shortness of breath could be a sign
- **43%** said they were aware that chest pain (especially when breathing deeply) could be a sign
- **29%** said they were aware that light-headedness/dizziness could be a sign
- **26%** said they were aware that an irregular heartbeat could be a sign
- **26%** said they were aware that coughing up blood could be a sign.

The diagnosis of cancer-associated thrombosis

Summary. Nearly half of respondents said they did not know that an ultrasound scan (**49%**) or CT scan (**46%**) could be used to diagnose thrombosis.

Asked about a range of tests that can be used to diagnose thrombosis:

- **51%** of respondents said they knew that an ultrasound scan could be used
- **54%** said they knew that a CT scan could be used.

Preventing the risk of cancer-associated thrombosis

Summary. Awareness of actions they can take to reduce their risk of thrombosis varied, with nearly three quarters of respondents (**74%**) saying they were aware that taking a walk could reduce their risk; but only a third (**35%**) that moving their feet could reduce their risk.

Asked about a range of actions that could reduce their risk of thrombosis:

- **74%** of respondents said they were aware that taking a walk could reduce their risk
- **60%** said they were aware that keeping hydrated could reduce their risk
- **58%** said they were aware that wearing compression socks/stockings, if these were prescribed, could reduce their risk
- **57%** said they were aware that stopping smoking could reduce their risk
- **40%** said they were aware that stretching their legs could reduce their risk
- **35%** said they were aware that moving their feet could reduce their risk.

Treating cancer-associated thrombosis

Summary. Two fifths of respondents (**41%**) said that they were currently using anticoagulants, although virtually all (**94%**) knew that they could be used to effectively treat thrombosis. Only **53%** of those using anticoagulants said they had been told about any possible side effects; and **8%** had suffered some of these themselves.

94% of respondents said they knew that thrombosis could be treated effectively using medicines known as anticoagulants (often referred to as “blood thinners”): **65%** completely, and **29%** to some extent.

41% of respondents said that they were currently using anticoagulants:

- **74%** of these as a treatment for an existing condition; and **22%** to reduce the risk of thrombosis in the future

- **61%** given orally; and **39%** using an injection.

53% of respondents said that they had been told about any possible side effects of anticoagulants/blood thinners. These respondents were asked if they had been told what to do if they were affected by any of these side effects:

- **37%** said that they were told to speak to their doctor or nurse
- **50%** said that they were told to contact emergency services
- **10%** said that they had not been told what to do.

8% of respondents said that they had suffered from any of these possible side effects of anticoagulants/blood thinners.

Spain

Overall summary

Only **26%** of respondents said that, before taking part in the survey, they were aware that people with cancer have a higher than normal risk of developing thrombosis. The other **74% were not aware**.

Asked to rate their overall understanding of cancer-associated thrombosis on a scale of 1 (low) to 10 (high), over half of respondents (**55%**) gave a rating of 4 or below, whilst only **19%** of respondents gave a rating of 7 or above. The average (mean) rating was **4.1** out of **10**; the median rating was **4** out of **10**.

19% of respondents said that they had suffered from thrombosis associated with their cancer.

The bulk of the questionnaire asked about respondents' understanding of the risks of cancer-associated thrombosis; their understanding of what to look out for; the diagnosis of cancer-associated thrombosis; preventing the risk of cancer-associated thrombosis; treating cancer-associated thrombosis; and how they know about cancer-associated thrombosis.

Understanding the risks of cancer-associated thrombosis

Summary. Awareness of the risk factors related to cancer-associated thrombosis varies a great deal. For example, virtually all respondents (**93%**) said that they were aware of the risks related to inactivity; but only just over half (**45%**) said that they were aware of the risks related to cancer surgery.

71% of respondents said that they were aware that certain cancers (including cancers of the stomach, brain, kidney and ovaries) have a higher risk than others of cancer-associated thrombosis: **only 12% completely aware**, and **60%** to some extent.

56% of respondents said they knew that the risk of increases for people with cancer at an advanced stage: **only 22% completely aware**, and **34%** to some extent.

45% of respondents said they knew that cancer surgery can increase the risk of thrombosis: **only 20% completely aware**, and **25%** to some extent.

64% of respondents said they knew that chemotherapy can increase the risk of thrombosis: **only 25% completely aware**, and **40%** to some extent.

52% of respondents said they knew that radiotherapy can increase the risk of thrombosis: **only 20% completely aware**, and **32%** to some extent.

47% of respondents said they knew that having a central venous catheter (a central line) can increase the risk of thrombosis: **only 25% completely aware**, and **22%** to some extent.

93% of respondents said they knew that they were more likely to suffer from thrombosis if they were inactive for long periods of time (e.g. if they were in bed for 4 days or more): **73% completely aware**, and **20%** to some extent.

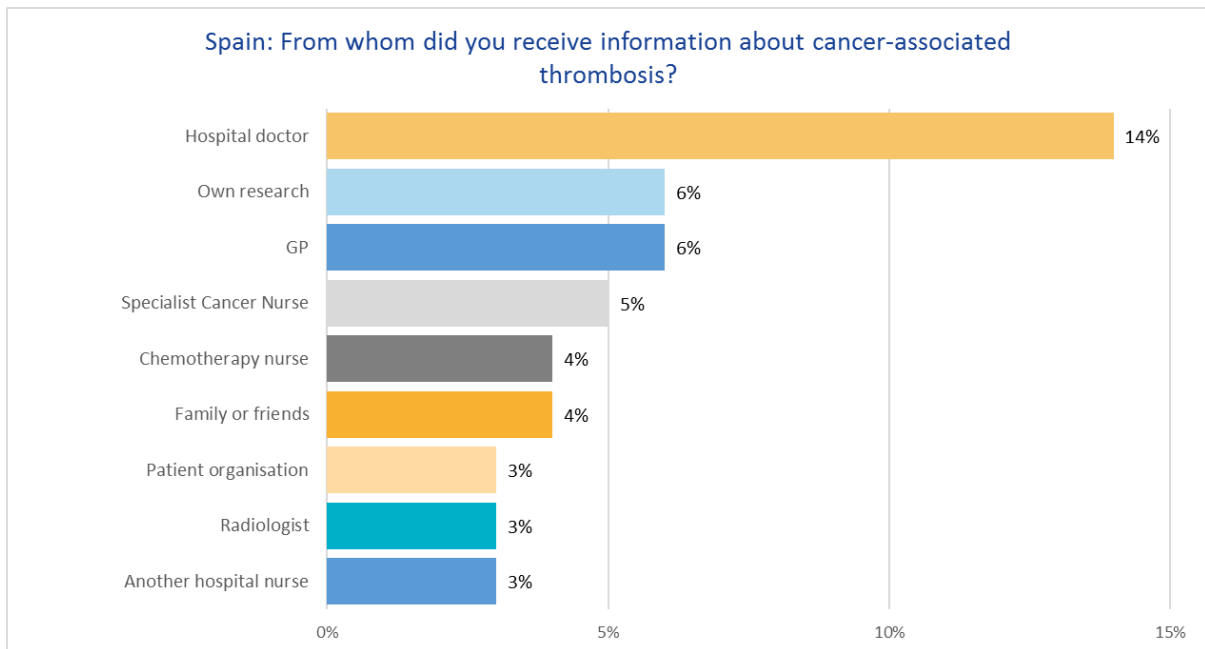
78% of respondents said they knew that they were more likely to suffer from thromboses if they had had them before: **only 45% completely aware**, and **33%** to some extent.

Risk factor for cancer-associated thrombosis	Percentage of respondents completely aware
Inactivity	73%
Previous thromboses	45%
Central line	25%
Chemotherapy	25%
Advanced stage cancers	22%
Radiotherapy	20%
Cancer surgery	20%
Certain cancer types	12%

First information about cancer-associated thrombosis

Summary. Asked how they got information about cancer-associated thrombosis, most received this verbally, usually from their hospital doctor (**12%**) or GP (**5%**). Some respondents (**6%**) said that they found out about it from their own research, usually online. Relatively few respondents said that they had got information in writing. **Most respondents said that they first became aware of cancer-associated thrombosis before/during chemotherapy (26%);** or when they suffered a blood clot (**24%**).

Respondents were asked in what form they had received information about cancer-associated thrombosis, and from whom. The chart overleaf summarises the results:



Most patients who said they received information from their hospital doctor (**12%** out of **14%**), or from their GP (**5%** out of **6%**), received this verbally. In contrast, half of those who said they used their own research (**3%** out of **6%**) found this out on-line.

Asked when they first became aware of cancer-associated thrombosis:

- **26%** said they were given information before/during chemotherapy
- **24%** of respondents said they became aware when they suffered a blood clot
- **17%** said they were given information during their cancer diagnosis
- **16%** said they already knew about it before they were diagnosed with cancer
- **12%** said they were given information following surgery
- **3%** said they were given information before surgery
- **2%** said they were given information before/during radiotherapy.

Understanding symptoms and what to look out for

Summary. Some of the symptoms of cancer-associated thrombosis are relatively well known: e.g. **86%** of respondents said they were aware that swelling in the foot, ankle or leg could be a sign of deep vein thrombosis; and **71%** that unexplained shortness of breath could be a sign of pulmonary embolism. However, other symptoms are much less well known: e.g. less than half (**44%**) said that they were aware that pain, cramping or tenderness, often in the calf, could be a sign of DVT; and only a third (**33%**) that an irregular heartbeat could be a sign of PE.

Asked about a range of signs of a blood clot in the arm/leg (deep vein thrombosis (DVT)):

- **86%** of respondents said they were aware that swelling in the foot, ankle or leg could be a sign
- **61%** said they were aware that redness or noticeable discoloration of the leg or arm could be a sign
- **60%** said they were aware that a warm or heavy sensation in the leg could be a sign
- **44%** said they were aware that pain, cramping or tenderness, often in the calf, could be a sign.

Asked about a range of signs of a blood clot in the lung (pulmonary embolism (PE)):

- **71%** of respondents said they were aware that unexplained shortness of breath could be a sign
- **63%** said they were aware that chest pain (especially when breathing deeply) could be a sign
- **37%** said they were aware that light-headedness/dizziness could be a sign
- **37%** said they were aware that coughing up blood could be a sign
- **33%** said they were aware that an irregular heartbeat could be a sign.

The diagnosis of cancer-associated thrombosis

Summary. Around half of respondents said they did not know that an ultrasound scan (**42%**) or CT scan (**51%**) could be used to diagnose thrombosis.

Asked about a range of tests that can be used to diagnose thrombosis:

- **58%** of respondents said they knew that an ultrasound scan could be used
- **49%** said they knew that a CT scan could be used.

Preventing the risk of cancer-associated thrombosis

Summary. Awareness of actions they can take to reduce their risk of thrombosis varied, with nearly all respondents (94%) saying they were aware that taking a walk could reduce their risk; but just under half (48%) that keeping hydrated could reduce their risk.

Asked about a range of actions that could reduce their risk of thrombosis:

- 94% of respondents said they were aware that taking a walk could reduce their risk
- 77% said they were aware that stopping smoking could reduce their risk
- 63% said they were aware that wearing compression socks/stockings, if these were prescribed, could reduce their risk
- 69% said they were aware that moving their feet could reduce their risk
- 56% said they were aware that stretching their legs could reduce their risk
- 48% said they were aware that keeping hydrated could reduce their risk.

Treating cancer-associated thrombosis

Summary. Just under a third of respondents (31%) said that they were currently using anticoagulants, although virtually all (96%) knew that they could be used to effectively treat thrombosis. Only 35% of those using anticoagulants said they had been told about any possible side effects; and 15% had suffered some of these themselves.

96% of respondents said they knew that thrombosis could be treated effectively using medicines known as anticoagulants (often referred to as “blood thinners”): 70% completely, and 26% to some extent.

31% of respondents said that they were currently using anticoagulants:

- 58% of these as a treatment for an existing condition; and 31% to reduce the risk of thrombosis in the future

- **52%** given orally; and **48%** using an injection.

35% of respondents said that they had been told about any possible side effects of anticoagulants/blood thinners. These respondents were asked if they had been told what to do if they were affected by any of these side effects:

- **38%** said that they were told to speak to their doctor or nurse
- **54%** said that they were told to contact emergency services
- **8%** said that they had not been told what to do.

15% of respondents said that they had suffered from any of these possible side effects of anticoagulants/blood thinners.

UK

Overall summary

Only **36%** of respondents said that, before taking part in the survey, they were aware that people with cancer have a higher than normal risk of developing thrombosis. The other **64% were not aware**.

Asked to rate their overall understanding of cancer-associated thrombosis on a scale of 1 (low) to 10 (high), over half of respondents (**58%**) gave a rating of 4 or below, whilst only **35%** of respondents gave a rating of 7 or above. The average (mean) rating was **4.0** out of **10**; the median rating was **3.5** out of **10**.

31% of respondents said that they had suffered from thrombosis associated with their cancer.

The bulk of the questionnaire asked about respondents' understanding of the risks of cancer-associated thrombosis; their understanding of what to look out for; the diagnosis of cancer-associated thrombosis; preventing the risk of cancer-associated thrombosis; treating cancer-associated thrombosis; and how they know about cancer-associated thrombosis.

Understanding the risks of cancer-associated thrombosis

Summary. Awareness of the risk factors related to cancer-associated thrombosis varies a great deal. For example, virtually all respondents (**92%**) said that they were aware of the risks related to inactivity; but less than half (**38%**) said that they were aware of the risks related to radiotherapy.

85% of respondents said that they were aware that certain cancers (including cancers of the stomach, brain, kidney and ovaries) have a higher risk than others of cancer-associated thrombosis: **only 8% completely aware**, and **76%** to some extent.

53% of respondents said they knew that the risk of increases for people with cancer at an advanced stage: **only 15% completely aware**, and **38%** to some extent.

73% of respondents said they knew that cancer surgery can increase the risk of thrombosis: **only 40% completely aware**, and **33%** to some extent.

76% of respondents said they knew that chemotherapy can increase the risk of thrombosis: **only 32% completely aware**, and **45%** to some extent.

38% of respondents said they knew that radiotherapy can increase the risk of thrombosis: **only 8% completely aware**, and **30%** to some extent.

48% of respondents said they knew that having a central venous catheter (a central line) can increase the risk of thrombosis: **only 18% completely aware**, and **30%** to some extent.

92% of respondents said they knew that they were more likely to suffer from thrombosis if they were inactive for long periods of time (e.g. if they were in bed for 4 days or more): **65% completely aware**, and **26%** to some extent.

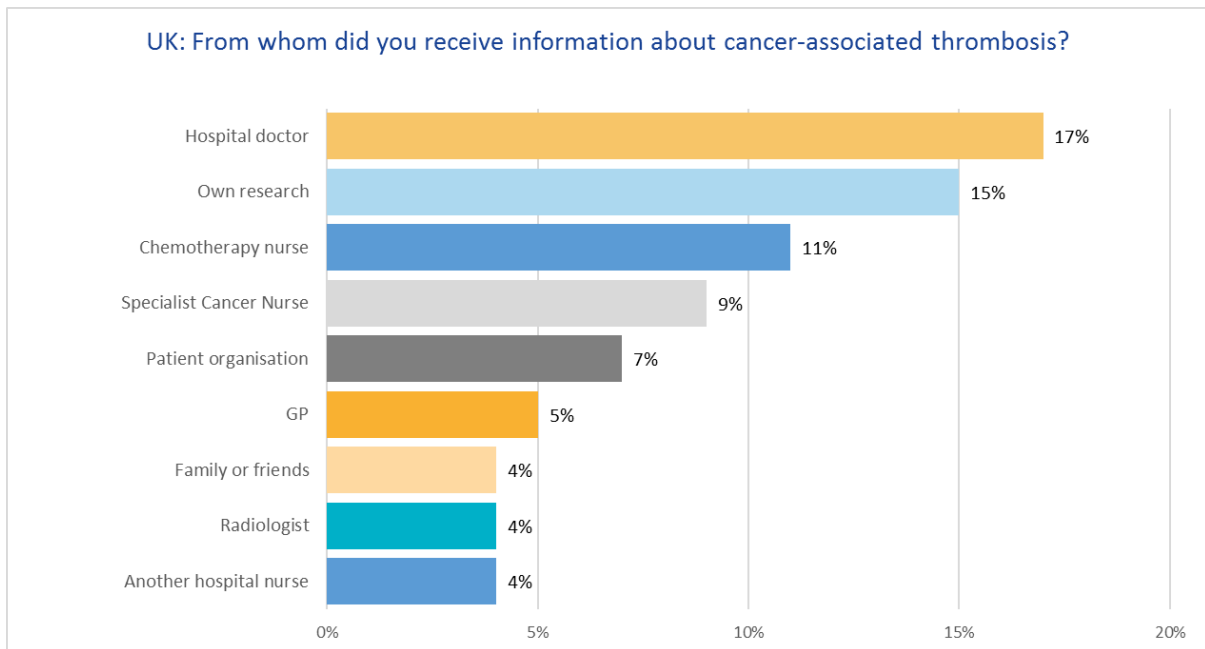
80% of respondents said they knew that they were more likely to suffer from thromboses if they had had them before: **only 44% completely aware**, and **36%** to some extent.

Risk factor for cancer-associated thrombosis	Percentage of respondents completely aware
Inactivity	65%
Previous thromboses	44%
Cancer surgery	40%
Chemotherapy	32%
Central line	18%
Advanced stage cancers	15%
Certain cancer types	8%
Radiotherapy	8%

First information about cancer-associated thrombosis

Summary. Asked how they got information about cancer-associated thrombosis, most received this verbally, usually from their hospital doctor (**12%**), chemotherapy nurse (**9%**), or Specialist Cancer Nurse (**8%**). Many respondents (**15%**) said that they found out about it from their own research, usually online. Relatively few respondents said that they had got information in writing. **Most respondents said that they first became aware of cancer-associated thrombosis when they suffered a blood clot (32%).**

Respondents were asked in what form they had received information about cancer-associated thrombosis, and from whom. The chart overleaf summarises the results:



Most patients who said they received information from their hospital doctor (**15%** out of **17%**), or from their GP (**3%** out of **5%**), received this verbally. In contrast, most of those who said they used their own research (**10%** out of **15%**) found this out on-line.

Asked when they first became aware of cancer-associated thrombosis:

- **32%** of respondents said they became aware when they suffered a blood clot
- **17%** said they were given information before/during chemotherapy
- **16%** said they were given information during their cancer diagnosis
- **13%** said they already knew about it before they were diagnosed with cancer
- **12%** said they were given information before surgery
- **10%** said they were given information following surgery
- **2%** said they were given information before/during radiotherapy.

Understanding symptoms and what to look out for

Summary. Some of the symptoms of cancer-associated thrombosis are relatively well known: e.g. **80%** of respondents said they were aware that pain, cramping or tenderness, often in the calf, could be a sign of deep vein thrombosis; and **75%** that unexplained shortness of breath could be a sign of pulmonary embolism. However, other symptoms are much less well known: e.g. only two thirds (**62%**) said that they were aware that pain, cramping or tenderness, often in the calf, could be a sign of DVT; and only a third (**32%**) that an irregular heartbeat could be a sign of PE.

Asked about a range of signs of a blood clot in the arm/leg (deep vein thrombosis (DVT)):

- **80%** said they were aware that pain, cramping or tenderness, often in the calf, could be a sign
- **75%** of respondents said they were aware that swelling in the foot, ankle or leg could be a sign
- **68%** said they were aware that redness or noticeable discoloration of the leg or arm could be a sign
- **62%** said they were aware that a warm or heavy sensation in the leg could be a sign.

Asked about a range of signs of a blood clot in the lung (pulmonary embolism (PE)):

- **75%** of respondents said they were aware that unexplained shortness of breath could be a sign
- **67%** said they were aware that chest pain (especially when breathing deeply) could be a sign
- **55%** said they were aware that coughing up blood could be a sign
- **39%** said they were aware that light-headedness/dizziness could be a sign
- **32%** said they were aware that an irregular heartbeat could be a sign.

The diagnosis of cancer-associated thrombosis

Summary. A third of respondents (**33%**) said they did not know that an ultrasound scan could be used to diagnose thrombosis, and nearly half (**41%**) said they did not know a CT scan could be used.

Asked about a range of tests that can be used to diagnose thrombosis:

- **67%** of respondents said they knew that an ultrasound scan could be used

- **59%** said they knew that a CT scan could be used.

Preventing the risk of cancer-associated thrombosis

Summary. Awareness of actions they can take to reduce their risk of thrombosis was high, with nearly all respondents (**94%**) saying they were aware that taking a walk could reduce their risk; but just under half (**74%**, the lowest percentage) aware that keeping hydrated could reduce their risk.

Asked about a range of actions that could reduce their risk of thrombosis:

- **94%** of respondents said they were aware that taking a walk could reduce their risk
- **88%** said they were aware that wearing compression socks/stockings, if these were prescribed, could reduce their risk
- **83%** said they were aware that moving their feet could reduce their risk
- **76%** said they were aware that stopping smoking could reduce their risk
- **75%** said they were aware that stretching their legs could reduce their risk
- **74%** said they were aware that keeping hydrated could reduce their risk.

Treating cancer-associated thrombosis

Summary. Two fifths of respondents (**41%**) said that they were currently using anticoagulants, although virtually all (**99%**) knew that they could be used to effectively treat thrombosis. Only **44%** of those using anticoagulants said they had been told about any possible side effects; and **34%** had suffered some of these themselves.

99% of respondents said they knew that thrombosis could be treated effectively using medicines known as anticoagulants (often referred to as “blood thinners”): **82%** completely, and **17%** to some extent.

41% of respondents said that they were currently using anticoagulants:

- **62%** of these as a treatment for an existing condition; and **29%** to reduce the risk of thrombosis in the future

- **52%** given orally; and **48%** using an injection.

44% of respondents said that they had been told about any possible side effects of anticoagulants/blood thinners. These respondents were asked if they had been told what to do if they were affected by any of these side effects:

- **51%** said that they were told to speak to their doctor or nurse
- **33%** said that they were told to contact emergency services
- **10%** said that they had not been told what to do.

34% of respondents said that they had suffered from any of these possible side effects of anticoagulants/blood thinners.

Analysis by cancer type

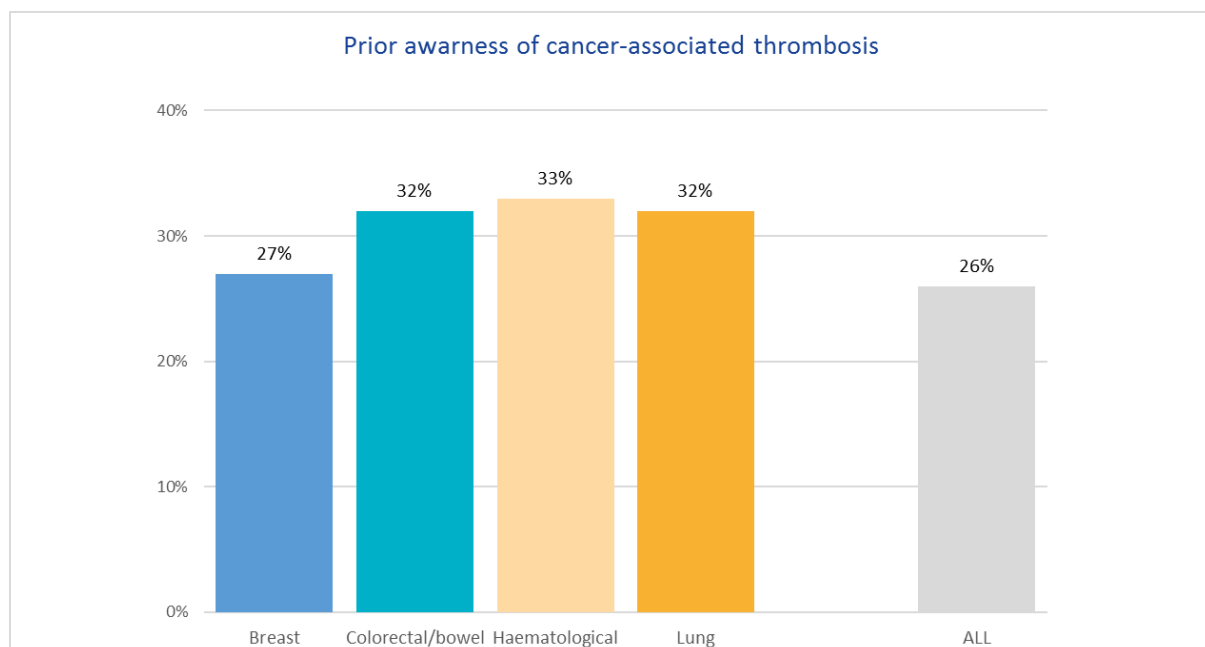
As set out earlier in this report, the survey respondents represent a large range of different cancer types. This section examines the differences in the nature of responses from the four largest groups of respondents:

Number of respondents	
Breast	598
Colorectal/bowel	99
Haematological	85
Lung	78

Overall summary

The key finding in this analysis is that haematological cancer patients seem to receive more information on cancer-associated thrombosis than other cancer patients, and at an earlier stage; and that they are more aware of the risk factors, and symptoms associated with the condition.

The proportion of respondents who said that, before taking part in the survey, they were aware that people with cancer have a higher than normal risk of developing thrombosis, was similar across the four cancer types – but all slightly higher than the overall average.



Asked to rate their overall understanding of cancer-associated thrombosis on a scale of 1 (low) to 10 (high), ratings across the four cancer types differs, with breast cancer patients on average reporting a lower level of understanding:

Median of overall understanding

Breast	3
Colorectal/bowel	5
Haematological	5
Lung	5
All cancers	4

Understanding the risks of cancer-associated thrombosis

Asked about their understanding of the risk factors related to cancer-associated thrombosis, ratings across the four cancer types differs, with haematological cancer patients reporting a better level of awareness on most factors:

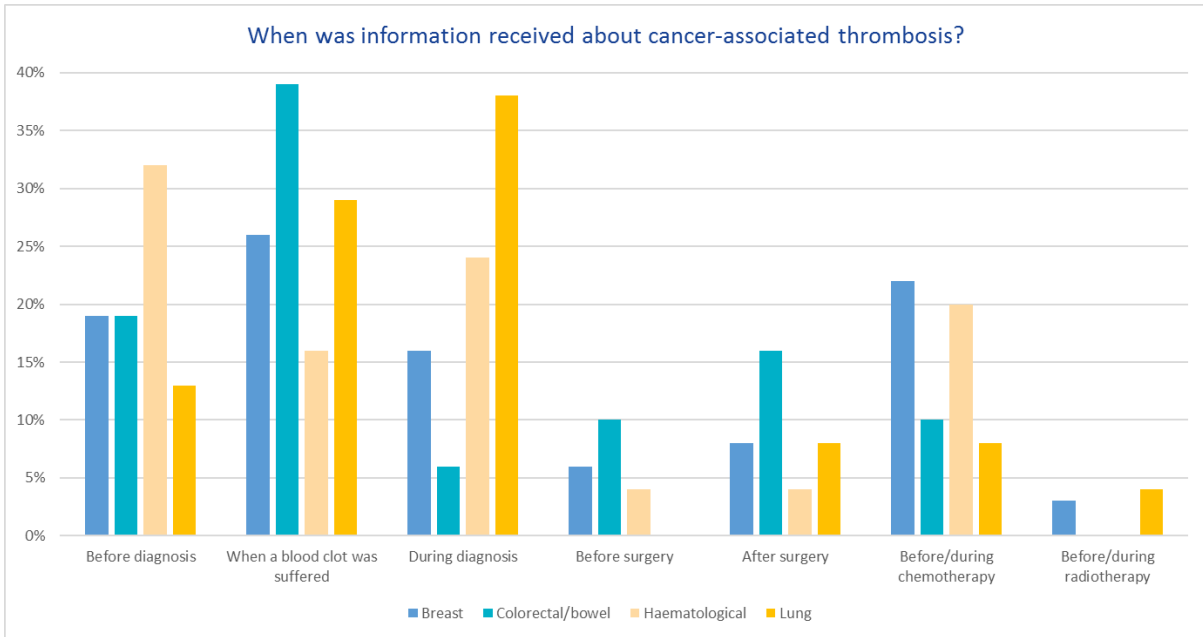
Awareness of risk factor for cancer-associated thrombosis

	Breast	Colorectal/bowel	Haematological	Lung	All cancers
Inactivity	91%	90%	96%	96%	90%
Previous thromboses	80%	77%	93%	84%	79%
Certain cancer types	75%	87%	86%	87%	78%
Chemotherapy	72%	80%	82%	64%	70%
Cancer surgery	60%	81%	75%	58%	65%
Advanced stage cancers	53%	52%	73%	76%	59%
Central line	53%	52%	56%	33%	50%
Radiotherapy	46%	50%	50%	40%	46%

First information about cancer-associated thrombosis

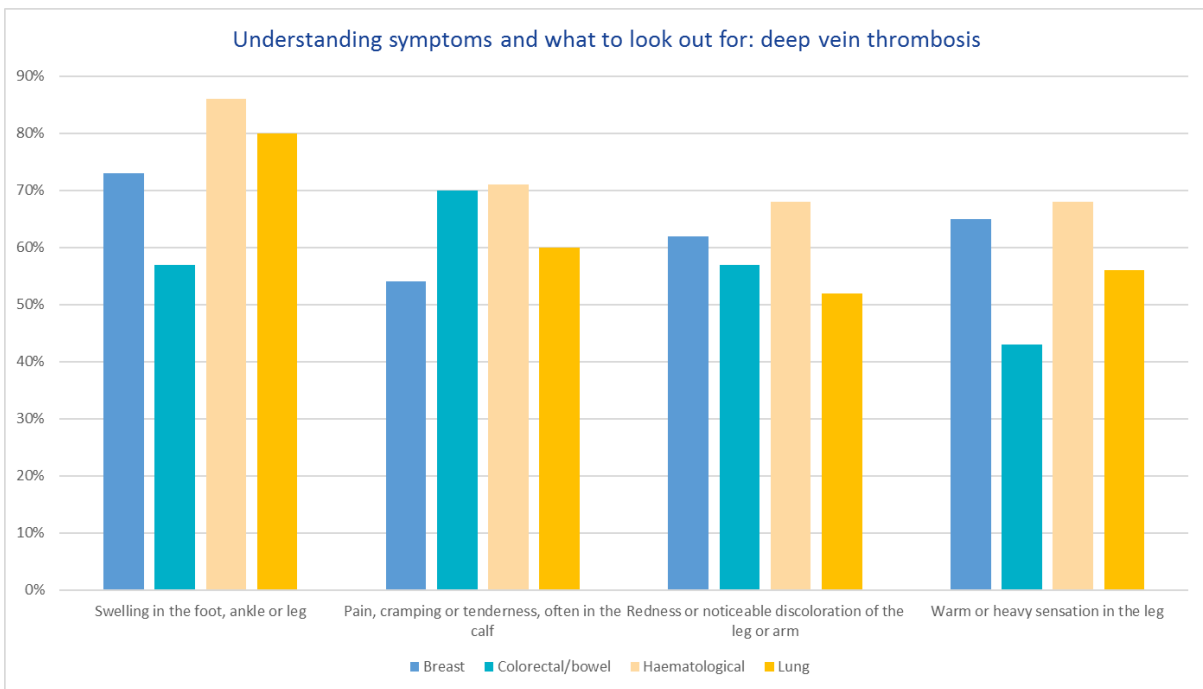
Asked about how they first became aware of cancer-associated thrombosis, there are few differences between the four cancer types. Like respondents more generally, most received this information verbally, usually from their hospital doctor or GP; many said that they found out about it from their own research, usually online; and relatively few respondents said that they had got information in writing.

However, there are some reported differences between cancer types in *when* they found out this information.

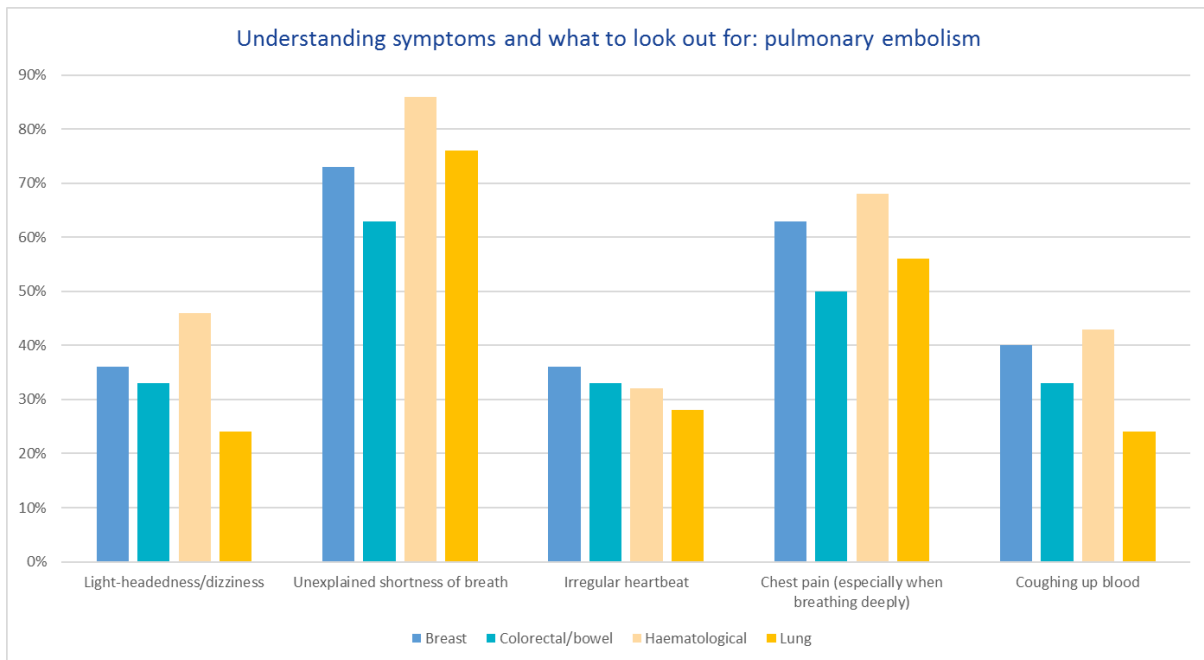


Understanding symptoms and what to look out for

Asked about their awareness of a range of signs of a blood clot in the arm/leg (deep vein thrombosis (DVT)), results differ across the four cancer types, with haematological cancer patients reporting a better level of awareness on most of these symptoms.



Asked about their awareness of a range of signs of a blood clot in the lung (pulmonary embolism (PE)), results differ across the four cancer types, with haematological cancer patients reporting a better level of awareness on most of these symptoms.



The diagnosis of cancer-associated thrombosis

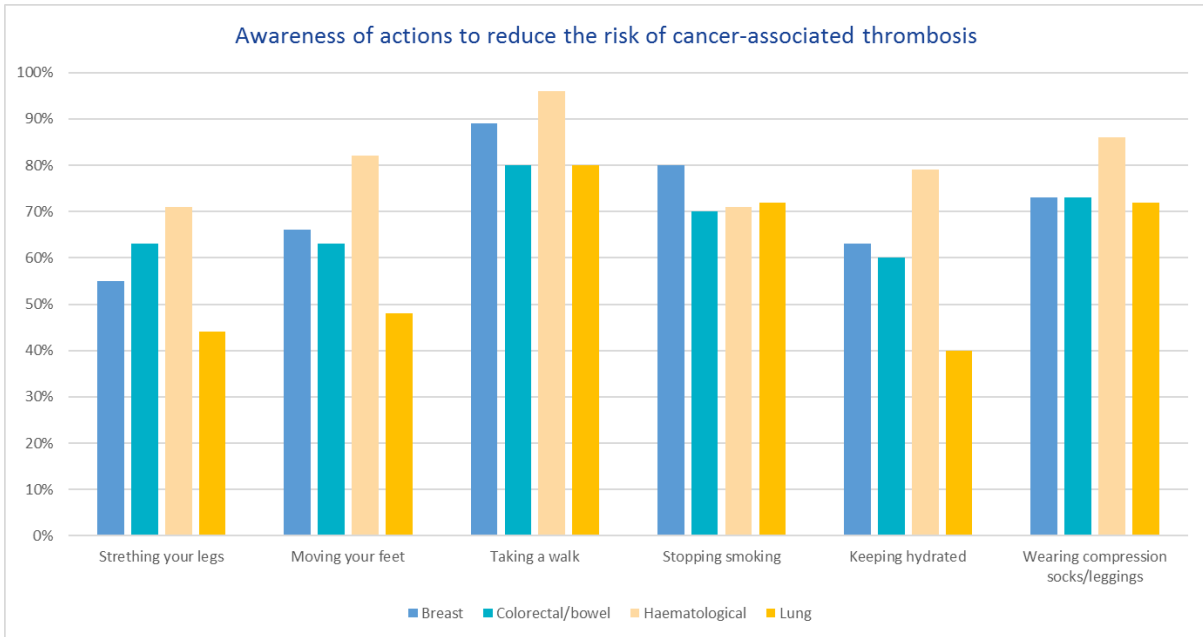
Asked about a range of tests that can be used to diagnose thrombosis, there were differences between the four cancer types, as follows:

Knowledge of diagnostic tests					
	Breast	Colorectal/bowel	Haematological	Lung	All cancers
An ultrasound scan	58%	50%	89%	60%	60%
A CT scan	54%	70%	64%	52%	55%

Preventing the risk of cancer-associated thrombosis

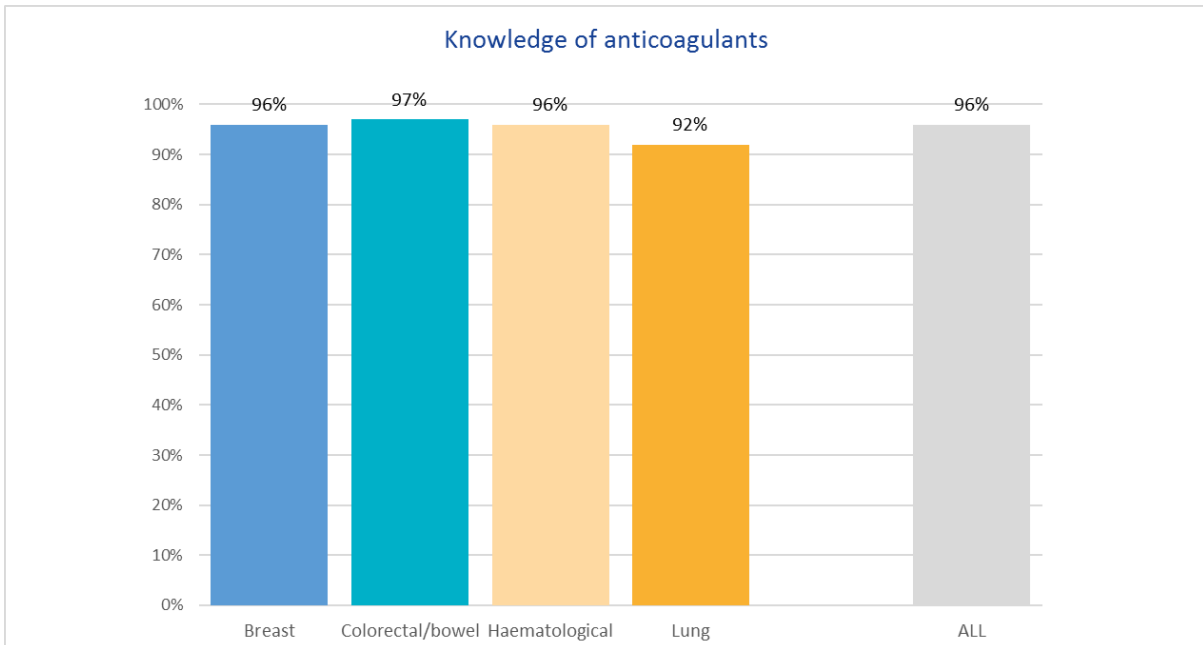
Asked about their knowledge of a range of actions that could reduce their risk of thrombosis, there were differences between the four cancer types, as follows:

Understanding preventative actions that can be taken					
	Breast	Colorectal/bowel	Haematological	Lung	All cancers
Stretching your legs	55%	63%	71%	44%	55%
Moving your feet	66%	63%	82%	48%	65%
Taking a walk	89%	80%	96%	80%	87%
Stopping smoking	80%	70%	71%	72%	75%
Keeping hydrated	63%	60%	79%	40%	64%
Wearing compression socks/leggings, if these are prescribed	73%	73%	86%	72%	74%



Treating cancer-associated thrombosis

Reported knowledge of the use of medicines known as anticoagulants (often referred to as “blood thinners”) to treat thrombosis was consistently high across all four cancer types.

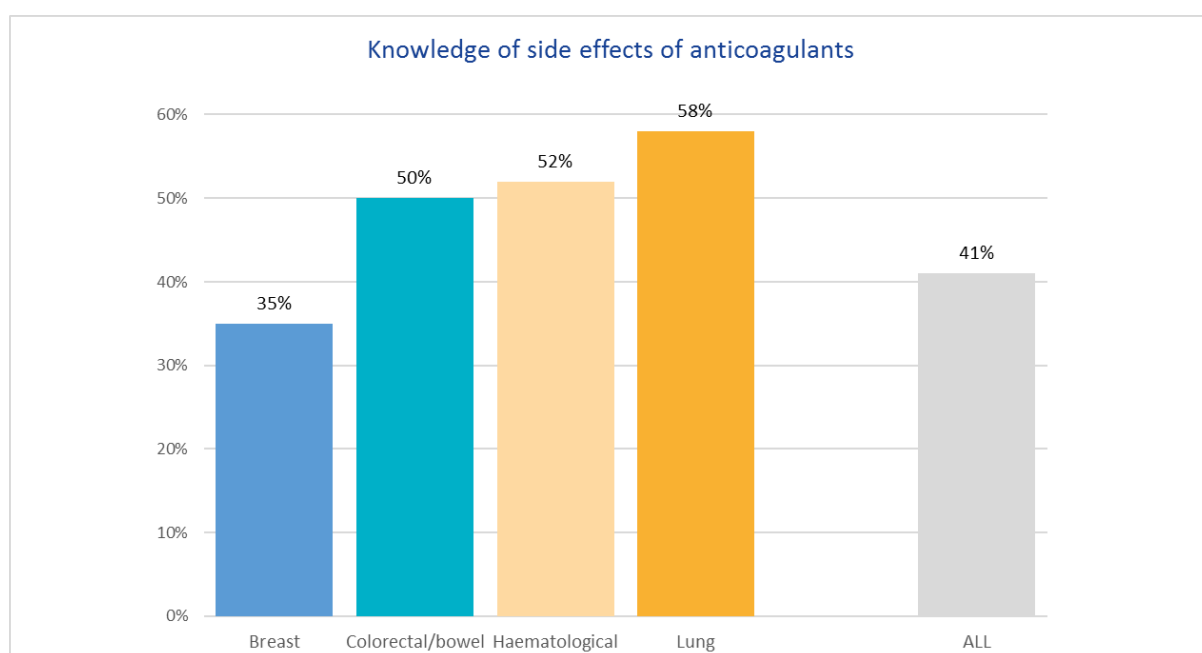


Reported current use of anticoagulants was much higher amongst respondents with colorectal/bowel or lung cancers, than amongst respondents with breast or haematological cancers. This is close to, but not exactly matching, the frequency of cancer-associated thrombosis amongst these different cancer types:

Current use of anticoagulants	Incidence of thrombosis per 100 person years ^[7]

Breast	29%	3.2
Colorectal/bowel	68%	6.7
Haematological	41%	4.5
Lung	58%	10.1
All cancers	37%	

Breast cancer patients were reportedly less likely to have been told about the possible side effects of anticoagulants than patients in the other three cancer groups.



Response numbers and demographics

Overall response numbers

There were **1,344** respondents to the survey overall⁴, including responses from the following countries:

- Germany, **175**
- Greece, **267**
- Italy, **246**
- Spain, **332**
- UK, **324**.

The majority of responses were cancer patients/survivors themselves (**966, 76%**), whilst many others were filled in on their behalf (**313, 24%**).

Cancer type

The breakdown of respondents by cancer type is as follows:

Breast	46%
Other	9%
Colorectal/bowel	8%
Haematological	7%
Lung	6%
Other gynaecological	5%
Ovarian	4%
Oesophageal, Stomach, Pancreatic, Liver, or Gall bladder	4%
Bladder	3%
Prostate	3%
Skin	2%
Brain/Central Nervous System	1%
Head and neck	1%
Sarcoma	1%
Other urological	1%

⁴ In addition to these numbers, there were also 21 respondents in France. Although included in the overall findings, a separate section analysing the French findings on their own has not been prepared, as these numbers on their own are insufficient for any robust statistical analysis.

Many respondents had first been treated for their cancer a number of years ago:

Less than 1 year	24%
1 to 5 years	38%
More than 5 years	33%
My cancer treatment hasn't yet started	2%
I will not receive any treatment for my cancer	2%
Don't know/can't remember	0%

Gender

Asked about their gender, **220** respondents (**16%**) said they were male; **1,019** (**75%**) female; **8** (**1%**) said they would prefer not to say; and **1** respondent ticked an 'other' option. **117** (**9%**) didn't answer this question at all.

Age

The majority of respondents were aged over 45:

Under 16	0%
16-24	0%
25-34	1%
35-44	5%
45-54	16%
55-64	42%
65-74	25%
75-84	6%
85+	1%
Out of Range	3%

Longstanding conditions

Asked about longstanding conditions:

- **6%** said that they were deaf or had a severe hearing impediment
- **2%** said that they were blind or partially sighted
- **11%** said that they had a long-standing physical condition
- **1%** said that they had a learning disability
- **4%** said that they had a mental health condition
- **10%** said that they had a long-standing illness, such as HIV, diabetes, chronic heart disease, or epilepsy.

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- [2] Horsted F, West J, Grainge MJ. "Risk of venous thromboembolism in patients with cancer: a systematic review and meta-analysis" *PloS Med* 2012; 9(7), e1001275.
- [3] Makaroff L, Young A, Serna C, Woodford E, Sharp L, Elalamy I, et al. *Supportive Care for People with Cancer*. Brussels: European Cancer Patient Coalition; 2018.
- [4] Monreal M, Knight E, Hernández M, Easaw J, Elalamy I, Young A, et al. *Cancer-associated thrombosis, a neglected cause of cancer death: Actions needed to increase health outcomes and reduce mortality*. Brussels: 2015.
- [5] Noble S, Prout H, Nelson A. Patients' Experiences of Living with Cancer-associated thrombosis: the PELICAN study. *Patient Prefer Adherence* 2015;9:337–45. doi:10.2147/PPA.S79373.
- [6] Noble S, Matzdorff A, Maraveyas A, Holm MV, Pisa G. Assessing patients' anticoagulation preferences for the treatment of cancer-associated thrombosis using conjoint methodology. *Haematologica* 2015;100:1486–92. doi:10.3324/haematol.2015.127126.
- [7] Cohen A, Katholing A, Rietbrock S, Bamber L, Martinez C. Epidemiology of first and recurrent venous thromboembolism in patients with active cancer. *Thrombosis and Haemostasis* 1/2017.

Appendices

Appendix A. Survey methodology

Questionnaire design and testing

It was agreed at the beginning of the project that the survey would be launched in the UK first, which would act as a pilot, in order to identify any issues early, and to ensure that the methodology was sound. Any issues arising following the launch of the UK pilot could then be discussed and elements of the project design adjusted as necessary.

The questionnaire design and testing included the following stages:

Initial design stages

- Initial months of the project were used to work with the European Cancer Patient Coalition (ECPC) and relevant other member organisations, to identify the most obvious themes around awareness of cancer-associated thrombosis to be tested through the survey – this involved face to face meetings, desk research and online consultation with stakeholders.
- The themes identified formed the focus of a questionnaire, which also included other contextual questions to collect the other data sets we need for analysis (demographic information, status of treatment, etc.).
- The draft set of questions was ordered in a way that follows the treatment pathway (diagnosis, testing, treatment, recovery, etc.).
- A final draft questionnaire was agreed, ready for testing.

Cognitive testing

- Cognitive Testing ensures that questions are properly understandable; that answer options are clear and comprehensive; and that the questions cover the most appropriate areas.
- We contacted around 10 potential volunteers who were identified through ECPC's member network.
- We were able to conduct the testing with 9 patients and ask them to complete the proposed questionnaire; one of Quality Health's consultants talked through each question with them (over the phone), to ensure that they had understood and answered sensibly, and that the questions would 'work'.
- The response to the questionnaire was overwhelmingly positive with only some minor amendments suggested.

Online set-up

- Once question and answer sets were agreed and approved, the questionnaire was set up on Quality Health's bespoke on-line survey system. We are very experienced at this, and know which elements of design will elicit the best response.
- The survey was set up using ECPC's branding and colour scheme.
- The 'landing page' on the on-line platform clearly explained the purpose of the survey, how it was being carried out, how individuals' details would be used, and the fact that the survey is anonymous.
- A "% complete" bar at the bottom of the screen to show progress in filling in the questionnaire was included.
- Only one or two questions per page were included, so that there was plenty of "white space" - as this makes it easier to understand what is being asked.
- There were clear section headings, with questions grouped together in a logical order.
- There was a mixture of types of answer options, so that respondents would avoid the temptation to give the same answer to every question.
- There was a clear signpost to Quality Health's helpline and email address, should respondents have any queries.

Questionnaire review and testing for other countries

- Following the launch of the UK Pilot – which remained open for completion as the other countries launched (see timelines below) – the questionnaire and accompanying introduction information was translated into: French, German, Greek, Italian and Spanish.
- Review and testing of the translations was then carried out through ECPC members and contacts within each of the countries taking part.
- The same questions were used in each country and there was no variation in the questions – ensuring that all questions were comparable for reporting and analysis purposes.

Online set-up and launch for other countries

- Following final agreement of each translated version, online set-up and testing was carried out.
- Test links were shared with relevant contacts to ensure that no errors had been introduced during the set-up period.

Paper copies of questionnaire

- In addition to online questionnaires, paper copies of the questionnaire were also produced - in French and English – and distributed to attendees at the ECPC Annual Congress in Brussels in June 2018. 30 were returned.

Dissemination plan

The dissemination of the survey was carried out through ECPC's membership network using social media; email newsletters; website posts; and through media work. The following activity list is not inclusive of all activity but gives an overview of the communications and dissemination which took place:

- Dissemination packages

Dissemination packages containing detailed information about the survey and suggestions on how to disseminate it, including visuals and accompanying texts in English, French, German, Greek, Italian and Spanish, were developed to support ECPC's members' ability to increase the outreach of the survey. The surveys and the dissemination packs were shared with the network of patient organisations and experts in ECPC membership and ECPC working groups.

- Email outreach

Tailored emails with the dissemination packages attached were sent digitally to 35 organisations in Greece, 5 organisations in France, 72 organizations in Italy, 8 organisations in Spain, and 15 organizations in Germany.

- Websites and newsletters

Dedicated webpages were created on ECPC's website and on Thrombosis UK's website, with direct links to the survey of each country in their respective languages.

Information about the survey and a link to it were also included in the newsletters of ECPC, of a number of member organisations at the national level, and of the European Organisation for Research and Treatment of Cancer (EORTC).

- Social Media activity

On Twitter, one paid campaign per language was created on the launch of the survey, while a further paid campaign was activated only for the countries where the respondents were lower at one month before the deadline. The targeting was obtained first via language and then refined through keywords ("cancer", "cancer support", and "thrombosis" translated in the different languages); and also via followers of the Ministers of Health and of the greatest cancer patient organisation in the given country. Where targeting via language was not allowed by the Social Network, e.g. Greek language, only the keywords and the look-alike followers refining was set up.

In addition to the targeted campaigns, several creative contents were posted on ECPC's Social Media Account in each of the surveyed languages, taking advantage of the organic reach allowed by the large audience offered by the ECPC Twitter account.

On Facebook, one paid campaign per language was created on the launch of the survey, targeting the audience first via language and then refining through keywords (“cancer”, “cancer support”, and “thrombosis” translated in the different languages).

A single visual referring to all the countries, and accompanied by a multi-language copy, was posted regularly on ECPC’s Facebook page with no targeting activated.

Timelines

The timelines for the survey were as follows:

Questionnaire development	December 2017 to February 2018
Questionnaire design and fieldwork	February to March 2018
Launch of fieldwork in UK	29 March 2018
Distribution of paper copies of questionnaires at ECPC Annual Congress in Brussels	8 – 10 June 2018
Launch of fieldwork in France, Germany, Greece, Italy, Spain	7 June 2018
Close of fieldwork in Greece, Spain, UK	10 August 2018
Close of fieldwork in France, Italy	17 August 2018
Close of fieldwork in Germany	24 August 2018
Results launch and publication	World Thrombosis Day, 13 October 2018

Appendix B. Detailed results tables



Quality
Health

ECPC Cancer-Associated Thrombosis Awareness Survey

Final Table of Detailed Results - All Countries

Produced October 2018
by Quality Health

Survey Results

This report sets out the results from the ECPC Cancer-Associated Thrombosis Awareness Survey, ordered in exactly the same way as in the survey questionnaire provided to patients.

This report has been produced using the final dataset extracted from the Quality Health database on 21st August 2018. This report covers the data for all countries (France, Germany, Greece, Italy, Spain & UK) combined.

Reading the columns of figures

The results are shown firstly in absolute numbers, then as percentage responses.

Conventions

The percentages are calculated after excluding those patients that did not answer that particular question. All percentages are rounded to the nearest whole number. When added together, the percentages for all answers to a particular question may not total 100% because of this rounding.

The number of patients that did not answer a particular question is shown as the 'missing' figure at the bottom of the actual number of responses.

On some questions there are figures which are italicised. These figures have been recalculated to exclude responses where the question was not applicable to the respondent's circumstances. For example, question 22 regarding awareness of the side effects of blood thinners where those not answering ("Missing") and those answering "Don't know/can't remember" or "Not applicable" have been excluded.

Respondent Details

1. Are you currently resident in [country as applicable]?	All Countries	
	Respondents	%
Yes	1,274	93%
No	91	7%
Missing	0	

3. Are you filling in this questionnaire on behalf of somebody else?	All Countries	
	Respondents	%
Yes	313	24%
No	966	76%
Missing	86	

Your General Awareness

4. Have you ever suffered from thrombosis (a blood clot) associated with your cancer?	All Countries	
	Respondents	%
* Yes	299	24%
* No	941	76%
Don't know / can't remember	97	7%
Missing	28	

5. Before taking part in this survey, were you aware that people with cancer have a higher than normal risk of developing thrombosis (a blood clot)?	All Countries	
	Respondents	%
Yes	376	28%
No	957	72%
Missing	32	

Your Understanding of the Risks

6. All people with cancer have a higher than normal risk of thrombosis. But certain cancers have a higher risk than others (including cancers of the stomach, brain, kidney and ovaries). To what extent are you aware of these risks?	All Countries	
	Respondents	%
* <i>Completely</i>	53	15%
* <i>To some extent</i>	232	64%
* <i>Not at all</i>	79	22%
Don't know / can't remember	10	3%
Missing	991	

7. Did you know that the risk of thrombosis increases for people with cancer at an advanced stage?	All Countries	
	Respondents	%
* <i>Yes, completely</i>	80	22%
* <i>Yes, to some extent</i>	135	37%
* <i>No, not at all</i>	150	41%
Don't know / can't remember	9	2%
Missing	991	

8. Did you know that cancer surgery can increase the risk of thrombosis?	All Countries	
	Respondents	%
* <i>Yes, completely</i>	127	35%
* <i>Yes, to some extent</i>	113	31%
* <i>No, not at all</i>	127	35%
Don't know / can't remember	6	2%
Missing	992	

Your Understanding of the Risks (continued)

9. Did you know that chemotherapy can increase the risk of thrombosis?	All Countries	
	Respondents	%
* Yes, completely	119	33%
* Yes, to some extent	135	37%
* No, not at all	111	30%
Don't know / can't remember	9	2%
Missing	991	

10. Did you know that radiotherapy can increase the risk of thrombosis?	All Countries	
	Respondents	%
* Yes, completely	61	17%
* Yes, to some extent	103	29%
* No, not at all	194	54%
Don't know / can't remember	16	4%
Missing	991	

11. Did you know that having a central venous catheter (a central line) can increase the risk of thrombosis?	All Countries	
	Respondents	%
* Yes, completely	83	23%
* Yes, to some extent	100	27%
* No, not at all	181	50%
Don't know / can't remember	10	3%
Missing	991	

Your Understanding of the Risks (continued)

12. Did you know that you are more likely to suffer from thrombosis if you are inactive for long periods of time (e.g. if you are in bed for 4 days or more)?	All Countries	
	Respondents	%
* <i>Yes, completely</i>	240	65%
* <i>Yes, to some extent</i>	93	25%
* <i>No, not at all</i>	39	10%
Don't know / can't remember	2	1%
Missing	991	

13. Did you know that you are more likely to suffer from thrombosis if you have had them before?	All Countries	
	Respondents	%
* <i>Yes, completely</i>	170	46%
* <i>Yes, to some extent</i>	119	32%
* <i>No, not at all</i>	79	21%
Don't know / can't remember	5	1%
Missing	992	

Your Understanding of What to Look Out For

14. Are you aware that the following can be signs of a blood clot in the arm / leg (Deep Vein Thrombosis (DVT))?	All Countries	
	Respondents	%
Swelling in the foot, ankle or leg	270	73%
Missing	102	
Pain, cramping or tenderness, often in the calf	212	57%
Missing	162	
Redness or noticeable discoloration of the leg or arm	229	61%
Missing	145	
A warm or heavy sensation in the leg	213	57%
Missing	159	

15. Are you aware that the following can be signs of a blood clot in the lung (Pulmonary Embolism (PE))?	All Countries	
	Respondents	%
Light-headedness / dizziness	128	34%
Missing	245	
Unexplained shortness of breath	263	71%
Missing	110	
Irregular heartbeat	123	33%
Missing	249	
Chest pain (especially when breathing deeply)	229	61%
Missing	144	
Coughing up blood	140	38%
Missing	233	

Diagnosis of Cancer-Associated Thrombosis

16. Did you know that the following tests can be used to diagnose thrombosis?	All Countries	
	Respondents	%
An ultrasound scan	225	60%
Missing	148	
A CT scan	207	55%
Missing	166	

Preventing your risk of cancer-associated thrombosis

17. Are you aware that the following can reduce your risk of thrombosis?	All Countries	
	Respondents	%
Stretching your legs	207	55%
Missing	166	
Moving your feet	244	65%
Missing	130	
Taking a walk	325	87%
Missing	50	
Stopping smoking	282	75%
Missing	92	
Keeping hydrated	239	64%
Missing	136	
Wearing compression socks / stockings if these are prescribed	279	74%
Missing	96	

Treating cancer-associated thrombosis

18. Did you know that thrombosis can be treated effectively using medicines known as anticoagulants (often referred to as “blood thinners”)?	All Countries	
	Respondents	%
* Yes, completely	272	70%
* Yes, to some extent	99	26%
* No, not at all	15	4%
Don't know / can't remember	1	0%
Missing	978	

19. Are you currently using anticoagulants / blood thinners?	All Countries	
	Respondents	%
Yes	141	37%
No	244	63%
Missing	980	

20. Are you using these...	All Countries	
	Respondents	%
As a treatment for an existing condition	82	60%
To reduce the risk of thrombosis in the future	43	31%
For another reason	12	9%
Missing	1,228	

21. How do you receive this treatment?	All Countries	
	Respondents	%
Medicines given orally	84	60%
Medicines given by injection	56	40%
Missing	1,225	

Treating cancer-associated thrombosis (continued)

22. Have you been told about any possible side effects of anticoagulants / blood thinners?	All Countries	
	Respondents	%
* Yes	136	41%
* No	193	59%
Don't know / can't remember	41	10%
Not applicable	53	13%
Missing	942	

24. Have you been told what to do if you are affected by any of these possible side effects of anticoagulants / blood thinners?	All Countries	
	Respondents	%
* Yes - to speak to my doctor or nurse	62	48%
* Yes - to contact emergency services	51	39%
* Yes - other	5	4%
* No	12	9%
Don't know / can't remember	4	3%
Not applicable	4	3%
Missing	1,227	

25. Have you suffered from any of these possible side-effects of your anticoagulants / blood thinners?	All Countries	
	Respondents	%
* Yes	27	22%
* No	95	78%
Don't know / can't remember	5	4%
Not applicable	11	8%
Missing	1,227	

How do you know about cancer-associated thrombosis

27a. From which of the following did you get information about cancer-associated thrombosis? From my GP	All Countries	
	Respondents	%
Verbally	73	5%
Missing	1,292	
On paper	6	0%
Missing	1,359	
By email	0	0%
Missing	1,365	
Online	5	0%
Missing	1,360	
Social media	3	0%
Missing	1,362	

27b. From which of the following did you get information about cancer-associated thrombosis? From a hospital doctor	All Countries	
	Respondents	%
Verbally	163	12%
Missing	1,202	
On paper	14	1%
Missing	1,351	
By email	2	0%
Missing	1,363	
Online	2	0%
Missing	1,363	
Social media	0	0%
Missing	1,365	

How do you know about cancer-associated thrombosis (continued)

27c. From which of the following did you get information about cancer-associated thrombosis? From my chemotherapy nurse	All Countries	
	Respondents	%
Verbally	57	4%
Missing	1,308	
On paper	10	1%
Missing	1,355	
By email	0	0%
Missing	1,365	
Online	2	0%
Missing	1,363	
Social media	0	0%
Missing	1,365	

27d. From which of the following did you get information about cancer-associated thrombosis? From my radiologist	All Countries	
	Respondents	%
Verbally	29	2%
Missing	1,336	
On paper	8	1%
Missing	1,357	
By email	0	0%
Missing	1,365	
Online	2	0%
Missing	1,363	
Social media	0	0%
Missing	1,365	

How do you know about cancer-associated thrombosis (continued)

27e. From which of the following did you get information about cancer-associated thrombosis? From a specialist cancer nurse	All Countries	
	Respondents	%
Verbally	57	4%
Missing	1,308	
On paper	11	1%
Missing	1,354	
By email	0	0%
Missing	1,365	
Online	2	0%
Missing	1,363	
Social media	0	0%
Missing	1,365	

27f. From which of the following did you get information about cancer-associated thrombosis? From another hospital nurse	All Countries	
	Respondents	%
Verbally	23	2%
Missing	1,342	
On paper	4	0%
Missing	1,361	
By email	0	0%
Missing	1,365	
Online	2	0%
Missing	1,363	
Social media	0	0%
Missing	1,365	

How do you know about cancer-associated thrombosis (continued)

27g. From which of the following did you get information about cancer-associated thrombosis? Through educational materials provided by a patient organisation	All Countries	
	Respondents	%
Verbally	15	1%
Missing	1,350	
On paper	24	2%
Missing	1,341	
By email	3	0%
Missing	1,362	
Online	10	1%
Missing	1,355	
Social media	4	0%
Missing	1,361	

27h. From which of the following did you get information about cancer-associated thrombosis? Through my own research	All Countries	
	Respondents	%
Verbally	31	2%
Missing	1,334	
On paper	10	1%
Missing	1,355	
By email	1	0%
Missing	1,364	
Online	81	6%
Missing	1,284	
Social media	11	1%
Missing	1,354	

How do you know about cancer-associated thrombosis (continued)

27i. From which of the following did you get information about cancer-associated thrombosis? From my family or friends	All Countries	
	Respondents	%
Verbally	48	4%
Missing	1,317	
On paper	1	0%
Missing	1,364	
By email	0	0%
Missing	1,365	
Online	8	1%
Missing	1,357	
Social media	3	0%
Missing	1,362	

28. When did you first become aware of cancer-associated thrombosis?	All Countries	
	Respondents	%
* I already knew about it before I was diagnosed with cancer	58	19%
* I became aware of it when I suffered a blood clot	78	26%
* I was given information during my cancer diagnosis	47	16%
* I was given information before surgery	29	10%
* I was given information following surgery	34	11%
* I was given information before / during chemotherapy	48	16%
* I was given information before / during radiotherapy	6	2%
Don't know / can't remember	38	9%
Other	73	18%
Missing	954	

Overall awareness

29. How would you rate your overall understanding of cancer-associated thrombosis on a scale of 1 (low) to 10 (high)?	All Countries	
	Respondents	%
Rank 1	357	27%
Rank 2	137	10%
Rank 3	143	11%
Rank 4	93	7%
Rank 5	206	16%
Rank 6	104	8%
Rank 7	93	7%
Rank 8	97	7%
Rank 9	38	3%
Rank 10	53	4%
Missing	44	

About your condition

33. What type of cancer were you first diagnosed with?	All Countries	
	Respondents	%
Brain / Central Nervous System	10	1%
Breast	598	46%
Colorectal / Bowel	99	8%
Ovarian	47	4%
Other gynaecological	63	5%
Haematological	85	7%
Head and neck	19	1%
Lung	78	6%
Sarcoma	15	1%
Skin	29	2%
Oesophageal, Stomach, Pancreatic, Liver, or Gall bladder	55	4%
Bladder	40	3%
Prostate	33	3%
Other urological	13	1%
Other	118	9%
Missing	63	

34. How long is it since you were first treated for this cancer?	All Countries	
	Respondents	%
Less than 1 year	313	24%
1 to 5 years	497	38%
More than 5 years	425	33%
My cancer treatment hasn't yet started	30	2%
I will not receive any treatment for my cancer	32	2%
Don't know / can't remember	6	0%
Missing	62	

About you

35. Age Band (derived from "In what year were you born?")	All Countries	
	Respondents	%
Under 16	3	0%
16-24	3	0%
25-34	13	1%
35-44	62	5%
45-54	188	16%
55-64	488	42%
65-74	291	25%
75-84	73	6%
85+	13	1%
Out of Range	37	3%
Missing	194	

36. What is your gender?	All Countries	
	Respondents	%
Male	220	16%
Female	1,019	75%
Prefer not to say	8	1%
Other	1	0%
Missing	117	9%

About you (continued)

37. Do you have any of the following longstanding conditions?	All Countries	
	Respondents	%
Deafness or severe hearing impairment	78	6%
Missing	1,287	
Blindness or partially sighted	29	2%
Missing	1,336	
A long-standing physical condition	150	11%
Missing	1,215	
A learning disability	12	1%
Missing	1,353	
A mental health condition	52	4%
Missing	1,313	
A long-standing illness, such as HIV, diabetes, chronic heart disease, or epilepsy	139	10%
Missing	1,226	

About you (continued)

38. Where did you hear about this survey?	All Countries	
	Respondents	%
I saw a link to it online	926	68%
From family / friends	25	2%
From a patient organisation who keep in touch with me	194	14%
From a healthcare professional	8	1%
Other	88	6%
Missing	124	9%



Quality
Health

ECPC Cancer-Associated Thrombosis Awareness Survey

Final Table of Detailed Results - Germany

Produced October 2018
by Quality Health

Survey Results

This report sets out the results from the ECPC Cancer-Associated Thrombosis Awareness Survey, ordered in exactly the same way as in the survey questionnaire provided to patients.

This report has been produced using the final dataset extracted from the Quality Health database on 21st August 2018. This report shows the data for Germany against a comparator for all countries (France, Germany, Greece, Italy, Spain & UK).

Reading the columns of figures

The results are shown firstly in absolute numbers, then as percentage responses.

Conventions

The percentages are calculated after excluding those patients that did not answer that particular question. All percentages are rounded to the nearest whole number. When added together, the percentages for all answers to a particular question may not total 100% because of this rounding.

The number of patients that did not answer a particular question is shown as the 'missing' figure at the bottom of the actual number of responses.

On some questions there are figures which are italicised. These figures have been recalculated to exclude responses where the question was not applicable to the respondent's circumstances. For example, question 22 regarding awareness of the side effects of blood thinners where those not answering ("Missing") and those answering "Don't know/can't remember" or "Not applicable" have been excluded.

Respondent Details

1. Are you currently resident in Germany?	Germany Only		All Countries	
	#	%	#	%
Yes	166	95%	1,274	93%
No	9	5%	91	7%
Missing	0		0	

3. Are you filling in this questionnaire on behalf of somebody else?	Germany Only		All Countries	
	#	%	#	%
Yes	159	95%	313	24%
No	9	5%	966	76%
Missing	7		86	

Your General Awareness

4. Have you ever suffered from thrombosis (a blood clot) associated with your cancer?	Germany Only		All Countries	
	#	%	#	%
* Yes	50	30%	299	24%
* No	114	70%	941	76%
Don't know / can't remember	9	5%	97	7%
Missing	2		28	

5. Before taking part in this survey, were you aware that people with cancer have a higher than normal risk of developing thrombosis (a blood clot)?	Germany Only		All Countries	
	#	%	#	%
Yes	36	21%	376	28%
No	137	79%	957	72%
Missing	2		32	

Your Understanding of the Risks

6. All people with cancer have a higher than normal risk of thrombosis. But certain cancers have a higher risk than others (including cancers of the stomach, brain, kidney and ovaries). To what extent are you aware of these risks?	Germany Only		All Countries	
	#	%	#	%
* <i>Completely</i>	12	33%	53	15%
* <i>To some extent</i>	16	44%	232	64%
* <i>Not at all</i>	8	22%	79	22%
Don't know / can't remember	0	0%	10	3%
Missing	139		991	

7. Did you know that the risk of thrombosis increases for people with cancer at an advanced stage?	Germany Only		All Countries	
	#	%	#	%
* <i>Yes, completely</i>	13	36%	80	22%
* <i>Yes, to some extent</i>	9	25%	135	37%
* <i>No, not at all</i>	14	39%	150	41%
Don't know / can't remember	0	0%	9	2%
Missing	139		991	

8. Did you know that cancer surgery can increase the risk of thrombosis?	Germany Only		All Countries	
	#	%	#	%
* <i>Yes, completely</i>	21	58%	127	35%
* <i>Yes, to some extent</i>	3	8%	113	31%
* <i>No, not at all</i>	12	33%	127	35%
Don't know / can't remember	0	0%	6	2%
Missing	139		992	

Your Understanding of the Risks (continued)

9. Did you know that chemotherapy can increase the risk of thrombosis?	Germany Only		All Countries	
	#	%	#	%
* Yes, completely	19	53%	119	33%
* Yes, to some extent	4	11%	135	37%
* No, not at all	13	36%	111	30%
Don't know / can't remember	0	0%	9	2%
Missing	139		991	

10. Did you know that radiotherapy can increase the risk of thrombosis?	Germany Only		All Countries	
	#	%	#	%
* Yes, completely	12	33%	61	17%
* Yes, to some extent	5	14%	103	29%
* No, not at all	19	53%	194	54%
Don't know / can't remember	0	0%	16	4%
Missing	139		991	

11. Did you know that having a central venous catheter (a central line) can increase the risk of thrombosis?	Germany Only		All Countries	
	#	%	#	%
* Yes, completely	11	31%	83	23%
* Yes, to some extent	9	25%	100	27%
* No, not at all	16	44%	181	50%
Don't know / can't remember	0	0%	10	3%
Missing	139		991	

Your Understanding of the Risks (continued)

12. Did you know that you are more likely to suffer from thrombosis if you are inactive for long periods of time (e.g. if you are in bed for 4 days or more)?	Germany Only		All Countries	
	#	%	#	%
* <i>Yes, completely</i>	32	89%	240	65%
* <i>Yes, to some extent</i>	2	6%	93	25%
* <i>No, not at all</i>	2	6%	39	10%
Don't know / can't remember	0	0%	2	1%
Missing	139		991	

13. Did you know that you are more likely to suffer from thrombosis if you have had them before?	Germany Only		All Countries	
	#	%	#	%
* <i>Yes, completely</i>	24	67%	170	46%
* <i>Yes, to some extent</i>	4	11%	119	32%
* <i>No, not at all</i>	8	22%	79	21%
Don't know / can't remember	0	0%	5	1%
Missing	139		992	

Your Understanding of What to Look Out For

14. Are you aware that the following can be signs of a blood clot in the arm / leg (Deep Vein Thrombosis (DVT))?	Germany Only		All Countries	
	#	%	#	%
Swelling in the foot, ankle or leg	22	69%	270	73%
Missing	10		102	
Pain, cramping or tenderness, often in the calf	22	65%	212	57%
Missing	12		162	
Redness or noticeable discoloration of the leg or arm	27	79%	229	61%
Missing	7		145	
A warm or heavy sensation in the leg	19	59%	213	57%
Missing	13		159	

15. Are you aware that the following can be signs of a blood clot in the lung (Pulmonary Embolism (PE))?	Germany Only		All Countries	
	#	%	#	%
Light-headedness / dizziness	17	52%	128	34%
Missing	16		245	
Unexplained shortness of breath	30	91%	263	71%
Missing	3		110	
Irregular heartbeat	15	47%	123	33%
Missing	17		249	
Chest pain (especially when breathing deeply)	24	73%	229	61%
Missing	9		144	
Coughing up blood	11	33%	140	38%
Missing	22		233	

Diagnosis of Cancer-Associated Thrombosis

16. Did you know that the following tests can be used to diagnose thrombosis?	Germany Only		All Countries	
	#	%	#	%
An ultrasound scan	26	79%	225	60%
Missing	7		148	
A CT scan	18	55%	207	55%
Missing	15		166	

Preventing your risk of cancer-associated thrombosis

17. Are you aware that the following can reduce your risk of thrombosis?	Germany Only		All Countries	
	#	%	#	%
Stretching your legs	22	67%	207	55%
Missing	11		166	
Moving your feet	27	79%	244	65%
Missing	7		130	
Taking a walk	33	94%	325	87%
Missing	2		50	
Stopping smoking	33	97%	282	75%
Missing	1		92	
Keeping hydrated	32	91%	239	64%
Missing	3		136	
Wearing compression socks / stockings if these are prescribed	33	94%	279	74%
Missing	2		96	

Treating cancer-associated thrombosis

18. Did you know that thrombosis can be treated effectively using medicines known as anticoagulants (often referred to as “blood thinners”)?	Germany Only		All Countries	
	#	%	#	%
* Yes, completely	29	81%	272	70%
* Yes, to some extent	5	14%	99	26%
* No, not at all	2	6%	15	4%
Don't know / can't remember	0	0%	1	0%
Missing	139		978	

19. Are you currently using anticoagulants / blood thinners?	Germany Only		All Countries	
	#	%	#	%
Yes	17	47%	141	37%
No	19	53%	244	63%
Missing	139		980	

20. Are you using these...	Germany Only		All Countries	
	#	%	#	%
As a treatment for an existing condition	5	29%	82	60%
To reduce the risk of thrombosis in the future	10	59%	43	31%
For another reason	2	12%	12	9%
Missing	158		1,228	

21. How do you receive this treatment?	Germany Only		All Countries	
	#	%	#	%
Medicines given orally	13	76%	84	60%
Medicines given by injection	4	24%	56	40%
Missing	158		1,225	

Treating cancer-associated thrombosis (continued)

22. Have you been told about any possible side effects of anticoagulants / blood thinners?	Germany Only		All Countries	
	#	%	#	%
* Yes	11	34%	136	41%
* No	21	66%	193	59%
Don't know / can't remember	1	3%	41	10%
Not applicable	2	6%	53	13%
Missing	140		942	

24. Have you been told what to do if you are affected by any of these possible side effects of anticoagulants / blood thinners?	Germany Only		All Countries	
	#	%	#	%
* Yes - to speak to my doctor or nurse	6	67%	62	48%
* Yes - to contact emergency services	1	11%	51	39%
* Yes - other	1	11%	5	4%
* No	1	11%	12	9%
Don't know / can't remember	1	9%	4	3%
Not applicable	1	9%	4	3%
Missing	164		1,227	

25. Have you suffered from any of these possible side-effects of your anticoagulants / blood thinners?	Germany Only		All Countries	
	#	%	#	%
* Yes	6	55%	27	22%
* No	5	45%	95	78%
Don't know / can't remember	0	0%	5	4%
Not applicable	0	0%	11	8%
Missing	164		1,227	

How do you know about cancer-associated thrombosis

27a. From which of the following did you get information about cancer-associated thrombosis? From my GP	Germany Only		All Countries	
	#	%	#	%
Verbally	9	5%	73	5%
Missing	166		1,292	
On paper	0	0%	6	0%
Missing	175		1,359	
By email	0	0%	0	0%
Missing	175		1,365	
Online	0	0%	5	0%
Missing	175		1,360	
Social media	1	1%	3	0%
Missing	174		1,362	

27b. From which of the following did you get information about cancer-associated thrombosis? From a hospital doctor	Germany Only		All Countries	
	#	%	#	%
Verbally	18	10%	163	12%
Missing	157		1,202	
On paper	3	2%	14	1%
Missing	172		1,351	
By email	0	0%	2	0%
Missing	175		1,363	
Online	0	0%	2	0%
Missing	175		1,363	
Social media	0	0%	0	0%
Missing	175		1,365	

How do you know about cancer-associated thrombosis (continued)

27c. From which of the following did you get information about cancer-associated thrombosis? From my chemotherapy nurse	Germany Only		All Countries	
	#	%	#	%
Verbally	3	2%	57	4%
Missing	172		1,308	
On paper	1	1%	10	1%
Missing	174		1,355	
By email	0	0%	0	0%
Missing	175		1,365	
Online	0	0%	2	0%
Missing	175		1,363	
Social media	0	0%	0	0%
Missing	175		1,365	

27d. From which of the following did you get information about cancer-associated thrombosis? From my radiologist	Germany Only		All Countries	
	#	%	#	%
Verbally	7	4%	29	2%
Missing	168		1,336	
On paper	1	1%	8	1%
Missing	174		1,357	
By email	0	0%	0	0%
Missing	175		1,365	
Online	0	0%	2	0%
Missing	175		1,363	
Social media	0	0%	0	0%
Missing	175		1,365	

How do you know about cancer-associated thrombosis (continued)

27e. From which of the following did you get information about cancer-associated thrombosis? From a specialist cancer nurse	Germany Only		All Countries	
	#	%	#	%
Verbally	3	2%	57	4%
Missing	172		1,308	
On paper	1	1%	11	1%
Missing	174		1,354	
By email	0	0%	0	0%
Missing	175		1,365	
Online	0	0%	2	0%
Missing	175		1,363	
Social media	0	0%	0	0%
Missing	175		1,365	

27f. From which of the following did you get information about cancer-associated thrombosis? From another hospital nurse	Germany Only		All Countries	
	#	%	#	%
Verbally	1	1%	23	2%
Missing	174		1,342	
On paper	1	1%	4	0%
Missing	174		1,361	
By email	0	0%	0	0%
Missing	175		1,365	
Online	0	0%	2	0%
Missing	175		1,363	
Social media	0	0%	0	0%
Missing	175		1,365	

How do you know about cancer-associated thrombosis (continued)

27g. From which of the following did you get information about cancer-associated thrombosis? Through educational materials provided by a patient organisation	Germany Only		All Countries	
	#	%	#	%
Verbally	0	0%	15	1%
Missing	175		1,350	
On paper	2	1%	24	2%
Missing	173		1,341	
By email	0	0%	3	0%
Missing	175		1,362	
Online	0	0%	10	1%
Missing	175		1,355	
Social media	0	0%	4	0%
Missing	175		1,361	

27h. From which of the following did you get information about cancer-associated thrombosis? Through my own research	Germany Only		All Countries	
	#	%	#	%
Verbally	2	1%	31	2%
Missing	173		1,334	
On paper	2	1%	10	1%
Missing	173		1,355	
By email	0	0%	1	0%
Missing	175		1,364	
Online	6	3%	81	6%
Missing	169		1,284	
Social media	1	1%	11	1%
Missing	174		1,354	

How do you know about cancer-associated thrombosis (continued)

27i. From which of the following did you get information about cancer-associated thrombosis? From my family or friends	Germany Only		All Countries	
	#	%	#	%
Verbally	4	2%	48	4%
Missing	171		1,317	
On paper	1	1%	1	0%
Missing	174		1,364	
By email	0	0%	0	0%
Missing	175		1,365	
Online	0	0%	8	1%
Missing	175		1,357	
Social media	0	0%	3	0%
Missing	175		1,362	

28. When did you first become aware of cancer-associated thrombosis?	Germany Only		All Countries	
	#	%	#	%
* I already knew about it before I was diagnosed with cancer	8	24%	58	19%
* I became aware of it when I suffered a blood clot	7	21%	78	26%
* I was given information during my cancer diagnosis	7	21%	47	16%
* I was given information before surgery	4	12%	29	10%
* I was given information following surgery	3	9%	34	11%
* I was given information before / during chemotherapy	4	12%	48	16%
* I was given information before / during radiotherapy	0	0%	6	2%
Don't know / can't remember	0	0%	38	9%
Other	3	8%	73	18%
Missing	139		954	

Overall awareness

29. How would you rate your overall understanding of cancer-associated thrombosis on a scale of 1 (low) to 10 (high)?	Germany Only		All Countries	
	#	%	#	%
Rank 1	33	19%	357	27%
Rank 2	18	10%	137	10%
Rank 3	25	15%	143	11%
Rank 4	6	3%	93	7%
Rank 5	31	18%	206	16%
Rank 6	19	11%	104	8%
Rank 7	12	7%	93	7%
Rank 8	12	7%	97	7%
Rank 9	5	3%	38	3%
Rank 10	11	6%	53	4%
Missing	3		44	

About your condition

33. What type of cancer were you first diagnosed with?	Germany Only		All Countries	
	#	%	#	%
Brain / Central Nervous System	1	1%	10	1%
Breast	80	47%	598	46%
Colorectal / Bowel	8	5%	99	8%
Ovarian	6	4%	47	4%
Other gynaecological	10	6%	63	5%
Haematological	0	0%	85	7%
Head and neck	2	1%	19	1%
Lung	12	7%	78	6%
Sarcoma	0	0%	15	1%
Skin	18	11%	29	2%
Oesophageal, Stomach, Pancreatic, Liver, or Gall bladder	7	4%	55	4%
Bladder	2	1%	40	3%
Prostate	5	3%	33	3%
Other urological	2	1%	13	1%
Other	17	10%	118	9%
Missing	5		63	

34. How long is it since you were first treated for this cancer?	Germany Only		All Countries	
	#	%	#	%
Less than 1 year	43	25%	313	24%
1 to 5 years	61	35%	497	38%
More than 5 years	60	35%	425	33%
My cancer treatment hasn't yet started	3	2%	30	2%
I will not receive any treatment for my cancer	3	2%	32	2%
Don't know / can't remember	2	1%	6	0%
Missing	3		62	

About you

35. Age Band (derived from "In what year were you born?")	Germany Only		All Countries	
	#	%	#	%
Under 16	0	0%	3	0%
16-24	0	0%	3	0%
25-34	4	3%	13	1%
35-44	6	4%	62	5%
45-54	9	6%	188	16%
55-64	73	50%	488	42%
65-74	40	27%	291	25%
75-84	8	5%	73	6%
85+	1	1%	13	1%
Out of Range	5	3%	37	3%
Missing	29		194	

36. What is your gender?	Germany Only		All Countries	
	#	%	#	%
Male	18	10%	220	16%
Female	143	82%	1,019	75%
Prefer not to say	0	0%	8	1%
Other	0	0%	1	0%
Missing	14	8%	117	9%

About you (continued)

37. Do you have any of the following longstanding conditions?	Germany Only		All Countries	
	#	%	#	%
Deafness or severe hearing impairment	11	6%	78	6%
Missing	164		1,287	
Blindness or partially sighted	9	5%	29	2%
Missing	166		1,336	
A long-standing physical condition	16	9%	150	11%
Missing	159		1,215	
A learning disability	0	0%	12	1%
Missing	175		1,353	
A mental health condition	14	8%	52	4%
Missing	161		1,313	
A long-standing illness, such as HIV, diabetes, chronic heart disease, or epilepsy	20	11%	139	10%
Missing	155		1,226	

About you (continued)

38. Where did you hear about this survey?	Germany Only		All Countries	
	#	%	#	%
I saw a link to it online	132	75%	926	68%
From family / friends	4	2%	25	2%
From a patient organisation who keep in touch with me	9	5%	194	14%
From a healthcare professional	0	0%	8	1%
Other	13	7%	88	6%
Missing	17	10%	124	9%



Quality
Health

ECPC Cancer-Associated Thrombosis Awareness Survey

Final Table of Detailed Results - Greece

Produced October 2018
by Quality Health

Survey Results

This report sets out the results from the ECPC Cancer-Associated Thrombosis Awareness Survey, ordered in exactly the same way as in the survey questionnaire provided to patients.

This report has been produced using the final dataset extracted from the Quality Health database on 21st August 2018. This report shows the data for Greece against a comparator for all countries (France, Germany, Greece, Italy, Spain & UK).

Reading the columns of figures

The results are shown firstly in absolute numbers, then as percentage responses.

Conventions

The percentages are calculated after excluding those patients that did not answer that particular question. All percentages are rounded to the nearest whole number. When added together, the percentages for all answers to a particular question may not total 100% because of this rounding.

The number of patients that did not answer a particular question is shown as the 'missing' figure at the bottom of the actual number of responses.

On some questions there are figures which are italicised. These figures have been recalculated to exclude responses where the question was not applicable to the respondent's circumstances. For example, question 22 regarding awareness of the side effects of blood thinners where those not answering ("Missing") and those answering "Don't know/can't remember" or "Not applicable" have been excluded.

Respondent Details

1. Are you currently resident in Greece?	Greece Only		All Countries	
	#	%	#	%
Yes	261	98%	1,274	93%
No	6	2%	91	7%
Missing	0		0	

3. Are you filling in this questionnaire on behalf of somebody else?	Greece Only		All Countries	
	#	%	#	%
Yes	49	19%	313	24%
No	207	81%	966	76%
Missing	11		86	

Your General Awareness

4. Have you ever suffered from thrombosis (a blood clot) associated with your cancer?	Greece Only		All Countries	
	#	%	#	%
* Yes	37	16%	299	24%
* No	193	84%	941	76%
Don't know / can't remember	35	13%	97	7%
Missing	2		28	

5. Before taking part in this survey, were you aware that people with cancer have a higher than normal risk of developing thrombosis (a blood clot)?	Greece Only		All Countries	
	#	%	#	%
Yes	76	29%	376	28%
No	190	71%	957	72%
Missing	1		32	

Your Understanding of the Risks

6. All people with cancer have a higher than normal risk of thrombosis. But certain cancers have a higher risk than others (including cancers of the stomach, brain, kidney and ovaries). To what extent are you aware of these risks?	Greece Only		All Countries	
	#	%	#	%
* <i>Completely</i>	10	14%	53	15%
* <i>To some extent</i>	43	58%	232	64%
* <i>Not at all</i>	21	28%	79	22%
Don't know / can't remember	1	1%	10	3%
Missing	192		991	

7. Did you know that the risk of thrombosis increases for people with cancer at an advanced stage?	Greece Only		All Countries	
	#	%	#	%
* <i>Yes, completely</i>	15	21%	80	22%
* <i>Yes, to some extent</i>	32	44%	135	37%
* <i>No, not at all</i>	25	35%	150	41%
Don't know / can't remember	3	4%	9	2%
Missing	192		991	

8. Did you know that cancer surgery can increase the risk of thrombosis?	Greece Only		All Countries	
	#	%	#	%
* <i>Yes, completely</i>	17	24%	127	35%
* <i>Yes, to some extent</i>	31	43%	113	31%
* <i>No, not at all</i>	24	33%	127	35%
Don't know / can't remember	3	4%	6	2%
Missing	192		992	

Your Understanding of the Risks (continued)

9. Did you know that chemotherapy can increase the risk of thrombosis?	Greece Only		All Countries	
	#	%	#	%
* Yes, completely	18	26%	119	33%
* Yes, to some extent	27	39%	135	37%
* No, not at all	25	36%	111	30%
Don't know / can't remember	5	7%	9	2%
Missing	192		991	

10. Did you know that radiotherapy can increase the risk of thrombosis?	Greece Only		All Countries	
	#	%	#	%
* Yes, completely	9	13%	61	17%
* Yes, to some extent	21	31%	103	29%
* No, not at all	37	55%	194	54%
Don't know / can't remember	8	11%	16	4%
Missing	192		991	

11. Did you know that having a central venous catheter (a central line) can increase the risk of thrombosis?	Greece Only		All Countries	
	#	%	#	%
* Yes, completely	11	16%	83	23%
* Yes, to some extent	23	33%	100	27%
* No, not at all	35	51%	181	50%
Don't know / can't remember	6	8%	10	3%
Missing	192		991	

Your Understanding of the Risks (continued)

12. Did you know that you are more likely to suffer from thrombosis if you are inactive for long periods of time (e.g. if you are in bed for 4 days or more)?	Greece Only		All Countries	
	#	%	#	%
* <i>Yes, completely</i>	35	47%	240	65%
* <i>Yes, to some extent</i>	24	32%	93	25%
* <i>No, not at all</i>	15	20%	39	10%
Don't know / can't remember	1	1%	2	1%
Missing	192		991	

13. Did you know that you are more likely to suffer from thrombosis if you have had them before?	Greece Only		All Countries	
	#	%	#	%
* <i>Yes, completely</i>	32	44%	170	46%
* <i>Yes, to some extent</i>	22	30%	119	32%
* <i>No, not at all</i>	19	26%	79	21%
Don't know / can't remember	2	3%	5	1%
Missing	192		992	

Your Understanding of What to Look Out For

14. Are you aware that the following can be signs of a blood clot in the arm / leg (Deep Vein Thrombosis (DVT))?	Greece Only		All Countries	
	#	%	#	%
Swelling in the foot, ankle or leg	51	67%	270	73%
Missing	25		102	
Pain, cramping or tenderness, often in the calf	31	41%	212	57%
Missing	45		162	
Redness or noticeable discoloration of the leg or arm	41	54%	229	61%
Missing	35		145	
A warm or heavy sensation in the leg	36	47%	213	57%
Missing	40		159	

15. Are you aware that the following can be signs of a blood clot in the lung (Pulmonary Embolism (PE))?	Greece Only		All Countries	
	#	%	#	%
Light-headedness / dizziness	16	21%	128	34%
Missing	60		245	
Unexplained shortness of breath	47	62%	263	71%
Missing	29		110	
Irregular heartbeat	24	32%	123	33%
Missing	52		249	
Chest pain (especially when breathing deeply)	46	61%	229	61%
Missing	30		144	
Coughing up blood	17	22%	140	38%
Missing	59		233	

Diagnosis of Cancer-Associated Thrombosis

16. Did you know that the following tests can be used to diagnose thrombosis?	Greece Only		All Countries	
	#	%	#	%
An ultrasound scan	39	51%	225	60%
Missing	37		148	
A CT scan	45	59%	207	55%
Missing	31		166	

Preventing your risk of cancer-associated thrombosis

17. Are you aware that the following can reduce your risk of thrombosis?	Greece Only		All Countries	
	#	%	#	%
Stretching your legs	25	33%	207	55%
Missing	51		166	
Moving your feet	41	54%	244	65%
Missing	35		130	
Taking a walk	57	75%	325	87%
Missing	19		50	
Stopping smoking	59	78%	282	75%
Missing	17		92	
Keeping hydrated	43	57%	239	64%
Missing	33		136	
Wearing compression socks / stockings if these are prescribed	54	71%	279	74%
Missing	22		96	

Treating cancer-associated thrombosis

18. Did you know that thrombosis can be treated effectively using medicines known as anticoagulants (often referred to as “blood thinners”)?	Greece Only		All Countries	
	#	%	#	%
* Yes, completely	39	53%	272	70%
* Yes, to some extent	31	42%	99	26%
* No, not at all	4	5%	15	4%
Don't know / can't remember	1	1%	1	0%
Missing	192		978	

19. Are you currently using anticoagulants / blood thinners?	Greece Only		All Countries	
	#	%	#	%
Yes	19	26%	141	37%
No	55	74%	244	63%
Missing	193		980	

20. Are you using these...	Greece Only		All Countries	
	#	%	#	%
As a treatment for an existing condition	14	74%	82	60%
To reduce the risk of thrombosis in the future	4	21%	43	31%
For another reason	1	5%	12	9%
Missing	248		1,228	

21. How do you receive this treatment?	Greece Only		All Countries	
	#	%	#	%
Medicines given orally	14	74%	84	60%
Medicines given by injection	5	26%	56	40%
Missing	248		1,225	

Treating cancer-associated thrombosis (continued)

22. Have you been told about any possible side effects of anticoagulants / blood thinners?	Greece Only		All Countries	
	#	%	#	%
* Yes	25	36%	136	41%
* No	44	64%	193	59%
Don't know / can't remember	11	14%	41	10%
Not applicable	0	0%	53	13%
Missing	187		942	

24. Have you been told what to do if you are affected by any of these possible side effects of anticoagulants / blood thinners?	Greece Only		All Countries	
	#	%	#	%
* Yes - to speak to my doctor or nurse	14	58%	62	48%
* Yes - to contact emergency services	8	33%	51	39%
* Yes - other	1	4%	5	4%
* No	1	4%	12	9%
Don't know / can't remember	0	0%	4	3%
Not applicable	0	0%	4	3%
Missing	243		1,227	

25. Have you suffered from any of these possible side-effects of your anticoagulants / blood thinners?	Greece Only		All Countries	
	#	%	#	%
* Yes	3	14%	27	22%
* No	19	86%	95	78%
Don't know / can't remember	1	4%	5	4%
Not applicable	1	4%	11	8%
Missing	243		1,227	

How do you know about cancer-associated thrombosis

27a. From which of the following did you get information about cancer-associated thrombosis? From my GP	Greece Only		All Countries	
	#	%	#	%
Verbally	24	9%	73	5%
Missing	243		1,292	
On paper	0	0%	6	0%
Missing	267		1,359	
By email	0	0%	0	0%
Missing	267		1,365	
Online	2	1%	5	0%
Missing	265		1,360	
Social media	0	0%	3	0%
Missing	267		1,362	

27b. From which of the following did you get information about cancer-associated thrombosis? From a hospital doctor	Greece Only		All Countries	
	#	%	#	%
Verbally	27	10%	163	12%
Missing	240		1,202	
On paper	0	0%	14	1%
Missing	267		1,351	
By email	1	0%	2	0%
Missing	266		1,363	
Online	0	0%	2	0%
Missing	267		1,363	
Social media	0	0%	0	0%
Missing	267		1,365	

How do you know about cancer-associated thrombosis (continued)

27c. From which of the following did you get information about cancer-associated thrombosis? From my chemotherapy nurse	Greece Only		All Countries	
	#	%	#	%
Verbally	6	2%	57	4%
Missing	261		1,308	
On paper	0	0%	10	1%
Missing	267		1,355	
By email	0	0%	0	0%
Missing	267		1,365	
Online	1	0%	2	0%
Missing	266		1,363	
Social media	0	0%	0	0%
Missing	267		1,365	

27d. From which of the following did you get information about cancer-associated thrombosis? From my radiologist	Greece Only		All Countries	
	#	%	#	%
Verbally	2	1%	29	2%
Missing	265		1,336	
On paper	1	0%	8	1%
Missing	266		1,357	
By email	0	0%	0	0%
Missing	267		1,365	
Online	1	0%	2	0%
Missing	266		1,363	
Social media	0	0%	0	0%
Missing	267		1,365	

How do you know about cancer-associated thrombosis (continued)

27e. From which of the following did you get information about cancer-associated thrombosis? From a specialist cancer nurse	Greece Only		All Countries	
	#	%	#	%
Verbally	8	3%	57	4%
Missing	259		1,308	
On paper	0	0%	11	1%
Missing	267		1,354	
By email	0	0%	0	0%
Missing	267		1,365	
Online	1	0%	2	0%
Missing	266		1,363	
Social media	0	0%	0	0%
Missing	267		1,365	

27f. From which of the following did you get information about cancer-associated thrombosis? From another hospital nurse	Greece Only		All Countries	
	#	%	#	%
Verbally	2	1%	23	2%
Missing	265		1,342	
On paper	0	0%	4	0%
Missing	267		1,361	
By email	0	0%	0	0%
Missing	267		1,365	
Online	1	0%	2	0%
Missing	266		1,363	
Social media	0	0%	0	0%
Missing	267		1,365	

How do you know about cancer-associated thrombosis (continued)

27g. From which of the following did you get information about cancer-associated thrombosis? Through educational materials provided by a patient organisation	Greece Only		All Countries	
	#	%	#	%
Verbally	3	1%	15	1%
Missing	264		1,350	
On paper	4	1%	24	2%
Missing	263		1,341	
By email	0	0%	3	0%
Missing	267		1,362	
Online	2	1%	10	1%
Missing	265		1,355	
Social media	1	0%	4	0%
Missing	266		1,361	

27h. From which of the following did you get information about cancer-associated thrombosis? Through my own research	Greece Only		All Countries	
	#	%	#	%
Verbally	6	2%	31	2%
Missing	261		1,334	
On paper	2	1%	10	1%
Missing	265		1,355	
By email	0	0%	1	0%
Missing	267		1,364	
Online	22	8%	81	6%
Missing	245		1,284	
Social media	0	0%	11	1%
Missing	267		1,354	

How do you know about cancer-associated thrombosis (continued)

27i. From which of the following did you get information about cancer-associated thrombosis? From my family or friends	Greece Only		All Countries	
	#	%	#	%
Verbally	11	4%	48	4%
Missing	256		1,317	
On paper	0	0%	1	0%
Missing	267		1,364	
By email	0	0%	0	0%
Missing	267		1,365	
Online	3	1%	8	1%
Missing	264		1,357	
Social media	1	0%	3	0%
Missing	266		1,362	

28. When did you first become aware of cancer-associated thrombosis?	Greece Only		All Countries	
	#	%	#	%
* I already knew about it before I was diagnosed with cancer	11	23%	58	19%
* I became aware of it when I suffered a blood clot	11	23%	78	26%
* I was given information during my cancer diagnosis	5	10%	47	16%
* I was given information before surgery	5	10%	29	10%
* I was given information following surgery	9	19%	34	11%
* I was given information before / during chemotherapy	7	15%	48	16%
* I was given information before / during radiotherapy	0	0%	6	2%
Don't know / can't remember	11	14%	38	9%
Other	17	22%	73	18%
Missing	191		954	

Overall awareness

29. How would you rate your overall understanding of cancer-associated thrombosis on a scale of 1 (low) to 10 (high)?	Greece Only		All Countries	
	#	%	#	%
Rank 1	54	21%	357	27%
Rank 2	20	8%	137	10%
Rank 3	29	11%	143	11%
Rank 4	23	9%	93	7%
Rank 5	51	20%	206	16%
Rank 6	14	5%	104	8%
Rank 7	17	7%	93	7%
Rank 8	23	9%	97	7%
Rank 9	9	4%	38	3%
Rank 10	16	6%	53	4%
Missing	11		44	

About your condition

33. What type of cancer were you first diagnosed with?	Greece Only		All Countries	
	#	%	#	%
Brain / Central Nervous System	4	2%	10	1%
Breast	111	44%	598	46%
Colorectal / Bowel	18	7%	99	8%
Ovarian	8	3%	47	4%
Other gynaecological	9	4%	63	5%
Haematological	24	9%	85	7%
Head and neck	6	2%	19	1%
Lung	17	7%	78	6%
Sarcoma	4	2%	15	1%
Skin	2	1%	29	2%
Oesophageal, Stomach, Pancreatic, Liver, or Gall bladder	7	3%	55	4%
Bladder	6	2%	40	3%
Prostate	7	3%	33	3%
Other urological	4	2%	13	1%
Other	27	11%	118	9%
Missing	13		63	

34. How long is it since you were first treated for this cancer?	Greece Only		All Countries	
	#	%	#	%
Less than 1 year	45	18%	313	24%
1 to 5 years	81	32%	497	38%
More than 5 years	115	45%	425	33%
My cancer treatment hasn't yet started	4	2%	30	2%
I will not receive any treatment for my cancer	8	3%	32	2%
Don't know / can't remember	1	0%	6	0%
Missing	13		62	

About you

35. Age Band (derived from "In what year were you born?")	Greece Only		All Countries	
	#	%	#	%
Under 16	2	1%	3	0%
16-24	1	0%	3	0%
25-34	2	1%	13	1%
35-44	20	8%	62	5%
45-54	47	20%	188	16%
55-64	87	36%	488	42%
65-74	50	21%	291	25%
75-84	15	6%	73	6%
85+	4	2%	13	1%
Out of Range	13	5%	37	3%
Missing	26		194	

36. What is your gender?	Greece Only		All Countries	
	#	%	#	%
Male	61	23%	220	16%
Female	186	70%	1,019	75%
Prefer not to say	3	1%	8	1%
Other	0	0%	1	0%
Missing	17	6%	117	9%

About you (continued)

37. Do you have any of the following longstanding conditions?	Greece Only		All Countries	
	#	%	#	%
Deafness or severe hearing impairment	11	4%	78	6%
Missing	256		1,287	
Blindness or partially sighted	6	2%	29	2%
Missing	261		1,336	
A long-standing physical condition	21	8%	150	11%
Missing	246		1,215	
A learning disability	4	1%	12	1%
Missing	263		1,353	
A mental health condition	22	8%	52	4%
Missing	245		1,313	
A long-standing illness, such as HIV, diabetes, chronic heart disease, or epilepsy	18	7%	139	10%
Missing	249		1,226	

About you (continued)

38. Where did you hear about this survey?	Greece Only		All Countries	
	#	%	#	%
I saw a link to it online	198	74%	926	68%
From family / friends	4	1%	25	2%
From a patient organisation who keep in touch with me	47	18%	194	14%
From a healthcare professional	1	0%	8	1%
Other	7	3%	88	6%
Missing	10	4%	124	9%



Quality
Health

ECPC Cancer-Associated Thrombosis Awareness Survey

Final Table of Detailed Results - Italy

Produced October 2018
by Quality Health

Survey Results

This report sets out the results from the ECPC Cancer-Associated Thrombosis Awareness Survey, ordered in exactly the same way as in the survey questionnaire provided to patients.

This report has been produced using the final dataset extracted from the Quality Health database on 21st August 2018. This report shows the data for Italy against a comparator for all countries (France, Germany, Greece, Italy, Spain & UK).

Reading the columns of figures

The results are shown firstly in absolute numbers, then as percentage responses.

Conventions

The percentages are calculated after excluding those patients that did not answer that particular question. All percentages are rounded to the nearest whole number. When added together, the percentages for all answers to a particular question may not total 100% because of this rounding.

The number of patients that did not answer a particular question is shown as the 'missing' figure at the bottom of the actual number of responses.

On some questions there are figures which are italicised. These figures have been recalculated to exclude responses where the question was not applicable to the respondent's circumstances. For example, question 22 regarding awareness of the side effects of blood thinners where those not answering ("Missing") and those answering "Don't know/can't remember" or "Not applicable" have been excluded.

Respondent Details

1. Are you currently resident in Italy?	Italy Only		All Countries	
	#	%	#	%
Yes	244	99%	1,274	93%
No	2	1%	91	7%
Missing	0		0	

3. Are you filling in this questionnaire on behalf of somebody else?	Italy Only		All Countries	
	#	%	#	%
Yes	47	20%	313	24%
No	185	80%	966	76%
Missing	14		86	

Your General Awareness

4. Have you ever suffered from thrombosis (a blood clot) associated with your cancer?	Italy Only		All Countries	
	#	%	#	%
* Yes	58	27%	299	24%
* No	159	73%	941	76%
Don't know / can't remember	26	11%	97	7%
Missing	3		28	

5. Before taking part in this survey, were you aware that people with cancer have a higher than normal risk of developing thrombosis (a blood clot)?	Italy Only		All Countries	
	#	%	#	%
Yes	65	27%	376	28%
No	176	73%	957	72%
Missing	5		32	

Your Understanding of the Risks

6. All people with cancer have a higher than normal risk of thrombosis. But certain cancers have a higher risk than others (including cancers of the stomach, brain, kidney and ovaries). To what extent are you aware of these risks?	Italy Only		All Countries	
	#	%	#	%
* <i>Completely</i>	12	20%	53	15%
* <i>To some extent</i>	38	64%	232	64%
* <i>Not at all</i>	9	15%	79	22%
Don't know / can't remember	5	8%	10	3%
Missing	182		991	

7. Did you know that the risk of thrombosis increases for people with cancer at an advanced stage?	Italy Only		All Countries	
	#	%	#	%
* <i>Yes, completely</i>	18	29%	80	22%
* <i>Yes, to some extent</i>	21	33%	135	37%
* <i>No, not at all</i>	24	38%	150	41%
Don't know / can't remember	1	2%	9	2%
Missing	182		991	

8. Did you know that cancer surgery can increase the risk of thrombosis?	Italy Only		All Countries	
	#	%	#	%
* <i>Yes, completely</i>	27	42%	127	35%
* <i>Yes, to some extent</i>	21	33%	113	31%
* <i>No, not at all</i>	16	25%	127	35%
Don't know / can't remember	0	0%	6	2%
Missing	182		992	

Your Understanding of the Risks (continued)

9. Did you know that chemotherapy can increase the risk of thrombosis?	Italy Only		All Countries	
	#	%	#	%
* Yes, completely	26	41%	119	33%
* Yes, to some extent	22	34%	135	37%
* No, not at all	16	25%	111	30%
Don't know / can't remember	0	0%	9	2%
Missing	182		991	

10. Did you know that radiotherapy can increase the risk of thrombosis?	Italy Only		All Countries	
	#	%	#	%
* Yes, completely	15	23%	61	17%
* Yes, to some extent	18	28%	103	29%
* No, not at all	31	48%	194	54%
Don't know / can't remember	0	0%	16	4%
Missing	182		991	

11. Did you know that having a central venous catheter (a central line) can increase the risk of thrombosis?	Italy Only		All Countries	
	#	%	#	%
* Yes, completely	19	31%	83	23%
* Yes, to some extent	16	26%	100	27%
* No, not at all	27	44%	181	50%
Don't know / can't remember	2	3%	10	3%
Missing	182		991	

Your Understanding of the Risks (continued)

12. Did you know that you are more likely to suffer from thrombosis if you are inactive for long periods of time (e.g. if you are in bed for 4 days or more)?	Italy Only		All Countries	
	#	%	#	%
* <i>Yes, completely</i>	37	59%	240	65%
* <i>Yes, to some extent</i>	19	30%	93	25%
* <i>No, not at all</i>	7	11%	39	10%
Don't know / can't remember	1	2%	2	1%
Missing	182		991	

13. Did you know that you are more likely to suffer from thrombosis if you have had them before?	Italy Only		All Countries	
	#	%	#	%
* <i>Yes, completely</i>	27	43%	170	46%
* <i>Yes, to some extent</i>	25	40%	119	32%
* <i>No, not at all</i>	11	17%	79	21%
Don't know / can't remember	1	2%	5	1%
Missing	182		992	

Your Understanding of What to Look Out For

14. Are you aware that the following can be signs of a blood clot in the arm / leg (Deep Vein Thrombosis (DVT))?	Italy Only		All Countries	
	#	%	#	%
Swelling in the foot, ankle or leg	38	58%	270	73%
Missing	27		102	
Pain, cramping or tenderness, often in the calf	30	46%	212	57%
Missing	35		162	
Redness or noticeable discoloration of the leg or arm	33	51%	229	61%
Missing	32		145	
A warm or heavy sensation in the leg	38	58%	213	57%
Missing	27		159	

15. Are you aware that the following can be signs of a blood clot in the lung (Pulmonary Embolism (PE))?	Italy Only		All Countries	
	#	%	#	%
Light-headedness / dizziness	19	29%	128	34%
Missing	46		245	
Unexplained shortness of breath	38	58%	263	71%
Missing	27		110	
Irregular heartbeat	17	26%	123	33%
Missing	48		249	
Chest pain (especially when breathing deeply)	28	43%	229	61%
Missing	37		144	
Coughing up blood	17	26%	140	38%
Missing	48		233	

Diagnosis of Cancer-Associated Thrombosis

16. Did you know that the following tests can be used to diagnose thrombosis?	Italy Only		All Countries	
	#	%	#	%
An ultrasound scan	33	51%	225	60%
Missing	32		148	
A CT scan	35	54%	207	55%
Missing	30		166	

Preventing your risk of cancer-associated thrombosis

17. Are you aware that the following can reduce your risk of thrombosis?	Italy Only		All Countries	
	#	%	#	%
Stretching your legs	26	40%	207	55%
Missing	39		166	
Moving your feet	23	35%	244	65%
Missing	42		130	
Taking a walk	48	74%	325	87%
Missing	17		50	
Stopping smoking	37	57%	282	75%
Missing	28		92	
Keeping hydrated	39	60%	239	64%
Missing	26		136	
Wearing compression socks / stockings if these are prescribed	38	58%	279	74%
Missing	27		96	

Treating cancer-associated thrombosis

18. Did you know that thrombosis can be treated effectively using medicines known as anticoagulants (often referred to as “blood thinners”)?	Italy Only		All Countries	
	#	%	#	%
* Yes, completely	45	65%	272	70%
* Yes, to some extent	20	29%	99	26%
* No, not at all	4	6%	15	4%
Don't know / can't remember	0	0%	1	0%
Missing	177		978	

19. Are you currently using anticoagulants / blood thinners?	Italy Only		All Countries	
	#	%	#	%
Yes	28	41%	141	37%
No	41	59%	244	63%
Missing	177		980	

20. Are you using these...	Italy Only		All Countries	
	#	%	#	%
As a treatment for an existing condition	20	74%	82	60%
To reduce the risk of thrombosis in the future	6	22%	43	31%
For another reason	1	4%	12	9%
Missing	219		1,228	

21. How do you receive this treatment?	Italy Only		All Countries	
	#	%	#	%
Medicines given orally	17	61%	84	60%
Medicines given by injection	11	39%	56	40%
Missing	218		1,225	

Treating cancer-associated thrombosis (continued)

22. Have you been told about any possible side effects of anticoagulants / blood thinners?	Italy Only		All Countries	
	#	%	#	%
* Yes	31	53%	136	41%
* No	28	47%	193	59%
Don't know / can't remember	4	6%	41	10%
Not applicable	9	13%	53	13%
Missing	174		942	

24. Have you been told what to do if you are affected by any of these possible side effects of anticoagulants / blood thinners?	Italy Only		All Countries	
	#	%	#	%
* Yes - to speak to my doctor or nurse	11	37%	62	48%
* Yes - to contact emergency services	15	50%	51	39%
* Yes - other	1	3%	5	4%
* No	3	10%	12	9%
Don't know / can't remember	0	0%	4	3%
Not applicable	1	3%	4	3%
Missing	215		1,227	

25. Have you suffered from any of these possible side-effects of your anticoagulants / blood thinners?	Italy Only		All Countries	
	#	%	#	%
* Yes	2	8%	27	22%
* No	22	92%	95	78%
Don't know / can't remember	1	3%	5	4%
Not applicable	5	17%	11	8%
Missing	216		1,227	

How do you know about cancer-associated thrombosis

27a. From which of the following did you get information about cancer-associated thrombosis? From my GP	Italy Only		All Countries	
	#	%	#	%
Verbally	11	4%	73	5%
Missing	235		1,292	
On paper	2	1%	6	0%
Missing	244		1,359	
By email	0	0%	0	0%
Missing	246		1,365	
Online	0	0%	5	0%
Missing	246		1,360	
Social media	0	0%	3	0%
Missing	246		1,362	

27b. From which of the following did you get information about cancer-associated thrombosis? From a hospital doctor	Italy Only		All Countries	
	#	%	#	%
Verbally	26	11%	163	12%
Missing	220		1,202	
On paper	4	2%	14	1%
Missing	242		1,351	
By email	0	0%	2	0%
Missing	246		1,363	
Online	0	0%	2	0%
Missing	246		1,363	
Social media	0	0%	0	0%
Missing	246		1,365	

How do you know about cancer-associated thrombosis (continued)

27c. From which of the following did you get information about cancer-associated thrombosis? From my chemotherapy nurse	Italy Only		All Countries	
	#	%	#	%
Verbally	6	2%	57	4%
Missing	240		1,308	
On paper	1	0%	10	1%
Missing	245		1,355	
By email	0	0%	0	0%
Missing	246		1,365	
Online	0	0%	2	0%
Missing	246		1,363	
Social media	0	0%	0	0%
Missing	246		1,365	

27d. From which of the following did you get information about cancer-associated thrombosis? From my radiologist	Italy Only		All Countries	
	#	%	#	%
Verbally	4	2%	29	2%
Missing	242		1,336	
On paper	1	0%	8	1%
Missing	245		1,357	
By email	0	0%	0	0%
Missing	246		1,365	
Online	0	0%	2	0%
Missing	246		1,363	
Social media	0	0%	0	0%
Missing	246		1,365	

How do you know about cancer-associated thrombosis (continued)

27e. From which of the following did you get information about cancer-associated thrombosis? From a specialist cancer nurse	Italy Only		All Countries	
	#	%	#	%
Verbally	8	3%	57	4%
Missing	238		1,308	
On paper	2	1%	11	1%
Missing	244		1,354	
By email	0	0%	0	0%
Missing	246		1,365	
Online	0	0%	2	0%
Missing	246		1,363	
Social media	0	0%	0	0%
Missing	246		1,365	

27f. From which of the following did you get information about cancer-associated thrombosis? From another hospital nurse	Italy Only		All Countries	
	#	%	#	%
Verbally	2	1%	23	2%
Missing	244		1,342	
On paper	0	0%	4	0%
Missing	246		1,361	
By email	0	0%	0	0%
Missing	246		1,365	
Online	0	0%	2	0%
Missing	246		1,363	
Social media	0	0%	0	0%
Missing	246		1,365	

How do you know about cancer-associated thrombosis (continued)

27g. From which of the following did you get information about cancer-associated thrombosis? Through educational materials provided by a patient organisation	Italy Only		All Countries	
	#	%	#	%
Verbally	2	1%	15	1%
Missing	244		1,350	
On paper	4	2%	24	2%
Missing	242		1,341	
By email	1	0%	3	0%
Missing	245		1,362	
Online	2	1%	10	1%
Missing	244		1,355	
Social media	1	0%	4	0%
Missing	245		1,361	

27h. From which of the following did you get information about cancer-associated thrombosis? Through my own research	Italy Only		All Countries	
	#	%	#	%
Verbally	4	2%	31	2%
Missing	242		1,334	
On paper	1	0%	10	1%
Missing	245		1,355	
By email	0	0%	1	0%
Missing	246		1,364	
Online	9	4%	81	6%
Missing	237		1,284	
Social media	0	0%	11	1%
Missing	246		1,354	

How do you know about cancer-associated thrombosis (continued)

27i. From which of the following did you get information about cancer-associated thrombosis? From my family or friends	Italy Only		All Countries	
	#	%	#	%
Verbally	10	4%	48	4%
Missing	236		1,317	
On paper	0	0%	1	0%
Missing	246		1,364	
By email	0	0%	0	0%
Missing	246		1,365	
Online	2	1%	8	1%
Missing	244		1,357	
Social media	0	0%	3	0%
Missing	246		1,362	

28. When did you first become aware of cancer-associated thrombosis?	Italy Only		All Countries	
	#	%	#	%
* <i>I already knew about it before I was diagnosed with cancer</i>	16	30%	58	19%
* <i>I became aware of it when I suffered a blood clot</i>	13	24%	78	26%
* <i>I was given information during my cancer diagnosis</i>	7	13%	47	16%
* <i>I was given information before surgery</i>	6	11%	29	10%
* <i>I was given information following surgery</i>	4	7%	34	11%
* <i>I was given information before / during chemotherapy</i>	5	9%	48	16%
* <i>I was given information before / during radiotherapy</i>	3	6%	6	2%
Don't know / can't remember	5	7%	38	9%
Other	10	14%	73	18%
Missing	177		954	

Overall awareness

29. How would you rate your overall understanding of cancer-associated thrombosis on a scale of 1 (low) to 10 (high)?	Italy Only		All Countries	
	#	%	#	%
Rank 1	100	42%	357	27%
Rank 2	26	11%	137	10%
Rank 3	21	9%	143	11%
Rank 4	12	5%	93	7%
Rank 5	32	13%	206	16%
Rank 6	12	5%	104	8%
Rank 7	13	5%	93	7%
Rank 8	10	4%	97	7%
Rank 9	5	2%	38	3%
Rank 10	9	4%	53	4%
Missing	6		44	

About your condition

33. What type of cancer were you first diagnosed with?	Italy Only		All Countries	
	#	%	#	%
Brain / Central Nervous System	2	1%	10	1%
Breast	107	46%	598	46%
Colorectal / Bowel	22	9%	99	8%
Ovarian	12	5%	47	4%
Other gynaecological	10	4%	63	5%
Haematological	19	8%	85	7%
Head and neck	4	2%	19	1%
Lung	16	7%	78	6%
Sarcoma	3	1%	15	1%
Skin	1	0%	29	2%
Oesophageal, Stomach, Pancreatic, Liver, or Gall bladder	8	3%	55	4%
Bladder	4	2%	40	3%
Prostate	7	3%	33	3%
Other urological	5	2%	13	1%
Other	14	6%	118	9%
Missing	12		63	

34. How long is it since you were first treated for this cancer?	Italy Only		All Countries	
	#	%	#	%
Less than 1 year	66	28%	313	24%
1 to 5 years	92	39%	497	38%
More than 5 years	61	26%	425	33%
My cancer treatment hasn't yet started	9	4%	30	2%
I will not receive any treatment for my cancer	7	3%	32	2%
Don't know / can't remember	0	0%	6	0%
Missing	11		62	

About you

35. Age Band (derived from "In what year were you born?")	Italy Only		All Countries	
	#	%	#	%
Under 16	1	0%	3	0%
16-24	1	0%	3	0%
25-34	1	0%	13	1%
35-44	1	0%	62	5%
45-54	20	10%	188	16%
55-64	101	48%	488	42%
65-74	55	26%	291	25%
75-84	15	7%	73	6%
85+	3	1%	13	1%
Out of Range	11	5%	37	3%
Missing	37		194	

36. What is your gender?	Italy Only		All Countries	
	#	%	#	%
Male	38	15%	220	16%
Female	187	76%	1,019	75%
Prefer not to say	0	0%	8	1%
Other	1	0%	1	0%
Missing	20	8%	117	9%

About you (continued)

37. Do you have any of the following longstanding conditions?	Italy Only		All Countries	
	#	%	#	%
Deafness or severe hearing impairment	16	7%	78	6%
Missing	230		1,287	
Blindness or partially sighted	9	4%	29	2%
Missing	237		1,336	
A long-standing physical condition	41	17%	150	11%
Missing	205		1,215	
A learning disability	2	1%	12	1%
Missing	244		1,353	
A mental health condition	3	1%	52	4%
Missing	243		1,313	
A long-standing illness, such as HIV, diabetes, chronic heart disease, or epilepsy	23	9%	139	10%
Missing	223		1,226	

About you (continued)

38. Where did you hear about this survey?	Italy Only		All Countries	
	#	%	#	%
I saw a link to it online	195	79%	926	68%
From family / friends	6	2%	25	2%
From a patient organisation who keep in touch with me	3	1%	194	14%
From a healthcare professional	0	0%	8	1%
Other	13	5%	88	6%
Missing	29	12%	124	9%



Quality
Health

ECPC Cancer-Associated Thrombosis Awareness Survey

Final Table of Detailed Results - Spain

Produced October 2018
by Quality Health

Survey Results

This report sets out the results from the ECPC Cancer-Associated Thrombosis Awareness Survey, ordered in exactly the same way as in the survey questionnaire provided to patients.

This report has been produced using the final dataset extracted from the Quality Health database on 21st August 2018. This report shows the data for Spain against a comparator for all countries (France, Germany, Greece, Italy, Spain & UK).

Reading the columns of figures

The results are shown firstly in absolute numbers, then as percentage responses.

Conventions

The percentages are calculated after excluding those patients that did not answer that particular question. All percentages are rounded to the nearest whole number. When added together, the percentages for all answers to a particular question may not total 100% because of this rounding.

The number of patients that did not answer a particular question is shown as the 'missing' figure at the bottom of the actual number of responses.

On some questions there are figures which are italicised. These figures have been recalculated to exclude responses where the question was not applicable to the respondent's circumstances. For example, question 22 regarding awareness of the side effects of blood thinners where those not answering ("Missing") and those answering "Don't know/can't remember" or "Not applicable" have been excluded.

Respondent Details

1. Are you currently resident in Spain?	Spain Only		All Countries	
	#	%	#	%
Yes	324	98%	1,274	93%
No	8	2%	91	7%
Missing	0		0	

3. Are you filling in this questionnaire on behalf of somebody else?	Spain Only		All Countries	
	#	%	#	%
Yes	36	12%	313	24%
No	275	88%	966	76%
Missing	21		86	

Your General Awareness

4. Have you ever suffered from thrombosis (a blood clot) associated with your cancer?	Spain Only		All Countries	
	#	%	#	%
* Yes	59	19%	299	24%
* No	254	81%	941	76%
Don't know / can't remember	16	5%	97	7%
Missing	3		28	

5. Before taking part in this survey, were you aware that people with cancer have a higher than normal risk of developing thrombosis (a blood clot)?	Spain Only		All Countries	
	#	%	#	%
Yes	84	26%	376	28%
No	243	74%	957	72%
Missing	5		32	

Your Understanding of the Risks

6. All people with cancer have a higher than normal risk of thrombosis. But certain cancers have a higher risk than others (including cancers of the stomach, brain, kidney and ovaries). To what extent are you aware of these risks?	Spain Only		All Countries	
	#	%	#	%
* <i>Completely</i>	10	12%	53	15%
* <i>To some extent</i>	50	60%	232	64%
* <i>Not at all</i>	24	29%	79	22%
Don't know / can't remember	0	0%	10	3%
Missing	248		991	

7. Did you know that the risk of thrombosis increases for people with cancer at an advanced stage?	Spain Only		All Countries	
	#	%	#	%
* <i>Yes, completely</i>	18	22%	80	22%
* <i>Yes, to some extent</i>	28	34%	135	37%
* <i>No, not at all</i>	36	44%	150	41%
Don't know / can't remember	2	2%	9	2%
Missing	248		991	

8. Did you know that cancer surgery can increase the risk of thrombosis?	Spain Only		All Countries	
	#	%	#	%
* <i>Yes, completely</i>	16	20%	127	35%
* <i>Yes, to some extent</i>	20	25%	113	31%
* <i>No, not at all</i>	44	55%	127	35%
Don't know / can't remember	3	4%	6	2%
Missing	249		992	

Your Understanding of the Risks (continued)

9. Did you know that chemotherapy can increase the risk of thrombosis?	Spain Only		All Countries	
	#	%	#	%
* Yes, completely	20	25%	119	33%
* Yes, to some extent	32	40%	135	37%
* No, not at all	29	36%	111	30%
Don't know / can't remember	3	4%	9	2%
Missing	248		991	

10. Did you know that radiotherapy can increase the risk of thrombosis?	Spain Only		All Countries	
	#	%	#	%
* Yes, completely	16	20%	61	17%
* Yes, to some extent	26	32%	103	29%
* No, not at all	39	48%	194	54%
Don't know / can't remember	3	4%	16	4%
Missing	248		991	

11. Did you know that having a central venous catheter (a central line) can increase the risk of thrombosis?	Spain Only		All Countries	
	#	%	#	%
* Yes, completely	21	25%	83	23%
* Yes, to some extent	18	22%	100	27%
* No, not at all	44	53%	181	50%
Don't know / can't remember	1	1%	10	3%
Missing	248		991	

Your Understanding of the Risks (continued)

12. Did you know that you are more likely to suffer from thrombosis if you are inactive for long periods of time (e.g. if you are in bed for 4 days or more)?	Spain Only		All Countries	
	#	%	#	%
* <i>Yes, completely</i>	61	73%	240	65%
* <i>Yes, to some extent</i>	17	20%	93	25%
* <i>No, not at all</i>	6	7%	39	10%
Don't know / can't remember	0	0%	2	1%
Missing	248		991	

13. Did you know that you are more likely to suffer from thrombosis if you have had them before?	Spain Only		All Countries	
	#	%	#	%
* <i>Yes, completely</i>	37	45%	170	46%
* <i>Yes, to some extent</i>	27	33%	119	32%
* <i>No, not at all</i>	18	22%	79	21%
Don't know / can't remember	2	2%	5	1%
Missing	248		992	

Your Understanding of What to Look Out For

14. Are you aware that the following can be signs of a blood clot in the arm / leg (Deep Vein Thrombosis (DVT))?	Spain Only		All Countries	
	#	%	#	%
Swelling in the foot, ankle or leg	72	86%	270	73%
Missing	12		102	
Pain, cramping or tenderness, often in the calf	37	44%	212	57%
Missing	47		162	
Redness or noticeable discoloration of the leg or arm	51	61%	229	61%
Missing	33		145	
A warm or heavy sensation in the leg	50	60%	213	57%
Missing	34		159	

15. Are you aware that the following can be signs of a blood clot in the lung (Pulmonary Embolism (PE))?	Spain Only		All Countries	
	#	%	#	%
Light-headedness / dizziness	31	37%	128	34%
Missing	53		245	
Unexplained shortness of breath	60	71%	263	71%
Missing	24		110	
Irregular heartbeat	28	33%	123	33%
Missing	56		249	
Chest pain (especially when breathing deeply)	53	63%	229	61%
Missing	31		144	
Coughing up blood	31	37%	140	38%
Missing	53		233	

Diagnosis of Cancer-Associated Thrombosis

16. Did you know that the following tests can be used to diagnose thrombosis?	Spain Only		All Countries	
	#	%	#	%
An ultrasound scan	49	58%	225	60%
Missing	35		148	
A CT scan	41	49%	207	55%
Missing	43		166	

Preventing your risk of cancer-associated thrombosis

17. Are you aware that the following can reduce your risk of thrombosis?	Spain Only		All Countries	
	#	%	#	%
Stretching your legs	47	56%	207	55%
Missing	37		166	
Moving your feet	58	69%	244	65%
Missing	26		130	
Taking a walk	79	94%	325	87%
Missing	5		50	
Stopping smoking	65	77%	282	75%
Missing	19		92	
Keeping hydrated	40	48%	239	64%
Missing	44		136	
Wearing compression socks / stockings if these are prescribed	53	63%	279	74%
Missing	31		96	

Treating cancer-associated thrombosis

18. Did you know that thrombosis can be treated effectively using medicines known as anticoagulants (often referred to as “blood thinners”)?	Spain Only		All Countries	
	#	%	#	%
* Yes, completely	63	70%	272	70%
* Yes, to some extent	23	26%	99	26%
* No, not at all	4	4%	15	4%
Don't know / can't remember	0	0%	1	0%
Missing	242		978	

19. Are you currently using anticoagulants / blood thinners?	Spain Only		All Countries	
	#	%	#	%
Yes	28	31%	141	37%
No	61	69%	244	63%
Missing	243		980	

20. Are you using these...	Spain Only		All Countries	
	#	%	#	%
As a treatment for an existing condition	15	58%	82	60%
To reduce the risk of thrombosis in the future	8	31%	43	31%
For another reason	3	12%	12	9%
Missing	306		1,228	

21. How do you receive this treatment?	Spain Only		All Countries	
	#	%	#	%
Medicines given orally	14	52%	84	60%
Medicines given by injection	13	48%	56	40%
Missing	305		1,225	

Treating cancer-associated thrombosis (continued)

22. Have you been told about any possible side effects of anticoagulants / blood thinners?	Spain Only		All Countries	
	#	%	#	%
* Yes	25	35%	136	41%
* No	46	65%	193	59%
Don't know / can't remember	7	8%	41	10%
Not applicable	8	9%	53	13%
Missing	246		942	

24. Have you been told what to do if you are affected by any of these possible side effects of anticoagulants / blood thinners?	Spain Only		All Countries	
	#	%	#	%
* Yes - to speak to my doctor or nurse	10	38%	62	48%
* Yes - to contact emergency services	14	54%	51	39%
* Yes - other	0	0%	5	4%
* No	2	8%	12	9%
Don't know / can't remember	1	4%	4	3%
Not applicable	0	0%	4	3%
Missing	305		1,227	

25. Have you suffered from any of these possible side-effects of your anticoagulants / blood thinners?	Spain Only		All Countries	
	#	%	#	%
* Yes	4	15%	27	22%
* No	22	85%	95	78%
Don't know / can't remember	2	7%	5	4%
Not applicable	0	0%	11	8%
Missing	304		1,227	

How do you know about cancer-associated thrombosis

27a. From which of the following did you get information about cancer-associated thrombosis? From my GP	Spain Only		All Countries	
	#	%	#	%
Verbally	18	5%	73	5%
Missing	314		1,292	
On paper	0	0%	6	0%
Missing	332		1,359	
By email	0	0%	0	0%
Missing	332		1,365	
Online	2	1%	5	0%
Missing	330		1,360	
Social media	1	0%	3	0%
Missing	331		1,362	

27b. From which of the following did you get information about cancer-associated thrombosis? From a hospital doctor	Spain Only		All Countries	
	#	%	#	%
Verbally	40	12%	163	12%
Missing	292		1,202	
On paper	3	1%	14	1%
Missing	329		1,351	
By email	1	0%	2	0%
Missing	331		1,363	
Online	1	0%	2	0%
Missing	331		1,363	
Social media	0	0%	0	0%
Missing	332		1,365	

How do you know about cancer-associated thrombosis (continued)

27c. From which of the following did you get information about cancer-associated thrombosis? From my chemotherapy nurse	Spain Only		All Countries	
	#	%	#	%
Verbally	11	3%	57	4%
Missing	321		1,308	
On paper	2	1%	10	1%
Missing	330		1,355	
By email	0	0%	0	0%
Missing	332		1,365	
Online	1	0%	2	0%
Missing	331		1,363	
Social media	0	0%	0	0%
Missing	332		1,365	

27d. From which of the following did you get information about cancer-associated thrombosis? From my radiologist	Spain Only		All Countries	
	#	%	#	%
Verbally	7	2%	29	2%
Missing	325		1,336	
On paper	2	1%	8	1%
Missing	330		1,357	
By email	0	0%	0	0%
Missing	332		1,365	
Online	1	0%	2	0%
Missing	331		1,363	
Social media	0	0%	0	0%
Missing	332		1,365	

How do you know about cancer-associated thrombosis (continued)

27e. From which of the following did you get information about cancer-associated thrombosis? From a specialist cancer nurse	Spain Only		All Countries	
	#	%	#	%
Verbally	12	4%	57	4%
Missing	320		1,308	
On paper	3	1%	11	1%
Missing	329		1,354	
By email	0	0%	0	0%
Missing	332		1,365	
Online	1	0%	2	0%
Missing	331		1,363	
Social media	0	0%	0	0%
Missing	332		1,365	

27f. From which of the following did you get information about cancer-associated thrombosis? From another hospital nurse	Spain Only		All Countries	
	#	%	#	%
Verbally	5	2%	23	2%
Missing	327		1,342	
On paper	3	1%	4	0%
Missing	329		1,361	
By email	0	0%	0	0%
Missing	332		1,365	
Online	1	0%	2	0%
Missing	331		1,363	
Social media	0	0%	0	0%
Missing	332		1,365	

How do you know about cancer-associated thrombosis (continued)

27g. From which of the following did you get information about cancer-associated thrombosis? Through educational materials provided by a patient organisation	Spain Only		All Countries	
	#	%	#	%
Verbally	4	1%	15	1%
Missing	328		1,350	
On paper	4	1%	24	2%
Missing	328		1,341	
By email	1	0%	3	0%
Missing	331		1,362	
Online	2	1%	10	1%
Missing	330		1,355	
Social media	0	0%	4	0%
Missing	332		1,361	

27h. From which of the following did you get information about cancer-associated thrombosis? Through my own research	Spain Only		All Countries	
	#	%	#	%
Verbally	9	3%	31	2%
Missing	323		1,334	
On paper	3	1%	10	1%
Missing	329		1,355	
By email	0	0%	1	0%
Missing	332		1,364	
Online	10	3%	81	6%
Missing	322		1,284	
Social media	7	2%	11	1%
Missing	325		1,354	

How do you know about cancer-associated thrombosis (continued)

27i. From which of the following did you get information about cancer-associated thrombosis? From my family or friends	Spain Only		All Countries	
	#	%	#	%
Verbally	11	3%	48	4%
Missing	321		1,317	
On paper	0	0%	1	0%
Missing	332		1,364	
By email	0	0%	0	0%
Missing	332		1,365	
Online	1	0%	8	1%
Missing	331		1,357	
Social media	0	0%	3	0%
Missing	332		1,362	

28. When did you first become aware of cancer-associated thrombosis?	Spain Only		All Countries	
	#	%	#	%
* I already knew about it before I was diagnosed with cancer	9	16%	58	19%
* I became aware of it when I suffered a blood clot	14	24%	78	26%
* I was given information during my cancer diagnosis	10	17%	47	16%
* I was given information before surgery	2	3%	29	10%
* I was given information following surgery	7	12%	34	11%
* I was given information before / during chemotherapy	15	26%	48	16%
* I was given information before / during radiotherapy	1	2%	6	2%
Don't know / can't remember	12	14%	38	9%
Other	14	17%	73	18%
Missing	248		954	

Overall awareness

29. How would you rate your overall understanding of cancer-associated thrombosis on a scale of 1 (low) to 10 (high)?	Spain Only		All Countries	
	#	%	#	%
Rank 1	77	23%	357	27%
Rank 2	36	11%	137	10%
Rank 3	39	12%	143	11%
Rank 4	28	8%	93	7%
Rank 5	49	15%	206	16%
Rank 6	37	11%	104	8%
Rank 7	23	7%	93	7%
Rank 8	21	6%	97	7%
Rank 9	10	3%	38	3%
Rank 10	10	3%	53	4%
Missing	2		44	

About your condition

33. What type of cancer were you first diagnosed with?	Spain Only		All Countries	
	#	%	#	%
Brain / Central Nervous System	2	1%	10	1%
Breast	176	54%	598	46%
Colorectal / Bowel	22	7%	99	8%
Ovarian	10	3%	47	4%
Other gynaecological	12	4%	63	5%
Haematological	15	5%	85	7%
Head and neck	3	1%	19	1%
Lung	18	6%	78	6%
Sarcoma	5	2%	15	1%
Skin	5	2%	29	2%
Oesophageal, Stomach, Pancreatic, Liver, or Gall bladder	25	8%	55	4%
Bladder	7	2%	40	3%
Prostate	1	0%	33	3%
Other urological	0	0%	13	1%
Other	25	8%	118	9%
Missing	6		63	

34. How long is it since you were first treated for this cancer?	Spain Only		All Countries	
	#	%	#	%
Less than 1 year	79	25%	313	24%
1 to 5 years	130	40%	497	38%
More than 5 years	95	30%	425	33%
My cancer treatment hasn't yet started	6	2%	30	2%
I will not receive any treatment for my cancer	12	4%	32	2%
Don't know / can't remember	0	0%	6	0%
Missing	10		62	

About you

35. Age Band (derived from "In what year were you born?")	Spain Only		All Countries	
	#	%	#	%
Under 16	0	0%	3	0%
16-24	1	0%	3	0%
25-34	4	1%	13	1%
35-44	29	10%	62	5%
45-54	74	26%	188	16%
55-64	106	37%	488	42%
65-74	50	18%	291	25%
75-84	10	4%	73	6%
85+	4	1%	13	1%
Out of Range	6	2%	37	3%
Missing	48		194	

36. What is your gender?	Spain Only		All Countries	
	#	%	#	%
Male	46	14%	220	16%
Female	257	77%	1,019	75%
Prefer not to say	3	1%	8	1%
Other	0	0%	1	0%
Missing	26	8%	117	9%

About you (continued)

37. Do you have any of the following longstanding conditions?	Spain Only		All Countries	
	#	%	#	%
Deafness or severe hearing impairment	16	5%	78	6%
Missing	316		1,287	
Blindness or partially sighted	2	1%	29	2%
Missing	330		1,336	
A long-standing physical condition	38	11%	150	11%
Missing	294		1,215	
A learning disability	6	2%	12	1%
Missing	326		1,353	
A mental health condition	5	2%	52	4%
Missing	327		1,313	
A long-standing illness, such as HIV, diabetes, chronic heart disease, or epilepsy	32	10%	139	10%
Missing	300		1,226	

About you (continued)

38. Where did you hear about this survey?	Spain Only		All Countries	
	#	%	#	%
I saw a link to it online	182	55%	926	68%
From family / friends	4	1%	25	2%
From a patient organisation who keep in touch with me	94	28%	194	14%
From a healthcare professional	5	2%	8	1%
Other	18	5%	88	6%
Missing	29	9%	124	9%



Quality
Health

ECPC Cancer-Associated Thrombosis Awareness Survey

Final Table of Detailed Results - UK

Produced October 2018
by Quality Health

Survey Results

This report sets out the results from the ECPC Cancer-Associated Thrombosis Awareness Survey, ordered in exactly the same way as in the survey questionnaire provided to patients.

This report has been produced using the final dataset extracted from the Quality Health database on 21st August 2018. This report shows the data for the UK against a comparator for all countries (France, Germany, Greece, Italy, Spain & UK).

Reading the columns of figures

The results are shown firstly in absolute numbers, then as percentage responses.

Conventions

The percentages are calculated after excluding those patients that did not answer that particular question. All percentages are rounded to the nearest whole number. When added together, the percentages for all answers to a particular question may not total 100% because of this rounding.

The number of patients that did not answer a particular question is shown as the 'missing' figure at the bottom of the actual number of responses.

On some questions there are figures which are italicised. These figures have been recalculated to exclude responses where the question was not applicable to the respondent's circumstances. For example, question 22 regarding awareness of the side effects of blood thinners where those not answering ("Missing") and those answering "Don't know/can't remember" or "Not applicable" have been excluded.

Respondent Details

1. Are you currently resident in the United Kingdom?	UK Only		All Countries	
	#	%	#	%
Yes	261	81%	1,274	93%
No	63	19%	91	7%
Missing	0		0	

3. Are you filling in this questionnaire on behalf of somebody else?	UK Only		All Countries	
	#	%	#	%
Yes	20	7%	313	24%
No	275	93%	966	76%
Missing	29		86	

Your General Awareness

4. Have you ever suffered from thrombosis (a blood clot) associated with your cancer?	UK Only		All Countries	
	#	%	#	%
* Yes	92	31%	299	24%
* No	205	69%	941	76%
Don't know / can't remember	9	3%	97	7%
Missing	18		28	

5. Before taking part in this survey, were you aware that people with cancer have a higher than normal risk of developing thrombosis (a blood clot)?	UK Only		All Countries	
	#	%	#	%
Yes	110	36%	376	28%
No	195	64%	957	72%
Missing	19		32	

Your Understanding of the Risks

6. All people with cancer have a higher than normal risk of thrombosis. But certain cancers have a higher risk than others (including cancers of the stomach, brain, kidney and ovaries). To what extent are you aware of these risks?	UK Only		All Countries	
	#	%	#	%
* <i>Completely</i>	9	8%	53	15%
* <i>To some extent</i>	81	76%	232	64%
* <i>Not at all</i>	16	15%	79	22%
Don't know / can't remember	4	4%	10	3%
Missing	214		991	

7. Did you know that the risk of thrombosis increases for people with cancer at an advanced stage?	UK Only		All Countries	
	#	%	#	%
* <i>Yes, completely</i>	16	15%	80	22%
* <i>Yes, to some extent</i>	41	38%	135	37%
* <i>No, not at all</i>	50	47%	150	41%
Don't know / can't remember	3	3%	9	2%
Missing	214		991	

8. Did you know that cancer surgery can increase the risk of thrombosis?	UK Only		All Countries	
	#	%	#	%
* <i>Yes, completely</i>	44	40%	127	35%
* <i>Yes, to some extent</i>	36	33%	113	31%
* <i>No, not at all</i>	30	27%	127	35%
Don't know / can't remember	0	0%	6	2%
Missing	214		992	

Your Understanding of the Risks (continued)

9. Did you know that chemotherapy can increase the risk of thrombosis?	UK Only		All Countries	
	#	%	#	%
* Yes, completely	35	32%	119	33%
* Yes, to some extent	49	45%	135	37%
* No, not at all	26	24%	111	30%
Don't know / can't remember	0	0%	9	2%
Missing	214		991	

10. Did you know that radiotherapy can increase the risk of thrombosis?	UK Only		All Countries	
	#	%	#	%
* Yes, completely	9	8%	61	17%
* Yes, to some extent	32	30%	103	29%
* No, not at all	66	62%	194	54%
Don't know / can't remember	3	3%	16	4%
Missing	214		991	

11. Did you know that having a central venous catheter (a central line) can increase the risk of thrombosis?	UK Only		All Countries	
	#	%	#	%
* Yes, completely	20	18%	83	23%
* Yes, to some extent	33	30%	100	27%
* No, not at all	57	52%	181	50%
Don't know / can't remember	0	0%	10	3%
Missing	214		991	

Your Understanding of the Risks (continued)

12. Did you know that you are more likely to suffer from thrombosis if you are inactive for long periods of time (e.g. if you are in bed for 4 days or more)?	UK Only		All Countries	
	#	%	#	%
* <i>Yes, completely</i>	72	65%	240	65%
* <i>Yes, to some extent</i>	29	26%	93	25%
* <i>No, not at all</i>	9	8%	39	10%
Don't know / can't remember	0	0%	2	1%
Missing	214		991	

13. Did you know that you are more likely to suffer from thrombosis if you have had them before?	UK Only		All Countries	
	#	%	#	%
* <i>Yes, completely</i>	48	44%	170	46%
* <i>Yes, to some extent</i>	39	36%	119	32%
* <i>No, not at all</i>	22	20%	79	21%
Don't know / can't remember	0	0%	5	1%
Missing	215		992	

Your Understanding of What to Look Out For

14. Are you aware that the following can be signs of a blood clot in the arm / leg (Deep Vein Thrombosis (DVT))?	UK Only		All Countries	
	#	%	#	%
Swelling in the foot, ankle or leg	83	75%	270	73%
Missing	27		102	
Pain, cramping or tenderness, often in the calf	88	80%	212	57%
Missing	22		162	
Redness or noticeable discoloration of the leg or arm	75	68%	229	61%
Missing	35		145	
A warm or heavy sensation in the leg	68	62%	213	57%
Missing	42		159	

15. Are you aware that the following can be signs of a blood clot in the lung (Pulmonary Embolism (PE))?	UK Only		All Countries	
	#	%	#	%
Light-headedness / dizziness	43	39%	128	34%
Missing	67		245	
Unexplained shortness of breath	83	75%	263	71%
Missing	27		110	
Irregular heartbeat	35	32%	123	33%
Missing	75		249	
Chest pain (especially when breathing deeply)	74	67%	229	61%
Missing	36		144	
Coughing up blood	61	55%	140	38%
Missing	49		233	

Diagnosis of Cancer-Associated Thrombosis

16. Did you know that the following tests can be used to diagnose thrombosis?	UK Only		All Countries	
	#	%	#	%
An ultrasound scan	74	67%	225	60%
Missing	36		148	
A CT scan	65	59%	207	55%
Missing	45		166	

Preventing your risk of cancer-associated thrombosis

17. Are you aware that the following can reduce your risk of thrombosis?	UK Only		All Countries	
	#	%	#	%
Stretching your legs	83	75%	207	55%
Missing	27		166	
Moving your feet	91	83%	244	65%
Missing	19		130	
Taking a walk	103	94%	325	87%
Missing	7		50	
Stopping smoking	84	76%	282	75%
Missing	26		92	
Keeping hydrated	81	74%	239	64%
Missing	29		136	
Wearing compression socks / stockings if these are prescribed	97	88%	279	74%
Missing	13		96	

Treating cancer-associated thrombosis

18. Did you know that thrombosis can be treated effectively using medicines known as anticoagulants (often referred to as “blood thinners”)?	UK Only		All Countries	
	#	%	#	%
* Yes, completely	92	82%	272	70%
* Yes, to some extent	19	17%	99	26%
* No, not at all	1	1%	15	4%
Don't know / can't remember	0	0%	1	0%
Missing	212		978	

19. Are you currently using anticoagulants / blood thinners?	UK Only		All Countries	
	#	%	#	%
Yes	46	41%	141	37%
No	66	59%	244	63%
Missing	212		980	

20. Are you using these...	UK Only		All Countries	
	#	%	#	%
As a treatment for an existing condition	28	62%	82	60%
To reduce the risk of thrombosis in the future	13	29%	43	31%
For another reason	4	9%	12	9%
Missing	279		1,228	

21. How do you receive this treatment?	UK Only		All Countries	
	#	%	#	%
Medicines given orally	24	52%	84	60%
Medicines given by injection	22	48%	56	40%
Missing	278		1,225	

Treating cancer-associated thrombosis (continued)

22. Have you been told about any possible side effects of anticoagulants / blood thinners?	UK Only		All Countries	
	#	%	#	%
* Yes	41	44%	136	41%
* No	53	56%	193	59%
Don't know / can't remember	17	12%	41	10%
Not applicable	32	22%	53	13%
Missing	181		942	

24. Have you been told what to do if you are affected by any of these possible side effects of anticoagulants / blood thinners?	UK Only		All Countries	
	#	%	#	%
* Yes - to speak to my doctor or nurse	20	51%	62	48%
* Yes - to contact emergency services	13	33%	51	39%
* Yes - other	2	5%	5	4%
* No	4	10%	12	9%
Don't know / can't remember	0	0%	4	3%
Not applicable	2	5%	4	3%
Missing	283		1,227	

25. Have you suffered from any of these possible side-effects of your anticoagulants / blood thinners?	UK Only		All Countries	
	#	%	#	%
* Yes	12	34%	27	22%
* No	23	66%	95	78%
Don't know / can't remember	1	2%	5	4%
Not applicable	5	12%	11	8%
Missing	283		1,227	

How do you know about cancer-associated thrombosis

27a. From which of the following did you get information about cancer-associated thrombosis? From my GP	UK Only		All Countries	
	#	%	#	%
Verbally	10	3%	73	5%
Missing	314		1,292	
On paper	4	1%	6	0%
Missing	320		1,359	
By email	0	0%	0	0%
Missing	324		1,365	
Online	1	0%	5	0%
Missing	323		1,360	
Social media	1	0%	3	0%
Missing	323		1,362	

27b. From which of the following did you get information about cancer-associated thrombosis? From a hospital doctor	UK Only		All Countries	
	#	%	#	%
Verbally	50	15%	163	12%
Missing	274		1,202	
On paper	4	1%	14	1%
Missing	320		1,351	
By email	0	0%	2	0%
Missing	324		1,363	
Online	1	0%	2	0%
Missing	323		1,363	
Social media	0	0%	0	0%
Missing	324		1,365	

How do you know about cancer-associated thrombosis (continued)

27c. From which of the following did you get information about cancer-associated thrombosis? From my chemotherapy nurse	UK Only		All Countries	
	#	%	#	%
Verbally	30	9%	57	4%
Missing	294		1,308	
On paper	6	2%	10	1%
Missing	318		1,355	
By email	0	0%	0	0%
Missing	324		1,365	
Online	0	0%	2	0%
Missing	324		1,363	
Social media	0	0%	0	0%
Missing	324		1,365	

27d. From which of the following did you get information about cancer-associated thrombosis? From my radiologist	UK Only		All Countries	
	#	%	#	%
Verbally	9	3%	29	2%
Missing	315		1,336	
On paper	3	1%	8	1%
Missing	321		1,357	
By email	0	0%	0	0%
Missing	324		1,365	
Online	0	0%	2	0%
Missing	324		1,363	
Social media	0	0%	0	0%
Missing	324		1,365	

How do you know about cancer-associated thrombosis (continued)

27e. From which of the following did you get information about cancer-associated thrombosis? From a specialist cancer nurse	UK Only		All Countries	
	#	%	#	%
Verbally	25	8%	57	4%
Missing	299		1,308	
On paper	5	2%	11	1%
Missing	319		1,354	
By email	0	0%	0	0%
Missing	324		1,365	
Online	0	0%	2	0%
Missing	324		1,363	
Social media	0	0%	0	0%
Missing	324		1,365	

27f. From which of the following did you get information about cancer-associated thrombosis? From another hospital nurse	UK Only		All Countries	
	#	%	#	%
Verbally	13	4%	23	2%
Missing	311		1,342	
On paper	0	0%	4	0%
Missing	324		1,361	
By email	0	0%	0	0%
Missing	324		1,365	
Online	0	0%	2	0%
Missing	324		1,363	
Social media	0	0%	0	0%
Missing	324		1,365	

How do you know about cancer-associated thrombosis (continued)

27g. From which of the following did you get information about cancer-associated thrombosis? Through educational materials provided by a patient organisation	UK Only		All Countries	
	#	%	#	%
Verbally	6	2%	15	1%
Missing	318		1,350	
On paper	10	3%	24	2%
Missing	314		1,341	
By email	1	0%	3	0%
Missing	323		1,362	
Online	4	1%	10	1%
Missing	320		1,355	
Social media	2	1%	4	0%
Missing	322		1,361	

27h. From which of the following did you get information about cancer-associated thrombosis? Through my own research	UK Only		All Countries	
	#	%	#	%
Verbally	9	3%	31	2%
Missing	315		1,334	
On paper	2	1%	10	1%
Missing	322		1,355	
By email	1	0%	1	0%
Missing	323		1,364	
Online	34	10%	81	6%
Missing	290		1,284	
Social media	2	1%	11	1%
Missing	322		1,354	

How do you know about cancer-associated thrombosis (continued)

27i. From which of the following did you get information about cancer-associated thrombosis? From my family or friends	UK Only		All Countries	
	#	%	#	%
Verbally	10	3%	48	4%
Missing	314		1,317	
On paper	0	0%	1	0%
Missing	324		1,364	
By email	0	0%	0	0%
Missing	324		1,365	
Online	2	1%	8	1%
Missing	322		1,357	
Social media	2	1%	3	0%
Missing	322		1,362	

28. When did you first become aware of cancer-associated thrombosis?	UK Only		All Countries	
	#	%	#	%
* I already knew about it before I was diagnosed with cancer	13	13%	58	19%
* I became aware of it when I suffered a blood clot	33	32%	78	26%
* I was given information during my cancer diagnosis	16	16%	47	16%
* I was given information before surgery	12	12%	29	10%
* I was given information following surgery	10	10%	34	11%
* I was given information before / during chemotherapy	17	17%	48	16%
* I was given information before / during radiotherapy	2	2%	6	2%
Don't know / can't remember	9	7%	38	9%
Other	26	19%	73	18%
Missing	186		954	

Overall awareness

29. How would you rate your overall understanding of cancer-associated thrombosis on a scale of 1 (low) to 10 (high)?	UK Only		All Countries	
	#	%	#	%
Rank 1	88	29%	357	27%
Rank 2	36	12%	137	10%
Rank 3	27	9%	143	11%
Rank 4	23	8%	93	7%
Rank 5	36	12%	206	16%
Rank 6	20	7%	104	8%
Rank 7	26	9%	93	7%
Rank 8	30	10%	97	7%
Rank 9	9	3%	38	3%
Rank 10	7	2%	53	4%
Missing	22		44	

About your condition

33. What type of cancer were you first diagnosed with?	UK Only		All Countries	
	#	%	#	%
Brain / Central Nervous System	1	0%	10	1%
Breast	113	38%	598	46%
Colorectal / Bowel	28	9%	99	8%
Ovarian	10	3%	47	4%
Other gynaecological	21	7%	63	5%
Haematological	24	8%	85	7%
Head and neck	4	1%	19	1%
Lung	14	5%	78	6%
Sarcoma	3	1%	15	1%
Skin	3	1%	29	2%
Oesophageal, Stomach, Pancreatic, Liver, or Gall bladder	8	3%	55	4%
Bladder	19	6%	40	3%
Prostate	12	4%	33	3%
Other urological	2	1%	13	1%
Other	35	12%	118	9%
Missing	27		63	

34. How long is it since you were first treated for this cancer?	UK Only		All Countries	
	#	%	#	%
Less than 1 year	75	25%	313	24%
1 to 5 years	127	42%	497	38%
More than 5 years	84	28%	425	33%
My cancer treatment hasn't yet started	8	3%	30	2%
I will not receive any treatment for my cancer	2	1%	32	2%
Don't know / can't remember	3	1%	6	0%
Missing	25		62	

About you

35. Age Band (derived from "In what year were you born?")	UK Only		All Countries	
	#	%	#	%
Under 16	0	0%	3	0%
16-24	0	0%	3	0%
25-34	2	1%	13	1%
35-44	6	2%	62	5%
45-54	36	13%	188	16%
55-64	117	43%	488	42%
65-74	88	32%	291	25%
75-84	20	7%	73	6%
85+	1	0%	13	1%
Out of Range	1	0%	37	3%
Missing	53		194	

36. What is your gender?	UK Only		All Countries	
	#	%	#	%
Male	54	17%	220	16%
Female	228	70%	1,019	75%
Prefer not to say	2	1%	8	1%
Other	0	0%	1	0%
Missing	40	12%	117	9%

About you (continued)

37. Do you have any of the following longstanding conditions?	UK Only		All Countries	
	#	%	#	%
Deafness or severe hearing impairment	20	6%	78	6%
Missing	304		1,287	
Blindness or partially sighted	3	1%	29	2%
Missing	321		1,336	
A long-standing physical condition	34	10%	150	11%
Missing	290		1,215	
A learning disability	0	0%	12	1%
Missing	324		1,353	
A mental health condition	8	2%	52	4%
Missing	316		1,313	
A long-standing illness, such as HIV, diabetes, chronic heart disease, or epilepsy	40	12%	139	10%
Missing	284		1,226	

About you (continued)

38. Where did you hear about this survey?	UK Only		All Countries	
	#	%	#	%
I saw a link to it online	210	65%	926	68%
From family / friends	6	2%	25	2%
From a patient organisation who keep in touch with me	40	12%	194	14%
From a healthcare professional	2	1%	8	1%
Other	30	9%	88	6%
Missing	36	11%	124	9%

Appendix C. The questionnaire

European Cancer Patient Coalition

Survey on awareness of cancer-associated thrombosis in people with cancer Questionnaire

Introduction

People with cancer have a higher than normal risk of developing thrombosis (a blood clot). This condition is known as cancer-associated thrombosis. Yet it remains under-reported, seldom discussed and often misdiagnosed. This survey is about trying to understand how much cancer patients know about thrombosis, and when and where they find this information.

The survey is being conducted in 6 countries, including the UK where it is being piloted. The results will be used to inform policymakers and other stakeholders, in order to improve their understanding of cancer patients' awareness of thrombosis, so that its risks and symptoms can be dealt with better.

Blood clots in the arm or leg are known as Deep Vein Thrombosis (DVT). Blood clots in the lung are known as a Pulmonary Embolism (PE). ***If you have any concerns about your risks of cancer-associated thrombosis, or if you think you might be suffering from any of its symptoms, you should speak to your doctor.***

About ECPC :

ECPC, the European Cancer Patient Coalition (www.ecpc.org) is the voice of cancer patients in Europe. With over 400 members, ECPC is Europe's largest umbrella cancer patients' association, covering all 28 EU member states and many other European and non European countries. ECPC represents patients affected by all types of cancers, from the rarest to the most common.

About Quality Health:

Quality Health (www.quality-health.co.uk) is a specialist health and social care survey organisation, working with public, private and voluntary sector organisations to understand and improve patients' experience of their care and treatment.

Informed consent and use of data

By completing this questionnaire, you are giving your consent for the information you provide to be used for the above purpose. The information is being collected for ECPC by Quality Health, an experienced survey provider. Quality Health will be subject to strict obligations regarding the security and confidentiality of your information, and will not be allowed to use your details for any other purpose. Your personal information will not be released unless required by law or where there is a clear overriding public interest.

No personal information, or individual responses, will be passed on to any ECPC members or funding companies - only aggregated survey data on overall results.

Quality Health is registered under the UK Data Protection Act 1998, and this survey is being undertaken in line with all relevant requirements of the UK Information Commissioner and forthcoming General Data Protection Regulation (GDPR).

Thank you for taking part in this survey. Your insights will help improve cancer care for other patients today and in the future.

Filling in the questionnaire

The questionnaire should take no more than 15 minutes to complete.

If you have any queries about filling in the questionnaire, please call the FREEPHONE helpline number on 0800 783 1775; or email info@quality-health.co.uk

Your general awareness of cancer-associated thrombosis

In this section, we ask about your general awareness of cancer-associated thrombosis.

1. Have you ever suffered from thrombosis (a blood clot) associated with your cancer?

- 1 Yes
2 No
3 Don't know / can't remember

2. Before taking part in this survey, were you aware that people with cancer have a higher than normal risk of developing thrombosis (a blood clot)?

- 1 Yes → **Go to Q3**
2 No → **Go to Q15**

Your understanding of the risks of cancer-associated thrombosis

In this section, we ask about your understanding of the reasons that thrombosis is a particular risk for cancer patients..

3. All people with cancer have a higher than normal risk of thrombosis. But certain cancers have a higher risk than others (including cancers of the stomach, brain, kidney and ovaries). To what extent are you aware of these risks?

- 1 Completely
2 To some extent
3 Not at all
4 Don't know / can't remember

4. Did you know that the risk of thrombosis increases for people with cancer at an advanced stage?

- 1 Yes, completely
2 Yes, to some extent
3 No, not at all
4 Don't know / can't remember

5. Did you know that cancer surgery can increase the risk of thrombosis?

- 1 Yes, completely
2 Yes, to some extent
3 No, not at all
4 Don't know / can't remember

6. Did you know that chemotherapy can increase the risk of thrombosis?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No, not at all
- 4 Don't know / can't remember

7. Did you know that radiotherapy can increase the risk of thrombosis?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No, not at all
- 4 Don't know / can't remember

8. Did you know that having a central venous catheter (a central line) can increase the risk of thrombosis?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No, not at all
- 4 Don't know / can't remember

9. Did you know that you are more likely to suffer from thrombosis if you are inactive for long periods of time (e.g. if you are in bed for 4 days or more)?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No, not at all
- 4 Don't know / can't remember

10. Did you know that you are more likely to suffer from thrombosis if you have had them before?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No, not at all
- 4 Don't know / can't remember

If you have any concerns about cancer-associated thrombosis, you should speak to your doctor.

Your understanding of what to look out for

In this section, we ask about how well you would recognise the symptoms of cancer-associated thrombosis.

11. Are you aware that the following can be signs of a blood clot in the arm / leg (**Deep Vein Thrombosis (DVT)**)? **Tick all that apply.**

- 1 Swelling in the foot, ankle or leg
- 2 Pain, cramping or tenderness, often in the calf
- 3 Redness or noticeable discoloration of the leg or arm
- 4 A warm or heavy sensation in the leg

If you think you have any of these symptoms, you should speak to your doctor or nurse immediately.

12. Are you aware that the following can be signs of a blood clot in the lung (**Pulmonary Embolism (PE)**)? **Tick all that apply.**

- 1 Light-headedness / dizziness
- 2 Unexplained shortness of breath
- 3 Irregular heartbeat
- 4 Chest pain (especially when breathing deeply)
- 5 Coughing up blood

If you experience any of these symptoms, you should CONTACT EMERGENCY SERVICES immediately.

Diagnosis of cancer-associated thrombosis

In this section, we ask how much you know about how cancer-associated thrombosis is diagnosed.

13. Did you know that following tests can be used to diagnose thrombosis? **Tick all that apply.**

- 1 An ultrasound scan
- 2 A CT scan

Preventing your risk of cancer-associated thrombosis

There are minor lifestyle changes that can reduce your risk of cancer-associated thrombosis. In this section, we ask about your awareness of these.

14. Are you aware that the following can reduce your risk of thrombosis? **Tick all that apply.**

- 1 Stretching your legs
- 2 Moving your feet
- 3 Taking a walk
- 4 Stopping smoking
- 5 Keeping hydrated
- 6 Wearing compression socks / stockings if these are prescribed

Treating cancer-associated thrombosis

Cancer-associated thrombosis can be treated effectively. It prevents blood clots from getting larger, and lowers the risk of new clots forming. In this section, we ask about your understanding of this treatment, and its possible side effects.

15. Did you know that thrombosis can be treated effectively using medicines known as anticoagulants (often referred to as “blood thinners”)?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No, not at all
- 4 Don't know / can't remember

16. Are you currently using anticoagulants / blood thinners?

- 1 Yes → **Go to Q17**
- 2 No → **Go to Q19**

17. Are you using these...

- 1 As a treatment for an existing condition
- 2 To reduce the risk of thrombosis in the future
- 3 For another reason

If 'For another reason', please specify below.

18. How do you receive this treatment?

- 1 Medicines given orally
- 2 Medicines given by injection

19. Have you been told about any possible side effects of anticoagulants / blood thinners?

- 1 Yes → **Go to Q20**
- 2 No → **Go to Q24**
- 3 Don't know / can't remember → **Go to Q24**
- 4 Not applicable → **Go to Q24**

20. Which side effects have you been told about?

21. Have you been told what to do if you are affected by any of these possible side effects of anticoagulants / blood thinners?

- 1 Yes – to speak to my doctor or nurse
- 2 Yes – to contact emergency services
- 3 Yes – other
- 4 No
- 5 Don't know / can't remember
- 6 Not applicable

If 'Yes – other', please specify below.

22. Have you suffered from any of these possible side effects of your anticoagulants / blood thinners?

- 1 Yes **→ Go to Q23**
- 2 No **→ Go to Q24**
- 3 Don't know / can't remember **→ Go to Q24**
- 4 Not applicable **→ Go to Q24**

23. Which side effects have you suffered?

How do you know about cancer-associated thrombosis?

In this section, we ask about where and when you became aware of cancer-associated thrombosis.

24. From which of the following did you get information about cancer-associated thrombosis?
Tick all that apply.

	Verbally	On paper	By email	Online	Social media
From my GP					
From a hospital doctor					
From my chemotherapy nurse					
From my radiologist					
From a specialist cancer nurse					
From another hospital nurse					
Through educational materials provided by a patient organisation					
Through my own research					
From my family or friends					

If you got information about cancer-associated thrombosis in any other way, please specify below.

25. When did you **first** become aware of cancer-associated thrombosis?

- 1 I already knew about it before I was diagnosed with cancer
- 2 I became aware of it when I suffered a blood clot
- 3 I was given information during my cancer diagnosis
- 4 I was given information before surgery
- 5 I was given information following surgery
- 6 I was given information before / during chemotherapy
- 7 I was given information before / during radiotherapy
- 8 Don't know / can't remember

If other, please specify below.

Overall awareness

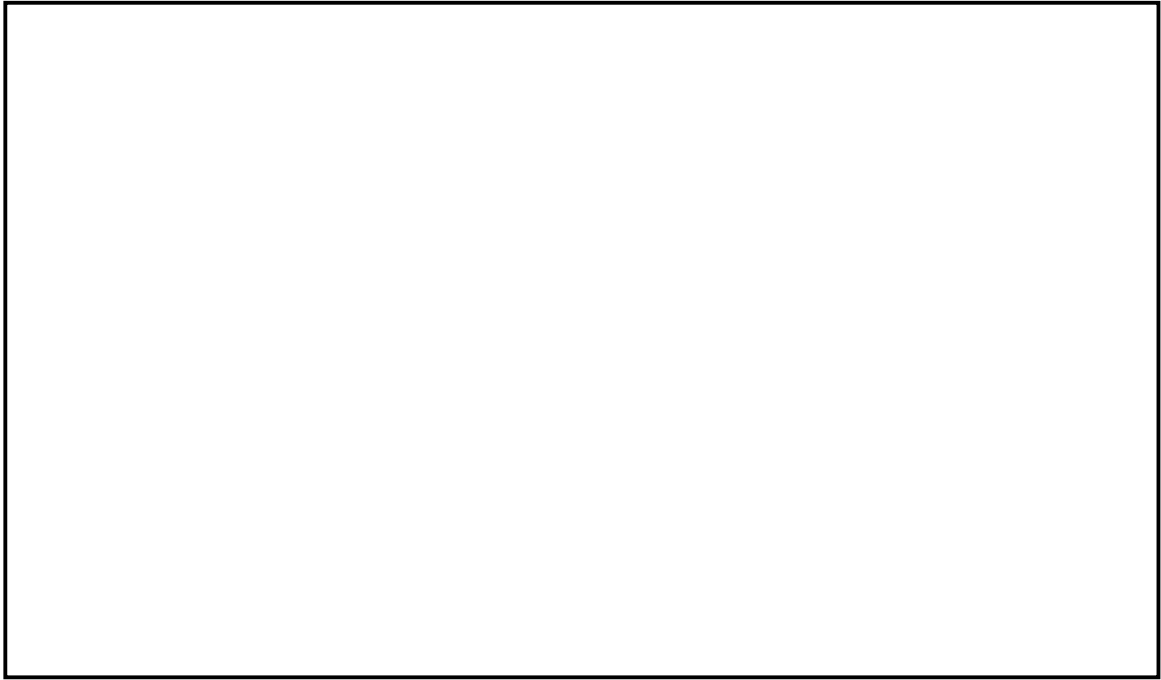
26. How would you rate your overall understanding of cancer-associated thrombosis on scale of 1 (low) to 10 (high)?

1	2	3	4	5	6	7	8	9	10

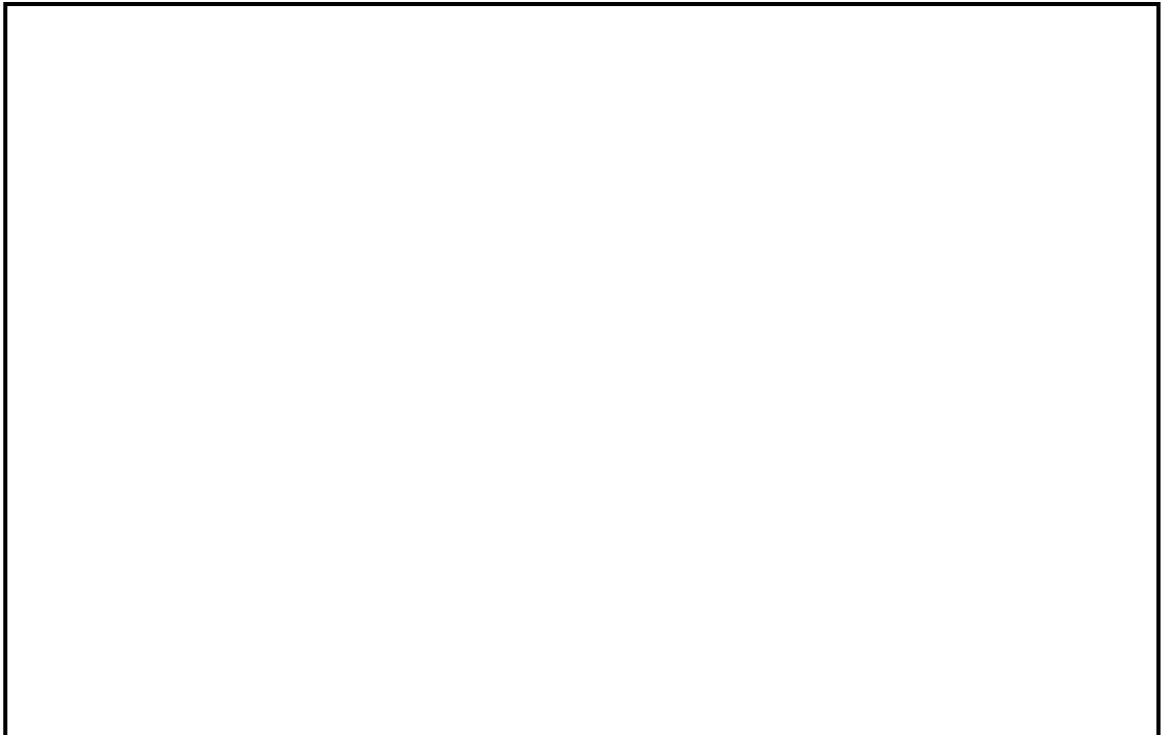
Any other comments

27. What do you think is the best way for cancer patients to find out about cancer-associated thrombosis?

28. What do you think should be done to make cancer patients more aware of the risk of thrombosis?



29. Do you have any other comments about cancer-associated thrombosis?



About your condition

In this section, we ask some details about your cancer, so we can understand the views of different groups of patients.

30. What type of cancer were you first diagnosed with?

- 1 Brain / Central Nervous System
- 2 Breast
- 3 Colorectal / Bowel
- 4 Ovarian
- 5 Other gynaecological
- 6 Haematological
- 7 Head and neck
- 8 Lung
- 9 Sarcoma
- 10 Skin
- 11 Oesophageal, Stomach, Pancreatic, Liver, or Gall bladder
- 12 Bladder
- 13 Prostate
- 14 Other urological
- 15 Other

If other, please specify below.

31. How long is it since you were first treated for this cancer?

- 1 Less than 1 year
- 2 1 to 5 years
- 3 More than 5 years
- 4 My cancer treatment hasn't yet started
- 5 I will not receive any treatment for my cancer
- 6 Don't know / can't remember

About you

In this section, we ask some details about you, so we can understand the views of different groups of patients.

32. Are you filling in this questionnaire on behalf of somebody else?

1 Yes

2 No

33. In what year were you born?

--	--	--	--

34. What is your gender?

1 Male

2 Female

3 Prefer not to say

4 Other

If other, please specify below.

--

35. Do you have any of the following longstanding conditions? **Tick all that apply.**

1 Deafness or severe hearing impairment

2 Blindness or partially sighted

3 A longstanding physical condition

4 A learning disability

5 A mental health condition

6 A long-standing illness, such as HIV, diabetes, chronic heart disease, or epilepsy

Keeping in touch

36. Where did you hear about this survey?

- 1 I saw a link to it online
- 2 From family/friends
- 3 From a patient organisation who keep in touch with me
- 4 From a healthcare professional
- 5 Other

If other, please specify below.

37. We might be interested in following up some of your answers in more detail. If you are happy for us to contact you again, please give us your email address here.

38. Please provide your email address if you wish to receive the results of the survey from the European Cancer Patient Coalition (ECPC).

If you agree to give your email address to ECPC, Quality Health will pass that information on to the ECPC secretariat.



For more information

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