



**LUCE REPORT  
ON LUNG CANCER**

Challenges in lung  
cancer in Europe



Lung Cancer Europe

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## Challenges in lung cancer in Europe

November 2016

The LuCE Report on Lung Cancer is an initiative of Lung Cancer Europe to raise awareness among health stakeholders on the main challenges in lung cancer in Europe. We, as patient representatives, want to highlight in this Report our priorities, needs and proposals, encouraging health authorities, health professionals, companies, patient organisations and the society to implement solutions.

## Working together to face challenges in lung cancer

Lung cancer is one of the major public health problems today and it requires a global solution. From a patient perspective, unfortunately the challenges and the needs in this area are still multiple and LuCE (Lung Cancer Europe) and its members work daily to face them; we are actively involved and committed to defending patients' rights and we aim at getting an early diagnosis and equal chances for the best possible treatment. This is not an easy goal to achieve because lung cancer is still considered the biggest cancer killer in Europe, with more than 410,000 people diagnosed every year (more than 312,000 in the European Union). A large portion of patients live with comorbidities and their quality of life is deeply affected by the disease and the side effects of the therapy; supportive care and educational resources are essential and must be provided at the different stages of their disease and adapted to patients' and carers' needs.

Diagnostic tools and therapies are more effective and safe nowadays, and in recent years have improved patient quality of life. New treatment options such as targeted therapies and immunotherapy have changed the lung cancer scenario, bringing new hope for patients. However, these advances are highly expensive, and the costs and reimbursement represent a barrier to the implementation of innovative treatments, and even more, a barrier to patient access.

Unfortunately, not all the European health systems are capable of adopting novel treatment strategies. The situation is heterogeneous across Europe and causes persisting inequities, particularly in the eastern part. Apart from inequalities, other factors affect this situation and they have been considered and analyzed in this report.

LuCE is the voice of lung cancer patients in Europe, while our aim is also to ensure that the European health systems remain sustainable. Thus, the fast access to lung cancer treatments already approved in Europe is promoted, but also the need to have a sustainable approach is taken into account. Having this in our mind, we have tried to propose tailored solutions adapted to the needs and the constraints of each country.

Early diagnosis and treatments are the key elements for a good outcome, but we consider it crucial to invest more on prevention. About 85% of lung cancer cases are related to tobacco use, so the incidence of this disease would be drastically reduced through effective primary prevention strategies. People in Europe are more informed about the health risks connected with this addiction, but one out of four adults still keeps smoking. All of us must cooperate in order to reduce the number of smokers and promote a healthy lifestyle, especially among teenagers and young people, and even more in order to ensure an equitable access to innovative treatments for all lung cancer patients.

LuCE is a non-profit organisation established in 2013. One of its main objectives is facing all the challenges related to lung cancer prevention, diagnosis, treatment and care, and promoting patient involvement in these processes. We invite all of you to read the report and join us in order to combine our effort. Thousands of people in Europe are still waiting for support and they count on us in this fight.

Many faces. One voice.



**Stefania Vallone**  
**President of Lung Cancer Europe (LuCE)**

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## The beginning of a new era for lung cancer patients

Nowadays, physicians are often making diagnoses using symptoms-based disease archetypes, as opposed to underlying pathophysiology. The growing concept of “precision medicine” addresses this challenge by recognizing the vast yet fractured state of biomedical data, and calls for a patient-centred view of data in which molecular, clinical, and environmental measurements are stored in large shareable databases. Such efforts have already enabled large-scale knowledge advancement, but they also risk enabling large-scale misuse. With the completion of the human genome we understand that life is based on dynamic molecular networks rather than on a direct connection between genotype and phenotype.

The genomic revolution is still ongoing and represents an unprecedented opportunity with regard to emerging cancer diagnosis and therapies. Advances in genomic technologies have made it possible to sequence candidate oncogenes in cancers quickly and affordably, and gene expression profiling, full exome and/or full genome sequencing characterize a reasonably wide collection of tumours. Soon the numbers will be in the thousands. These data provide critical information about the spectrum and frequencies of mutations in cancers and will facilitate the development of drugs against targets that are most frequently mutated. Despite the early successes of targeted therapies, it is also becoming evident that primary and acquired resistance will be major limitations. Most solid and liquid tumours will not be overcome by single-agent targeted therapies. Even in those cases in which a single agent dissolves the tumour, the victory is short-

lived and the tumours re-emerge. More often, single-agent trials involving targeted therapies administered to solid tumours result in modest effects or no responses, even when confined to patients who have mutations in the target oncogene. Clearly, there is much yet to understand about in vivo tumour biology, and exploring resistance mechanisms is essential to decide what combination of drugs will treat resistant tumours, or even to prevent the emergence of resistance.

We are at the beginning of a creative period of bottom-up research activity, organized through pilot projects of increasing scope and scale, from which best practices will progressively emerge. Particularly given the size and diversity of healthcare enterprises, a single approach to data gathering that will populate the space is probably not appropriate for all contributors. As in any initiative of this complexity, what will be needed is the right level of coordination and encouragement of the many players who will need to cooperate to create a higher level of biomedical knowledge.

In this patient-centred context, patients’ advocacies are and will be every day more critical, from one side, in promoting the right social pressure for the systematic implementation of the results of preclinical and clinical research and, from the other, in developing an ongoing and continuous discussion with the regulatory bodies and national health care systems in the attempt to guarantee to every patient drug accessibility, but also in helping national authorities in maintaining the long-term financial sustainability of healthcare systems.



**Giorgio Scagliotti**  
University of Torino. Department of Oncology

# LUNG CANCER NUMBERS IN EUROPE

Thousands of people are diagnosed with lung cancer every year. It is a disease with the highest mortality rate among all cancers, and one that produces serious morbidities that affect patients' lives. **This must change!** Behind the statistics there are people just like you and me. Patients and caregivers who need solutions. Let's join forces in daily work aimed at improving healthcare for lung cancer patients across Europe!

## INCIDENCE

More than 312,000 people with lung cancer every year in the EU

The highest age-standardized rates (ASR)\* of lung cancer incidence worldwide are found in North America and Europe<sup>1</sup>. In the European Union, lung cancer is the fourth most commonly diagnosed cancer, affecting more than 312,000 people every year. Only breast, colorectum and prostate cancers present higher incidence rates.

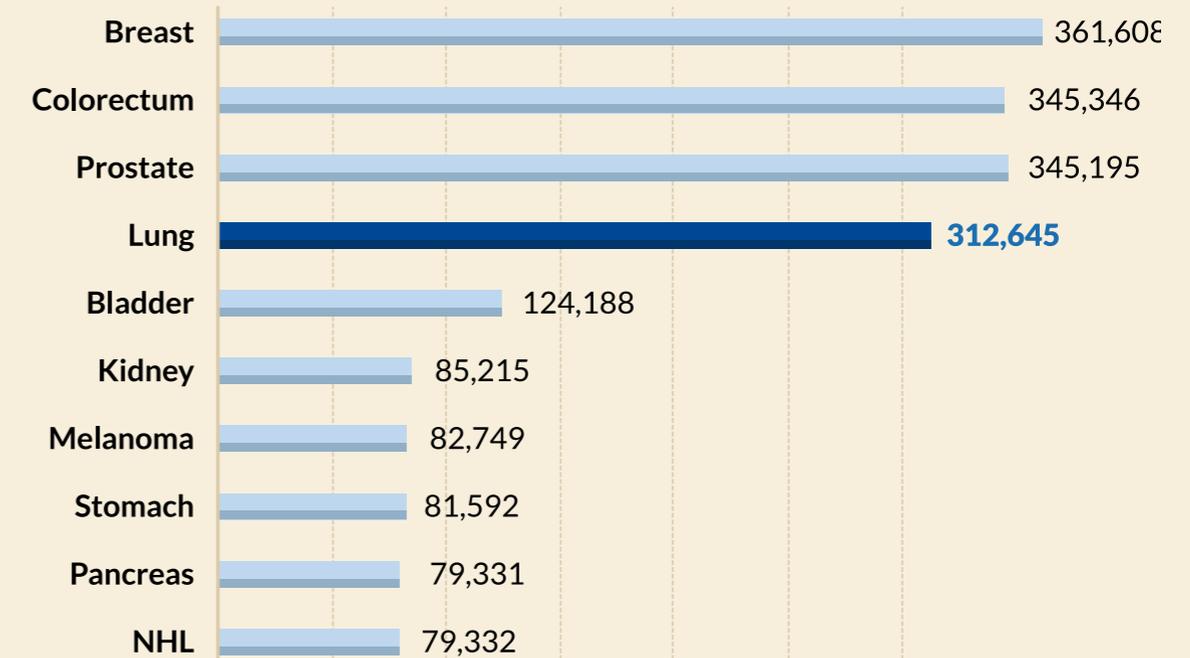
Cigarette smoking is the major cause of lung cancer<sup>2</sup>. Around 80-90% of all lung cancers are attributable to tobacco<sup>3</sup>, and we

must pay attention to the fact that one in four adults in Europe are still smokers<sup>4</sup>. Smoking rates are declining, but it will take many years until this decline translates into lower incidence rates<sup>5</sup>.

*Smokers are 15-30 times more likely to have lung cancer than non-smokers*

Active cigarette smoking is the main risk factor, but lung cancer has multifactorial causes. Around 10-25% of lung cancers worldwide occur in never smokers and the incidence of this disease among non-smokers is increasing in many countries<sup>6</sup>. Interactions between environmental, occupational and genetic factors are also important causes of lung cancer<sup>3</sup>.

## Cancer incidence cases in the EU



Source: GLOBOCAN 2012

\*This rate is a summary measure of the rate that a population would have if it had a standard age structure. It is necessary to use this rate to compare populations with different age-structures and time-periods. As cancer vary with age, countries with a relative high proportion of elderly people might have, proportionately, more cases.

## Lung cancer incidence in men and women

In Europe, around 213,663 men and 98,982 women are diagnosed with lung cancer every year. This makes lung cancer the second and third most commonly diagnosed cancer in men and women, respectively.

Worldwide, men are more frequently affected by lung cancer. However, the gender gap is decreasing in most European countries due to changes in the last few decades in the pattern of tobacco use<sup>2</sup>. Incidence rates of lung cancer in women are lower, but are on the rise in many countries<sup>7</sup>. In women, the decline in smoking rates has been less pronounced than in men, and some regions, like Eastern Europe, have experienced a net increase<sup>8</sup>.



1st Prostate cancer (345,195)  
**2nd Lung cancer (213,663)**  
 3rd Colorectum cancer (193,426)



1st Breast cancer (361,608)  
 2nd Colorectum cancer (151,920)  
**3rd Lung cancer (98,982)**

### Top 5 EU countries with highest incidence rates among men (ASR – World)



Hungary



Poland



Romania



Croatia



Latvia

### Top 5 EU countries with highest incidence rates among women (ASR – World)



Denmark



Hungary



Netherlands



Ireland



UK

*Lung cancer is more frequent in men, but the incidence is rising among women*

The highest smoking rates among women are in Austria, Bulgaria and Greece, but the risk of developing lung cancer in women is still higher in northern countries. This

is probably due to the approximate 20-year lag existing in the correlation between smoking prevalence rates and lung cancer incidence. Today, the highest incidence rates among women correspond to Denmark and the Netherlands (4 in every 100 women will develop lung cancer in these countries), followed by Ireland, United Kingdom and Norway (3 out of 100).

		ASR	Number of incidence cases
1	Hungary	51.6	9,288
2	Denmark	39.2	4,566
3	Poland	38.0	26,230
4	Netherlands	37.2	11,968
5	Belgium	36.8	7,794
6	France	35.0	40,043
7	Croatia	34.3	3,056
8	Slovenia	33.9	1,360
9	Romania	32.6	11,644
10	Czech Republic	32.5	6,683
11	Ireland	31.3	2,273
<b>EU</b>		<b>30.5</b>	<b>312,645</b>
12	Spain	30.3	26,715
13	United Kingdom	30.0	40,382
	Norway	30.0	2,845
14	Greece	28.5	6,884
15	Luxembourg	28.4	261
16	Slovakia	28.3	2,531
17	Bulgaria	28.1	3,936
18	Latvia	27.8	1,183
19	Austria	27.5	4,576
	Germany	27.5	50,813
20	Switzerland	27.3	4,237
21	Lithuania	26.2	1,555
22	Italy	24.5	37,238
23	Estonia	24.4	632
<b>World</b>		<b>23.1</b>	<b>1,824,701</b>
24	Israel	21.2	2,270
25	Malta	20.4	181
26	Portugal	20.2	4,192
27	Finland	20.1	2,494
28	Sweden	19.1	3,891
29	Cyprus	16.2	276

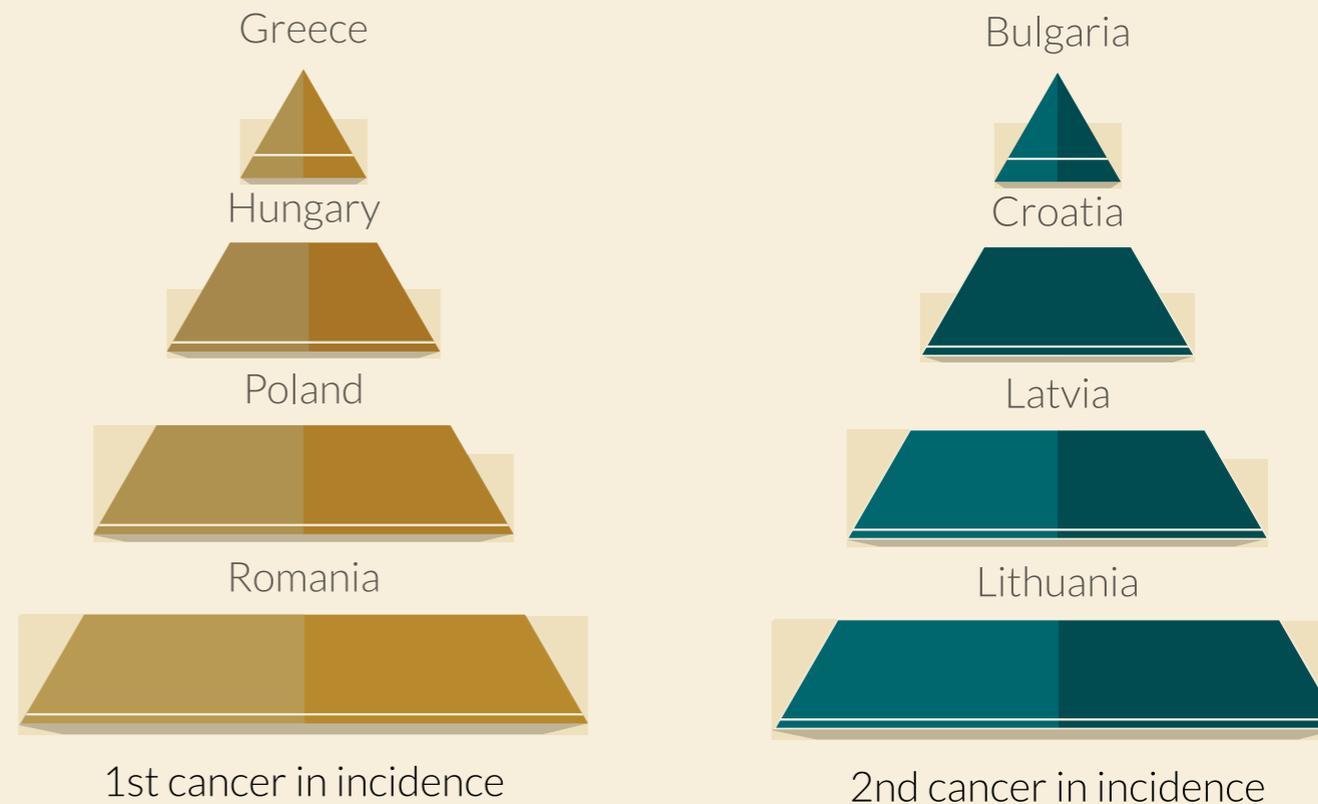
Source: GLOBOCAN 2012

## Incidence of lung cancer in the EU countries\*, by age-standardized rate (world) in both sexes

There are important differences in the lifetime risk of developing this disease across different countries. For instance, around 3 out of 100 men in Sweden, Cyprus, Finland and Malta will develop lung cancer during their lives, while this number goes up to 9 in every 100 in Hungary, and to 7 in every 100 men in Poland, Belgium, Croatia, Romania, Lithuania and Latvia<sup>3</sup>. The incidence rate in 23 European countries is higher than the worldwide average (23.1 per 100,000). Hungary has the highest incidence of lung cancer, with an age-standardized rate of 51.6 per 100,000. This is more than 20 points higher than the EU average, and 28 higher than the worldwide rate. In the EU, Hungary is followed by Denmark, Poland, the Netherlands and Belgium. These countries also present high rates of incidence (over 36.0 per 100,000).

Considering absolute numbers, lung cancer is the highest cancer incidence in four European countries (Greece, Hungary, Poland and Romania) and the second highest in Bulgaria, Croatia, Latvia and Lithuania

\*EU-28 (+ Israel + Norway + Switzerland: included because they have patient member organisations of Lung Cancer Europe)



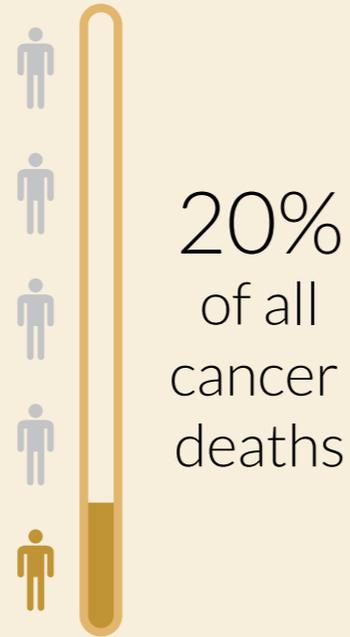
## MORTALITY

The leading cause of cancer death

Lung cancer is the main cause of cancer deaths in the EU, with 267,700 deaths recorded in 2012 and it accounts for approximately 20% of all cancer deaths<sup>4</sup>. It represents an average age-standardized rate of 24.7 deaths per 100,000 population, but this rate rises up to 37.7 among men. It is responsible for nearly one in five cancer deaths worldwide<sup>7</sup> and is the leading cause of cancer death in all European countries except in Portugal.

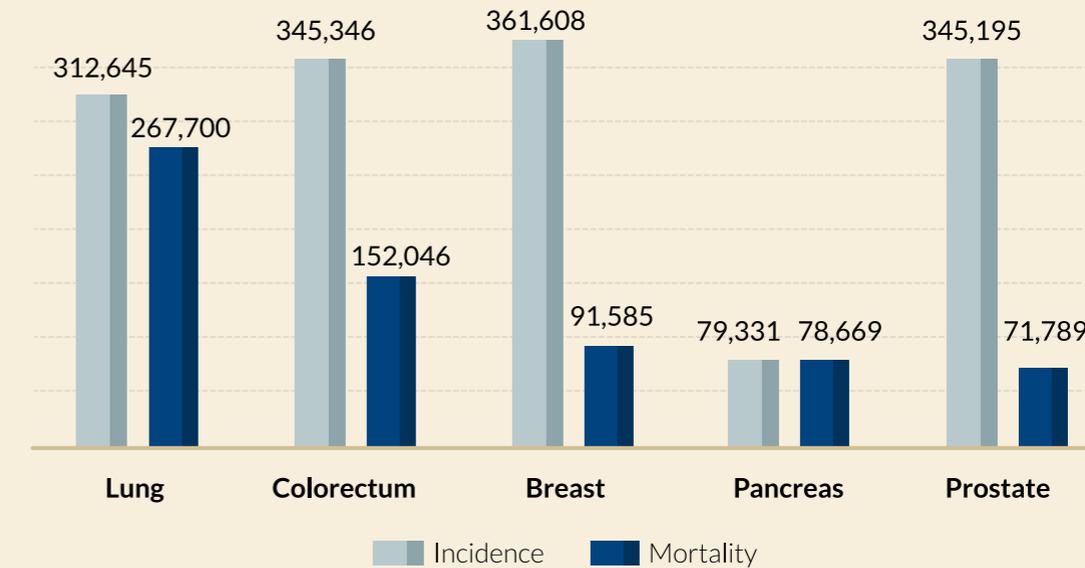
The main reason for this high mortality rate is the difficulty in detecting lung cancer in its early stages. Lung cancers are usually detected when the disease is in an advanced state, thus curative treatments are not possible in up to 90% of the cases<sup>4</sup>.

Lung cancer is the first cause of cancer death for European men and the third one among women. While mortality due to lung cancer has decreased in males, it is still increasing among females in many European countries<sup>9</sup>. As has happened with the increase in incidence, the main reason behind the increase in mortality rates among women seems to be the large number of women who have engaged in smoking in recent decades.

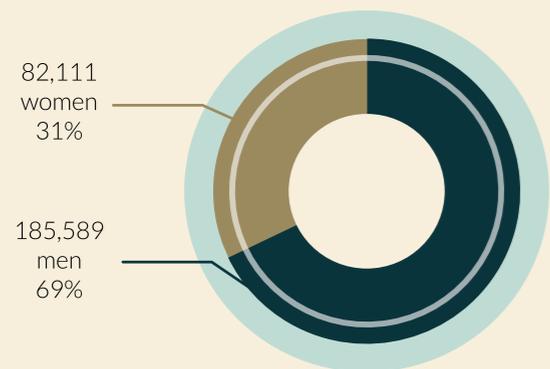


-LUNG CANCER IS RESPONSIBLE FOR  
1 IN 5 CANCER DEATHS-

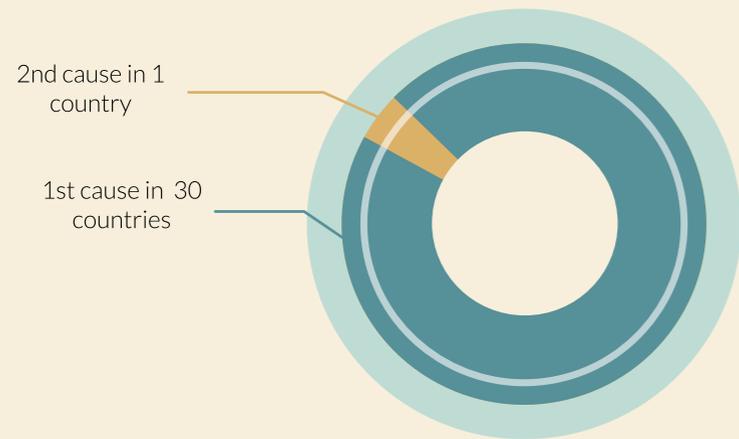
### 5 highest mortality cancers in EU



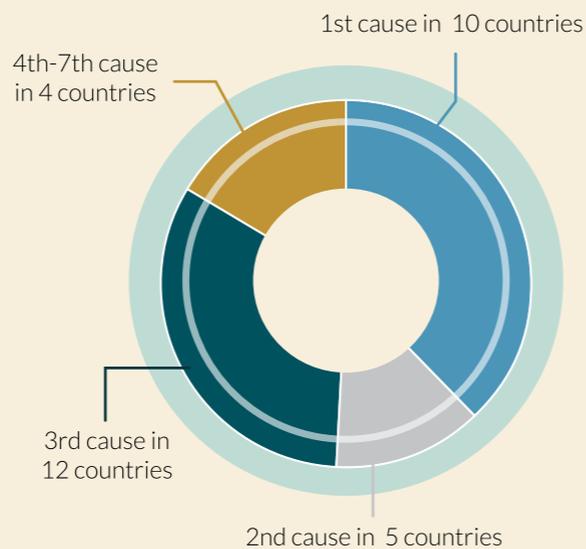
Source: GLOBOCAN 2012



Estimated number of deaths caused by lung cancer in EU (2012)<sup>1</sup>  
267,700 = 185,589 men + 82,111 women



Lung cancer as cause of cancer death among MEN in EU  
+ Israel, Norway and Switzerland



Lung cancer as cause of cancer death among WOMEN in EU  
+ Israel, Norway and Switzerland

## Mortality of lung cancer in the EU countries\*, by age-standardised rate (world) in both sexes

Mortality rates vary significantly between different European countries. Hungary is not only the top country in the EU in terms of lung cancer incidence, but it also shows the highest mortality rate of all European countries, with 43.3 deaths per 100,000. This rate increases up to 66.6 among men. It is followed by Poland, Denmark, Croatia, Netherlands and Belgium, with mortality rates of over 30.0 per 100,000 (ASR). The lowest death rates are observed in Sweden, Portugal, Malta and Cyprus.

Considering the age-standardized rate (world) in men and women, results show disparities in mortality of lung cancer across Europe. Countries from Eastern Europe have higher mortality rates in men. There are 15 countries that have rates above the EU average, of which 10 are from Eastern Europe.

On the other hand, the estimated age-standardized (world) of deaths in females is higher in Northern Europe, with six northern countries among the 12 with rates over the EU average.

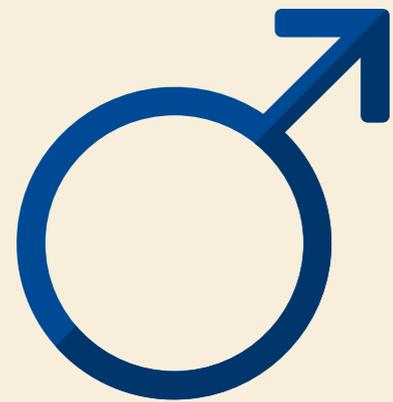
\*EU-28 (+ Israel + Norway + Switzerland: included because they have patient member organisations of Lung Cancer Europe)

		ASR	Number of deaths
1	Hungary	43.3	8,070
2	Poland	33.4	23,371
3	Denmark	31.4	3,806
4	Croatia	31.2	2,793
5	Netherlands	30.5	10,609
	Belgium	30.5	7,179
6	Romania	27.6	10,071
7	Slovenia	26.8	1,131
8	Bulgaria	25.9	3,659
9	United Kingdom	25.4	35,581
10	France	25.3	31,434
	Greece	25.3	6,434
11	Czech Republic	24.7	5,228
EU		24.7	267,700
12	Ireland	23.6	1,778
	Estonia	23.6	665
13	Luxembourg	23.1	218
14	Spain	22.8	21,118
15	Germany	22.2	43,420
	Latvia	22.2	1,002
	Norway	22.2	2,219
16	Slovakia	21.6	1,981
17	Lithuania	21.2	1,292
18	Italy	20.7	33,531
	Austria	20.7	3,658
19	Switzerland	20.0	3,194
World		19.7	1,589,925
20	Israel	17.9	1,956
21	Finland	16.7	2,138
22	Sweden	16.4	3,695
23	Portugal	15.7	3,441
24	Malta	15.6	139
25	Cyprus	14.7	258

Source: GLOBOCAN 2012

There are also socio-economic inequalities related to lung cancer mortality that vary between nations<sup>3</sup>. For example, there is some evidence that associates an increase in lung cancer mortality with a decreasing educational level in the Northern Europe and Continental populations, probably due to people being employed in high-risk industries (such as exposure to asbestos). This is in sharp contrast to Southern Europe, where mortality

increases with higher education among men. On the other hand, in women from Eastern Europe, there is a differential impact at the socio-economical level. While for young women, lower levels of education correlate with higher mortality rates, the trend reverses for women of advanced age. Older women tend to exhibit higher mortality rates when they have higher educational levels.



1. Hungary (66.6)
2. Poland (55.5)
3. Croatia (54.6)
4. Belgium (51.2)
5. Romania (50.0)
6. Latvia (49.4)
7. Estonia (48.6)
8. Bulgaria (47.8)
9. Lithuania (47.3)
10. Greece (45.4)

ASR (World) of deaths in males<sup>1</sup>



1. Denmark (28.4)
2. Hungary (26.6)
3. Netherland (24.5)
4. UK (21.4)
5. Norway (18.7)
6. Ireland (18.2)
7. Poland (17.6)
8. Sweden (16.1)
9. Switzerland (15.7)
10. Germany (14.5)

ASR (World) of deaths in females<sup>1</sup>

## SURVIVAL

Still a low survival rate

Lung cancer survival remains poor in Europe, although it is slightly increasing due to advances in cancer management. The overall 5-year survival is around 13% since diagnosis<sup>10</sup>, and it decreases in people with advanced ages at diagnosis. This rate is considerably influenced by the stage of the disease at diagnosis, but there are also variations depending on gender. Statistics show that women worldwide have better survival rates than men across all ages<sup>2</sup>. The 5-year survival rate is 11.2% for men, and 13.9% for women<sup>4</sup>.

On the other hand, in the EU, survival rates show little variation regionally. Eight out of the ten countries with the highest incidence rates are also among the 10 countries with the highest mortality rates. Disparities in national resources allocated to healthcare, early diagnosis and treatment have an impact on the survival rates of different cancers. For lung cancer, probably due to its low overall survival rate, these factors seem to have a minor influence<sup>7</sup>.

It is not realistic to expect a decrease in incidence in the near future; however, an improvement in survival rates has already been seen and will continue to rise in countries with successful and rapid implementation of novel treatment strategies.

*-THE BURDEN OF LUNG CANCER IN EUROPE REMAINS LARGE TODAY AND IS LIKELY TO REMAIN SO FOR SEVERAL DECADES-*





## DIAGNOSIS AND TREATMENT: CHALLENGES FROM THE PATIENT PERSPECTIVE

In lung cancer, time matters for patients. For a good prognosis we need early diagnosis and fast access to effective and safe treatments. The goal is to live longer, with a better quality of life than today

Early diagnosis is fundamental for a good prognosis but it is not always possible, and around 70% of patients are diagnosed at an advanced or metastatic stage<sup>11</sup>. The main reason for late diagnosis is that first symptoms usually appear when the disease has already spread to other parts of the body, mainly bones, brain, liver, adrenal glands, pleura and the other lung<sup>3</sup>. In the cases where the disease causes symptoms

at the beginning, they are often associated with some less serious causes, such as an infection or effects from smoking.

Screening programs may help to detect lung cancer in early stages and reduce the mortality rate. However, more research is needed to gather data about the efficiency and cost-effectiveness of lung cancer screening<sup>12</sup>. There are no screening

guidelines that provide a benchmark for member states<sup>13</sup>. Such guidelines are common practice in the US, and have also been implemented in Europe for other cancer types. Potential users could be the population at high risk, like smokers, people with lung disease and people with lung cancer history in the family. Several lines of research are trying to develop new methods for the early detection of lung cancer.

*-DIAGNOSTIC RESOURCES ARE NOT EQUAL ACROSS EUROPE, NOT EVEN WITHIN COUNTRIES-*

Treatment should be discussed within a multidisciplinary team<sup>14</sup> and must consider the type of tumour, the extension and stage of the disease. The overall fitness of the patient, his or her needs and preferences, and the existence of biological features (EGFR gene mutation or ALK rearrangement) must also be considered. All these parameters must be defined in an accurate diagnosis process that includes clinical, radiological, histopathological and cytological examination. An improvement in diagnosis provides better preconditions for successful medical treatment, but diagnostic resources are not equal across Europe, not even within countries.

The landscape of lung cancer treatment is changing quickly. There have been some progresses in surgery techniques, radiotherapy and chemotherapy, which remain the standard of care in many of the cases. However, lung cancer is no longer considered a single disease, and there are multiple combinations, depending on each individual case. Moreover, thanks to the advances in our understanding of the biology and molecular mechanism of lung cancer, new biological drugs have appeared to bring new hope to patients. New targeted therapies available for NSCLC patients with specific genetic mutations are providing meaningful outcomes<sup>15</sup>. These treatments require testing for the presence of ALK gene rearrangements and EGFR gene mutations in the diagnosis process. This is now crucial for metastatic lung cancer so we need more research to identify molecular markers that can lead to progress in personalized medicine.

## *-PERSONALIZED MEDICINE AND IMMUNOTHERAPY HOLD A PROMISING ROLE IN THE TREATMENT OF THE DISEASE, AND NOW MOLECULAR TESTING IS BECOMING AN IMPORTANT PART OF THE CLINICAL DECISION PROCESS-*

New treatments, like molecular targeted therapy and immunotherapy, are being increasingly used for lung cancer, and there are prospects of forthcoming advances. However, there are still important challenges related to these promising treatments:

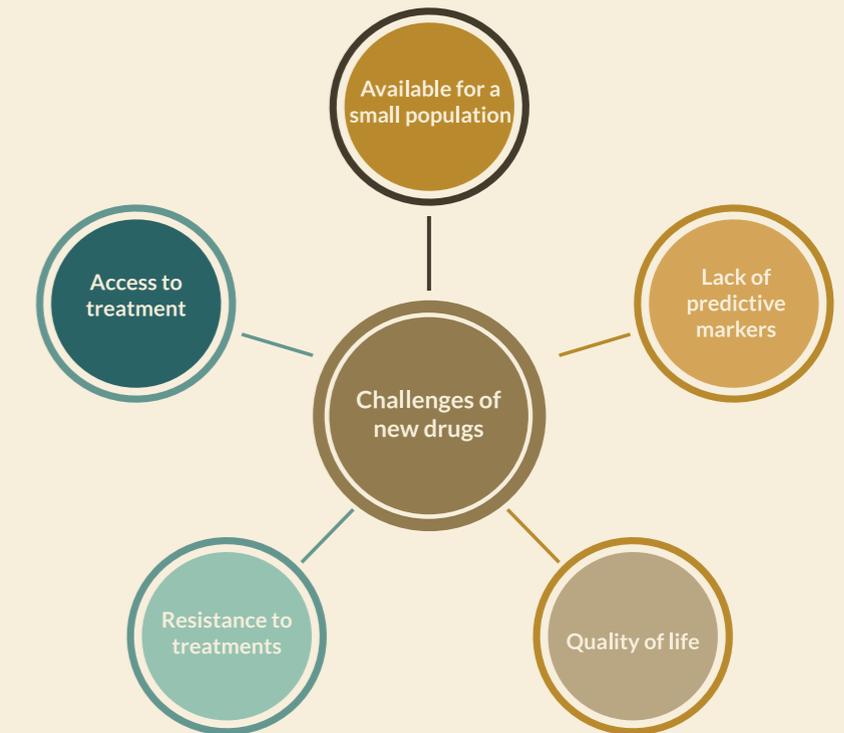
1. Among patients, there are great expectations about new therapies. They represent a first important step of a new therapeutic approach and a significant number of patients are accessing these treatments. However, we must consider that most of patients do not have specific genetic mutations expressed and they are not candidates for these targeted therapies. We should manage the expectations around these innovative drugs.

2. Lack of predictive markers. We need to have the possibility to treat the right patient with the right medicine in order to save the patient from a non-optimal toxic treatment.

3. Quality of life is an important issue for patients, so we need to improve outcomes in symptom relief. Even when the tolerance to these new treatments is higher, compared to conventional chemotherapy, some side effects are still severe.

4. Tumours often acquire resistance to targeted therapies. The therapies work for a period of time and then stop working. We must find out how to solve this problem and offer effective alternatives to patients.

5. Barriers in access to these new drugs are producing inequalities in the EU. The high price of these treatments is becoming a major issue on the political agenda. In addition, the access to novel therapies in the frame of clinical trials seems to be far from being optimal in numerous EU countries, especially in smaller ones.



## ACCESS TO INNOVATIVE TREATMENTS. A PRIORITY FOR PATIENTS

Recent research has produced new drugs approved by the European Medicines Agency (EMA) for lung cancer patients, especially at the advanced and metastatic stages. A new era has started, with drugs tailored to target specific signaling pathways, like the EGFR and ALK pathways. Erlotinib, gefitinib, crizotinib, ceritinib, osimertinib and necitumumab have proven useful in the management of patients in advanced stages. Also, immuno-oncological therapies like nivolumab or pembrolizumab have provided patients with more therapeutic options.

However, there are unacceptable disparities in the accessibility of these medicines across Europe. The high cost of some of these treatments has produced sharp differences in the ability of European patients to access these new treatments<sup>16-17</sup>. This affordability problem has caused some health care systems to be unable to reimburse all treatment options. New therapies are often given along with conventional treatments, thus considerably increasing the overall cost of treating patients. As new therapies are expected to become available in forthcoming years, combined treatment is likely to become the norm. Increasing costs, therefore, might become a major challenge for all health stakeholders in the near future.



*Every individual has the right of access to the health services that his or her health needs require. The health services must guarantee equal access to everyone, without discriminating on the basis of financial resources, place of residence, kind of illness or time of access to services*

European Charter of Patients' Rights<sup>18</sup>

Access to treatments is related to individual countries' economic strength and the human development index<sup>19</sup>. The IHE Report 2016:4 highlighted some variations between national uptakes of lung cancer drugs depending on their GDP/capita tier. For instance, the uptakes of pemetrexed, crizotinib and gefitinib in upper GDP/capita tier were more than double than in lower GDP/capita tier in 2014.

However, there are also disparities among countries with a similar economic level, which is probably explained by the implementation of national policies aiming at evidence-based as well as cost-effective care<sup>20</sup>. We must say that spending on cancer is usually associated with higher survival rates, but this correlation is lower in lung cancer<sup>5</sup>. As a consequence, we can find countries with different levels of spending with, at the same time, similar survival rates.

Time is another inequality factor for patients. 10 new drugs for lung cancer have been approved between 1995 and 2015<sup>5</sup> but not all European patients have accessed them at the same time. Once a cancer drug is authorized by EMA, it is supposed to be implemented at a national level in 180 days. However, this time can be considerably longer in many countries<sup>20</sup>. Delays to implementation (reimbursement) of cancer medicines are more pronounced in Eastern Europe.

Inequalities can also be found in the national treatment guidelines of different European healthcare systems<sup>5</sup>. Although there are

*-EXPENDITURE IS NOT ALWAYS LINKED TO OUTCOME, AND CAREFUL PLANNING AND MANAGEMENT IS NEEDED-*

European guidelines for the treatment of the different types of lung cancer, different views on best practices and budgetary constraints at the national and regional level can produce disparities in the recommended therapy. Tools like the ESMO Magnitude of Clinical Benefit Scale (ESMO-MCBS) could help EU countries to make priorities on evidence-based data. This is a way to assess the magnitude of clinical benefit that can be expected from a new cancer medicine and it helps to provide a cost-effective and affordable cancer care, considering the limited public resources<sup>21</sup>.

We should also consider potential inequalities in health outcomes within countries, presented as the difference in health status between socioeconomic groups, geographic location, employment status, gender or ethnic groups. Interventions must tackle the macroenvironmental factors and the physical and social environment, as well as adverse health behaviours and access to health care, but there are differences in national policy approaches to health inequalities<sup>22</sup>. Inequalities in health care are not only considered as regards diagnosis and treatment but also in the general spectrum of health information/education, early diagnosis, timely and adequate treatments, palliative care and quality of care in general<sup>23</sup>





Tom Simpson  
Lung cancer patient

I wish I had pushed for more checks sooner, or gone somewhere else for second opinions! But I regret to say that I didn't. I had been getting continuous rib and back pain and lung pain for over a year. My general doctor had considered pneumonia, a bashed rib, infection and asthma. When tests and X-rays showed nothing, even psychosomatic pain was considered.

The diagnosis was a real shock and it happened so quickly. Whilst at work, I got breathless and went to the hospital.

There, it was found that I had excessive fluid on my lung. At this point I was happy, because someone had spotted something was actually wrong. After a basic biopsy and a few days waiting, I was told that they had picked up cancer cells in the lung, and that also the fluid had malignant cells. My symptoms did not appear previously as red flags because I was only 45 and a non-smoker. If I had been diagnosed earlier could I have been caught before and got a better prognosis? Who knows...

I was then referred to a surgeon. At all appointments there has also been a dedicated cancer nurse, who is there to answer any questions. The surgeon advised me that, according to the biopsy and CT scan, I had Stage IV cancer and that I should get my affairs in order. On asking the surgeon for timescale, I was told 12 months! A procedure called a pleurodesis was to be done and a proper biopsy taken of the cancer.

When I got my first oncologist appointment, my nurse was again present. This was the start of dealing with people that are helping me a lot in my journey. She emailed me with

a full breakdown of my diagnosis with clear information about my treatment. This extra communication was important because you don't always hear what you are being told at consultations. The biopsy found that, despite being Stage IV, there is a genetic mutation and I can get great treatment results from a biological therapy that may extend my prognosis by an average of 11 months. As I am writing this testimony, I am beating that figure by more than double: it has been 26 months since I started the treatment. My doctor, who is always positive, says some of her patients have been on this drug for years.

Information from reliable sources and communication with my oncologist are helping me a lot in facing the disease. She keeps me informed about what drug they will consider when this one stops working due to resistance. And she also tells me about new treatments that I am not going to use because they would not work due to my specific cancer type. I am confident in my team: a team that includes family and work.

I hope my story can give others hope that diagnosis is not the end!

## BEYOND THE DISEASE: PEOPLE LIVING WITH LUNG CANCER

This is only one personal story but we must remember that behind every number, behind every diagnosis, there are real people like Tom. People whose lives and the life of their relatives changed after diagnosis. There are thousands of 'Toms' who are facing the disease and deserve the most effective, safe and human health care. Thanks to advances in diagnosis and treatment, and the support of health professionals and other stakeholders like patient organisations, lung cancer patients face the difficulties of the disease with more hope and resources.

Quality of life matters. Thus, we must offer a multi-disciplinary health assistance to patients and caregivers for a better management of the disease and a better wellbeing.

Lung cancer is associated with high associated co-morbidity, which

considerably reduces a patient's quality of life<sup>24</sup>. Information and access to a multi-disciplinary health team and support from patient organisations are key elements to get a better quality of life. We need accurate information and continued support services along the disease process to know how to manage side effects and symptoms. A facilitator or a navigator is also important, bearing in mind the proper outcome of the treatment, helping the patient to make his or her way through the therapy.

### -QUALITY OF LIFE MATTERS-

Improving our lives requires a patient-centric approach in healthcare. Patients must be able to have access to treatments against side effects, palliative services, rehabilitation resources, and psychosocial support. For these purposes, we need to retrieve more

information on the difficulties experienced by patients living with the disease.

We must also pay attention to the wellbeing of caregivers. Their lives also suffer important changes after diagnosis, and they often experience feelings of sadness, anxiety, fear or ire. However, they usually do not receive any support<sup>25</sup>. Health professionals and patient organisations must be aware about the impact of lung cancer on relatives and caregivers, providing them with personalized assistance to prevent and reduce the negative consequences of the disease.

It is also crucial to train the doctors on how to talk to patients in such situations. It is very important to be able to build an open relationship between the patient and the medical staff, which will affect the effectiveness of the therapy and the psychological health of the patient<sup>19</sup>.

## HOW CAN LUNG CANCER IMPACT ON OUR LIVES?

### Physical symptoms

Cough and breathing difficulties  
Pain  
Fatigue  
Nausea, vomiting  
Weight loss  
Speaking difficulties  
Diarrhoea  
Rash  
Loss of hair  
Mouth sores  
Haemothorax  
Pulmonary contusion

### Social impact

Limited social activity  
Impact on financial situation  
Consequences on the working sphere  
Difficulties on functioning in their former familial role

### Psychological difficulties

Anxiety / Worry  
Depression  
Sleeplessness  
Sadness  
Fear  
Anger  
Isolation  
Feelings of shame and guilt  
Stigma



## CALL-TO-ACTION. LET'S DO IT!

We, as patient organisation that represents the rights of thousands of people affected by lung cancer, demand a coordinated and sustainable action from all stakeholders in healthcare in order to get patient-centred care. Health professionals, European and national policy makers, health economists, patient organisations, research centres, pharmaceutical companies, media and society in general, must work together to reduce the number of people diagnosed with

lung cancer and improve the health and wellbeing of today's and tomorrow's lung cancer patients.

Wherever we are, and regardless of who we are, we all share similar challenges and must find solutions together. These are not easy challenges and they will probably require innovative solutions, so it is important to exchange information and best practices among the different countries as well as the different stakeholders.

*-YOU CAN'T SPELL CHALLENGE  
WITHOUT CHANGE. LET'S LOOK  
FOR NEW SOLUTIONS!-*

## TOP-4 CHALLENGES

- Provide quality smoking cessation services and support
- Promote smoking prevention policies such as advertising and marketing bans for tobacco control or higher taxes
- Public and occupational health policies to reduce exposure to carcinogens
- Control measures to prevent air pollution

- Higher investments in research for more effective and safer treatments
- Accelerate the referral from primary care to specialists
- Improve screening for people at high risk
- Raise awareness and education on the symptoms among the general public

Reduce the incidence of lung cancer

Improve the patients' and survivors' quality of life

Reduce the number of deaths caused by lung cancer

Promote equal and faster access to treatments, ensuring sustainability of health systems

- Promote early palliative care resources
- Offer emotional and social support to patients and caregivers
- Access to rehabilitation services
- More accurate and comprehensive information for patients
- Provide a facilitator/coordinator of the treatment

- Link the prices of medicines to the health benefits they produce (added value for patients)
- Ensure a high level of expertise and knowledge in lung cancer care centres
- Harmonize HTA bodies to set equal decisions about the same medicine
- Promote the collection of systematic data on expenditures in cancer care
- Decentralized solutions and flexible payment procedures

(AND SOME GLOBAL SOLUTIONS)

## WHAT CAN WE DO?

*PREVENTION, EARLY DETECTION, EFFECTIVE  
TREATMENT AND CARE*

*LET'S DO IT!*

## PATIENT ORGANISATIONS

- Raise social awareness to prevent lung cancer and to fight against stigma caused by the disease
- Collect patient data to identify unmet needs
- Play a role in research, reimbursement and technology assessment processes, providing the patient input into the clinical/economic recommendations
- Monitor the correct implementation of the EU cross-border healthcare directive to ensure access to treatments
- Recognize the value of working at European level for policy changes
- Work with policy makers and other stakeholders continuously, throughout the year
- Improve advocacy skills to be an effective health stakeholder
- Promote patient engagement and involvement in advocacy
- Share best practices among patient organisations

## HEALTH PROFESSIONALS

- Further research about effective technologies on screening, diagnosis, treatment, care and rehabilitation
- Closer collaboration between laboratory and the clinic, and between primary care and oncologists
- Improve the health education of the population, promoting healthy lifestyles, and allowing early consultation with the GP at symptom onset.
- Provide smoking cessation interventions to patients who smoke
- Offer coordinated and multidisciplinary health assistance to patients (including early palliative care), involving them in the decision-making process
- Develop guidelines on lung cancer care
- Report adverse drug reactions in order to identify outcomes in clinical practice
- Promote specialized nursing in lung cancer as a key source of support
- Develop a lung cancer care coordinator role for free flow of information between professionals, patients and caregivers
- Harmonize treatment guidelines for lung cancer in different countries

## POLICY MAKERS

- Promote effective smoking prevention policies and homogenize tobacco control legislation across Europe
- Ensure funds for research and innovation in the field of lung cancer
- Adopt effective screening programs for lung cancer
- Harmonize HTA approaches to close the gap in access
- Follow ESMO Score of clinical benefit when deciding on reimbursement policies
- Ensure transparent and regulated drug pricing and reimbursement, and get more collaboration among nation states on price negotiations
- Shorten the time for new drugs to be introduced in member states
- Ensure the access of patients to clinical research across borders
- Improve and harmonize data collection for patients in Europe
- Involve patient organisations and health professionals in the decision-making process of new policies
- Ensure implementation of guidelines for lung cancer diagnosis and treatment
- Develop guidelines for best practise to be advised, in order to get implementation nationally in healthcare centres
- Stimulate the development and accreditation of centres specializing in lung cancer across Europe, to create reference networks
- Develop uniform national cancer plans

# PHARMACEUTICAL INDUSTRY

- Improve transparency about costs of research and development of new drugs
- Introduce new flexible payment procedures in pricing/reimbursement negotiations
- Set a new approach in pricing based on the assessment of added value and cost-effectiveness of drugs for patients
- Implement effective procedures for post-market data collection
- Work with patient organisations to identify unmet needs to consider in research and to have the patient perspective on the medicine development process
- Reduce the avoidable waste in the production and reporting of research evidence



**T**ogether  
**E**veryone  
**A**chieves  
**M**ore

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## ABOUT LuCE

Lung Cancer Europe is the voice of lung cancer patients, their families and survivors at a European level. LuCE provides a European platform for already existing lung cancer patient advocacy groups and supports the establishment of national lung cancer patient groups in different European countries where such groups do not yet exist.

LuCE aims to raise awareness about inequities regarding the access to lung cancer treatment and care in Europe. Moreover, it advocates European policies that will lead to improvements in lung cancer prevention, early detection, treatment and care. LuCE also supports national lung cancer patient groups in helping raise awareness for lung cancer among the European public.

### Our objectives

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- Reduce the mortality of lung cancer.
- Promote the best possible treatment of the different types of lung cancer.
- Equal access to lung cancer care throughout Europe.
- Raise public awareness for lung cancer about symptoms, early detection and treatment.
- Reduce the stigma associated with lung cancer and more compassion for lung cancer patients and their loved ones.
- Increase European funding allocated to lung cancer research.

## About our members

LuCE gathers its strength from the combined action of different national patient organizations across Europe. These organizations give support to lung cancer patients, defend their rights and represent their interests on an everyday basis. They are the voice of the patients in national and international forums, and their work benefits society as a whole. We are stronger together, thus we thank each and every one of the members of LuCE for their generous contribution.

We encourage readers to learn more about these organisations and support them.



Asociación Española de Afectados de Cáncer de Pulmón

[www.aeacap.org](http://www.aeacap.org)



Forum Lungenkrebs Schweiz  
[www.forum-lungenkrebs.schweiz.ch](http://www.forum-lungenkrebs.schweiz.ch)



Bundesverband Selbsthilfe Lungenkrebs e.V.

[www.bundesverband-selbsthilfe-lungenkrebs.de](http://www.bundesverband-selbsthilfe-lungenkrebs.de)



Israel Lung Cancer Foundation

[www.ilcf.org.il](http://www.ilcf.org.il)



Landesverband Baden- Württemberg für  
Lungenkrebskranke und deren Angehörige e.V

[www.lungenkrebs-bw.de](http://www.lungenkrebs-bw.de)



Lungekreftforeningen

[www.lungekreftforeningen.no](http://www.lungekreftforeningen.no)



Pulmonale

[www.pulmonale.pt](http://www.pulmonale.pt)



Longkanker Nederland

[www.longkankernederland.nl](http://www.longkankernederland.nl)



National Lung Cancer Forum for  
Nurses (NLCFN)

[www.nlcfn.org.uk](http://www.nlcfn.org.uk)



Stowarzyszenie Walki z Rakiem Płuca

[www.rakpluca.org.pl](http://www.rakpluca.org.pl)  
[www.rakpluca.szczecin.pl](http://www.rakpluca.szczecin.pl)



Lungencancerförbundet Stödet

[www.stodet.se](http://www.stodet.se)



Patientforeningen Lungekræft

[www.lungekraeft.com](http://www.lungekraeft.com)



Women Against Lung Cancer in Europe

[www.womenagainstlungcancer.eu](http://www.womenagainstlungcancer.eu)

## Associate members

LuCE associate members are organisations committed to improve the lives of lung cancer patients. LuCE wishes to thank these organizations for their continuous support.



**Društvo onkoloških bolnikov Slovenije**

[www.onkologija.org](http://www.onkologija.org)



**European School of Oncology (ESO)**

[www.eso.net](http://www.eso.net)



**European Thoracic Oncology Platform (ETOP)**

[www.etop-eu.org](http://www.etop-eu.org)



**Fundación MÁS QUE IDEAS**

[www.fundacionmasqueideas.org](http://www.fundacionmasqueideas.org)

We would like to thank Amgen, Boehringer Ingelheim, Lilly, Pfizer, Bristol-Myers Squibb, Novartis, MSD and Roche for the great support they offer LuCE. We are very grateful for the interest they have always shown in our organisation. We hope we will continue working with them, as we encourage all individuals and organisations to join us in the endeavour of representing lung cancer patients across Europe.

We are indebted to Tom Simpson for his generosity in sharing with us a small (but very important) piece of his life, and to Giorgio Scagliotti for his call to action to all stakeholders.

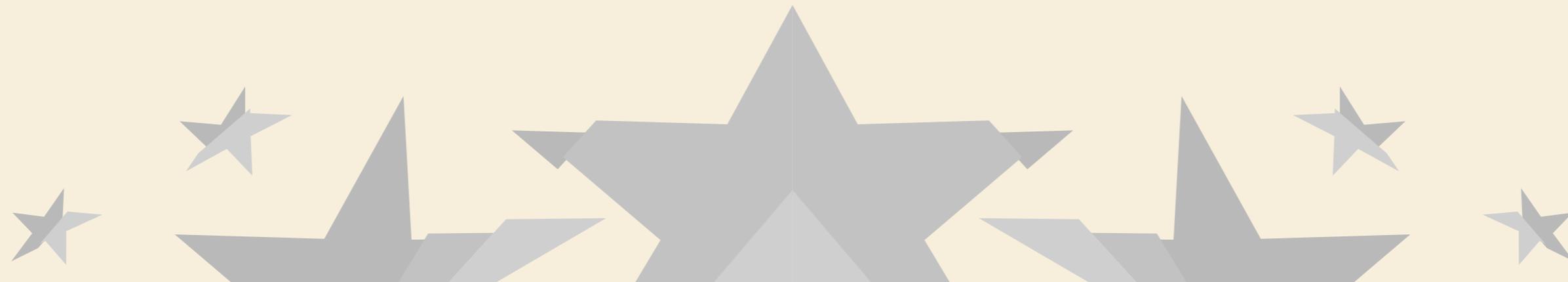
We would like to thank MÁS QUE IDEAS Foundation for their key role in elaborating this report.

If you are interested in joining LuCE, please contact us. We will be pleased to meet you!

[luce@etop-eu.org](mailto:luce@etop-eu.org)

# DIFFICULT ROADS OFTEN LEAD TO BEAUTIFUL DESTINATIONS

LET'S DO THE WALK TOGETHER!





Lung Cancer Europe

**LUCE REPORT  
ON LUNG CANCER**

Challenges in lung  
cancer in Europe

[www.lungcancereurope.eu](http://www.lungcancereurope.eu)

LuCE is the voice of lung cancer patients, their families and survivors at a European level