



EUROPEAN
CANCER
PATIENT
COALITION

Cancer-associated thrombosis awareness survey

Executive summary

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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

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.

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.

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.



For more information

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