



Lung Cancer Europe



# IV LuCE REPORT ON LUNG CANCER

Early diagnosis and screening  
challenges in lung cancer



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# FOREWORD

Lung cancer accounts for the most cancer related deaths in the world (Globocan 2018 data). In Europe, it is a major healthcare burden, and is the leading cause of cancer related deaths, as well as the second most often diagnosed cancer in Europe (Globocan 2018 data). It is well recognised that lung cancer is often diagnosed late, which means that less treatment options are available for people impacted by advanced disease. This results in almost as many patients being diagnosed, as the number of those who pass away each year because of lung cancer.

In recent years, LuCE has provided an overview of the barriers that we need to overcome in lung cancer in Europe (2016), identified poor and unequal access to treatment (2017) and outlined the challenges in lung cancer clinical trials (2018). This year we decided to focus on the topic of early diagnosis. If more patients were diagnosed earlier it could lead to much more effective treatment outcomes, better quality of life as well as improved overall survival rates. The sooner lung cancer is diagnosed the better the chances are for being cured or having more treatment possibilities to choose from and to get the most efficient results.

Sadly, there are many barriers of different types that need to be faced in this field. Firstly, people may not be aware that their symptoms are serious and need to be taken care of. Sometimes they deny that the symptoms they are experiencing may relate to

something serious and they decide to postpone a health check-up for various reasons. Secondly, some primary health providers may not recognize lung cancer symptoms and therefore do not refer patients for further tests in a timely manner. Many times the symptoms patients present with are not specific to lung cancer only and may relate to many different illnesses. Nevertheless, primary health providers also do not always recognize patients in higher risk groups to whom they should pay more attention to, if they report any symptoms that may be lung cancer related.

Much research has been done, and is ongoing, in the field of lung cancer screening including its' efficacy. There are concerns whether screening may be too expensive to implement, having in mind the amount of scans that may need to be performed to find a lung cancer diagnosis; as well as the rate of false positives, in which patients with suspicions scan results undergo multiple other invasive tests to find out that they do not have lung cancer after all.

Nevertheless, it must be taken into consideration that an earlier diagnosis means a reduction in healthcare burden. For patients it also means that their chance of getting back to their working life is improved. A patient diagnosed early, will lessen the impact on society by reducing the need for a long term hospital stay, expensive treatment, not being able to work and needing social care. Early diagnosis enables patients to avail of the most effective treatment options. Having in mind the above, investing in ways to improve early detection in lung cancer is the best possible aim to have for the national healthcare systems, decreasing the cost

*The sooner lung cancer is diagnosed; the better the chances are for being cured or having more treatment possibilities to choose from and to get the most efficient results.*

of treating a patient with late stage lung cancer, as well as for the patients - who will suffer less and have higher chances to live longer if they are diagnosed earlier.

However, it is not only the health care system that needs to be addressed in order to get best possible results for the early diagnosis of lung cancer. It is also society that needs to overcome the stigma of the disease, which can hold people back from getting checked. Once people are better informed and they believe that early diagnosis in lung cancer can save lives, there may be less fear to get checked. We need to educate society, so they understand that an early diagnosis in lung cancer is not a death sentence. Therefore, it is vital to create a new approach based on better knowledge. It is vital that society understands that getting checked increases the chance of early detection of lung cancer,

thus maximizing your chances to get healthy again and to be there for your beloved ones as long as possible, especially if you are in the high risk-group.

The aim of getting more people diagnosed with early stage lung cancer is complex and difficult, but we believe that there is a great potential to save lives with such an approach. Creating quality based (including patient satisfaction) procedures, increasing funding in national lung cancer care could help to reorganise national systems to be more efficient, reducing waste and enabling more patient friendly infrastructure/staff, ready to detect lung cancer as early as possible. Also, best quality campaigns aimed at creating better knowledge and fighting stigma in society is critical. There is a long way to go ahead of us, but I believe that by working together we will have stronger impact, and each step we take will help us reach a point where lung cancer is treated as a chronic disease with not such a dark reputation.



**Ewelina Szymtke**

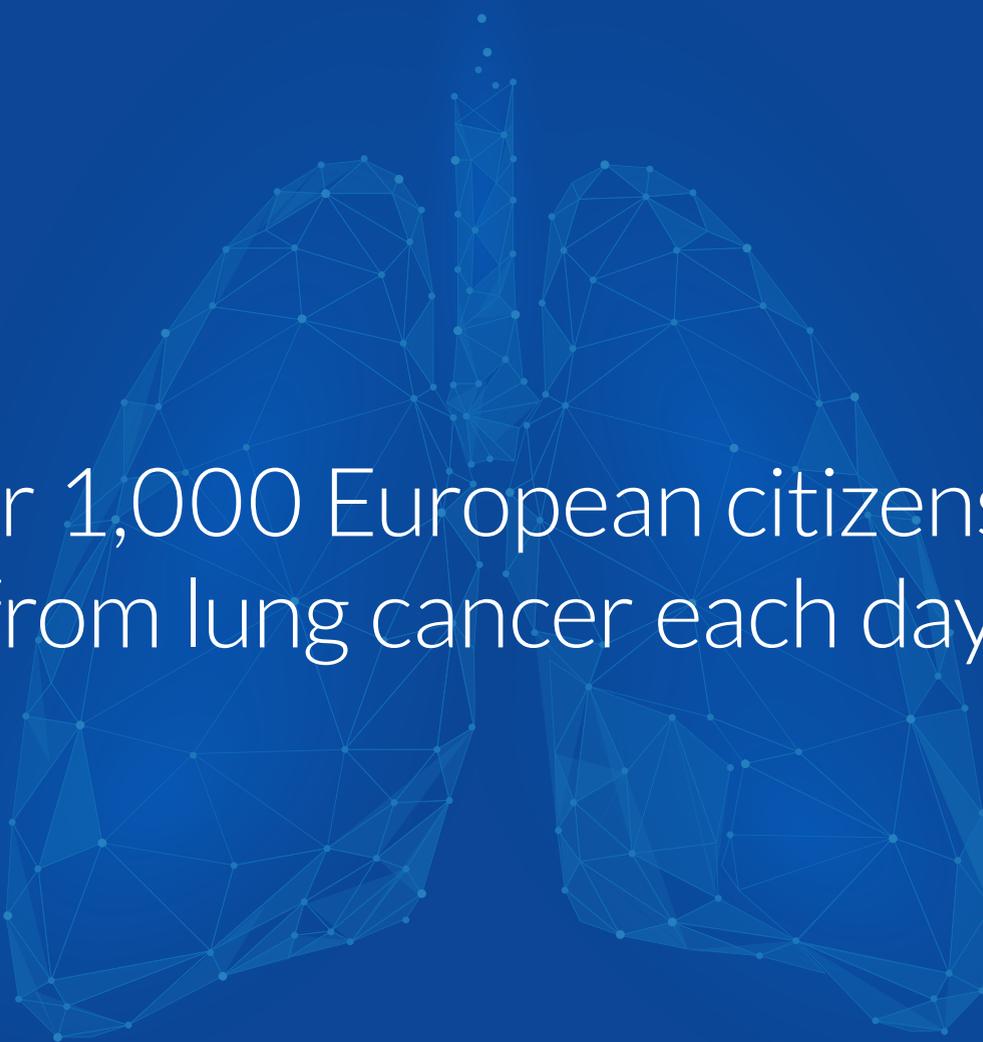
**Vice-President of Lung Cancer Europe**

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Over 1,000 European citizens die  
from lung cancer each day.

# 1. BACKGROUND

## THE LUNG CANCER LANDSCAPE

Currently, lung cancer impacts nearly 500,000 people in Europe each year, accounting for 11.1% of all cancer cases; with 1 in 5 Europeans dying from the disease (20% of all cancer related deaths)<sup>(1)</sup>. There have been major advances in the treatment of lung cancer, especially in the last decade or so with the introduction of new targeted therapies and immunotherapy, as well as more advanced diagnostic tools, radiotherapy and surgical methods. However, despite this, lung cancer survival rates remain poor, with an average European 5-year survival rate of less than 20% (European Cancer Information System). Survival rates are impacted by a number of complex factors such as lack of awareness, lung cancer stigma, late presentation of disease, healthcare infrastructure, poor or delayed access to biomarker testing and innovative therapies, and the absence of national public screening programmes. This report concentrates on two of these areas, early diagnosis and screening, with the aim of improving our understanding of the patient's diagnostic experience, and their perception of lung cancer screening.

## EARLY DIAGNOSIS OF LUNG CANCER

The majority of people with lung cancer present with advanced/late stage disease<sup>(2)</sup>. The stage at diagnosis is a key issue that has a tremendous impact on patient outcome and survival. A priority in the lung community is to find ways in which to improve the rates of early diagnosis. The public's understanding of 'early diagnosis' varies - so what exactly does 'early diagnosis' mean? The WHO (Cancer control: early detection. WHO Guide for effective programmes) defines it as:

*“THE EARLY IDENTIFICATION OF CANCER IN PATIENTS WHO HAVE SYMPTOMS OF THE DISEASE.”*

This definition highlights one of the key issues in the late presentation of lung cancer, which is a lack of symptom awareness<sup>(3-7)</sup>. However, it is not just as simple as that – issues also exist around symptom normalisation, and articulating what are often termed 'non-specific' or 'vague symptoms' to health care professionals (HCPs), particularly in a background of other health issues<sup>(4, 5, 7-9)</sup>. Added to this complexity, is the fact that general lung cancer awareness is poor among the public and the disease remains heavily stigmatised.



**THE EARLIER LUNG CANCER  
IS DETECTED THE BETTER  
THE OUTCOME.**

## **Lung Cancer Awareness**

Even though lung cancer is the biggest cancer related killer, the public tend to have a better awareness of breast and prostate cancer. Very few European countries undertake widespread lung cancer education activities throughout the year, instead tending to focus on awareness days or 'quit smoking' campaigns or indeed confining lung cancer risk factor education to just smoking. This means that lung cancer is not on the public's radar, and lulls non-smokers into a false sense of security given that they are also at risk of developing this disease<sup>(10)</sup>. This is best summed up by a tag line frequently used in the lung cancer community 'Anyone with lungs can get lung cancer'.

Outside of smoking there are a number of other factors which can increase the risk of this disease<sup>(11)</sup>:



Genetic risk factors



Tobacco smoking



Diet and alcohol



Chronic inflammation from  
infections and other medical conditions



Ionizing radiation



Occupational exposures



Air pollution

## The Complexity of Lung Cancer Symptoms

Common symptoms at the time of presentation of lung cancer include persistent cough, dyspnoea (shortness of breath), chest pain, fatigue, chest infection, haemoptysis (coughing up blood) and weight loss. Significant overlap can occur between these symptoms and symptoms of other chronic respiratory conditions as well as other non-respiratory related diseases.



Cough



Dyspnoea



Weight loss



Chest pain



Hemoptysis



Weakness



Bone pain



SVCO (Superior vena cava obstruction)



Finger clubbing



Dysphagia  
(difficulty swallowing)



Fever



Wheezing and stridor  
(high pitched wheezing sounds)

Such overlap in symptoms can cause a delayed lung cancer diagnosis. Patients should be made aware that certain pre-existing lung conditions; family history of disease; and exposure to certain environmental factors (i.e. radon and asbestos) can increase their risk of lung cancer, irrespective of their smoking status. Given the lack of general lung cancer awareness, it is not surprising that symptom awareness is also poor. In a recent Global Lung Cancer Coalition (GLCC) report, 4 in every 10 could not identify a symptom of lung cancer, and on average people could only name one or two symptoms associated with the disease (Global briefing: Symptom awareness and attitudes to lung cancer - Findings from a global study).

The lung cancer symptom landscape is complex. On review of the literature, some key themes emerged from multiple sources regarding barriers to early diagnosis for patients around lack of awareness; symptom misinterpretation and normalisation; as well as psycho-social issues<sup>(3-5, 7-9, 13-17)</sup>:

- **Lack of, or poor symptom awareness**

- i. Patients don't link their symptoms to any medical condition
- ii. Patients may be aware that something is wrong but don't think that it is serious
- iii. Patients experience symptoms for a long time and normalise them (wait and see)

- iv. Patients have vague but persistent symptoms which, may become lost in the context of other co-morbidities or conditions such as COPD, asthma or heart issues
- v. Patients think their symptoms are non-specific

- **Psycho-social issues**

- i. Patients, particularly those with a smoking history, may fear that they have lung cancer
- ii. Patients are frightened by the fatalistic attitude that persists around lung cancer
- iii. Patients worry about blame, stigma, guilt and shame related to smoking and a lung cancer diagnosis, leading to social isolation, depression and discrimination
- iv. Demographic, psychological, social and cultural factors (i.e. money and travel)
- v. Perceptions of being lectured or reprimanded about smoking

The delay in symptom reporting to a primary care physician or other HCP can have a knock-on effect on stage at diagnosis. There is clearly an unmet need with regards to lung cancer symptom education, and this can interact with fear, blame and

stigma as barriers to engage with the healthcare system when symptoms start. This, together with cultural influences or lack of understanding of risk in former or never smokers worsen the problem<sup>(4)</sup>.

## **Lung Cancer, and Primary and Hospital Care**

Regarding the presentation to a family doctor or other HCP, several reasons can potentially add more delay to the process, aside from the issues discussed above. A number of studies have shown that the most frequently reported barriers to early presentation and diagnosis of lung cancer reported by patients and carers related to poor relationships between HCPs and patients; a lack of access to services and care for patients; a lack of awareness of lung cancer symptoms by HCPs; and delays in accessing specialists and diagnostics. Below is a list of factors which have been identified from multiple sources<sup>(4, 5, 7, 17-20)</sup>:

- **Relationship with doctor**

- i. Don't trust the doctor
- ii. Are afraid of wasting the doctor's time (feeling unworthy)
- iii. Feeling that HCPs will not take symptoms seriously
- iv. Fear of stigma and blame from HCPs

- v. Nihilistic attitude from HCPs
- vi. Previous bad experience with doctors

- **Primary health care issues**

- i. Difficulty accessing appointments
- ii. Long waiting time for an appointment
- iii. Experiencing stigma, blame and nihilistic attitudes from HCPs
- iv. Missed opportunities - Patients reporting to their HCP multiple times but not evaluated for lung cancer (vague symptoms)
- v. Poor awareness of symptoms by HCPs
- vi. Seeing different doctors each time

- **Hospital issues**

- i. Delay from transitioning from primary to secondary care
- ii. Delay in accessing diagnostic tests (i.e. scans, biopsy)
- iii. Delay in accessing consultants

In an ideal situation, a patient showing symptoms which may

indicate a potential diagnosis of lung cancer would be referred quickly for diagnostic tests, leading into a referral pathway from primary care to a lung cancer specialist in the fastest time possible. A review of 128 published articles revealed that although most patients' saw a specialist within a reasonable timeframe, treatment commencement was often delayed (Reviewed in<sup>(18)</sup>). Another study, determined that multiple referrals combined with delays in presenting to the doctor, referral to specialist and then diagnostic investigations meant that it took up to six months for a diagnosis from patients' first reporting of symptoms<sup>(21)</sup>. It should be noted, however, time to diagnosis can vary widely not just between countries but also within countries as well.

### **What can we do to address these issues?**

In terms of lung cancer and symptom awareness – educational campaigns have shown some success. Campaigns concentrating on specific symptoms such as coughing and/or breathlessness can encourage patients to engage with their HCPs. An example of this is a campaign undertaken in the UK – called 'Be Clear on Cancer', which was based on the recognition of a persistent cough for three weeks. The findings suggested that symptom awareness was increased, prompting people to engage with their HCP, resulting in increased referrals and thus a shift in the number of people diagnosed with earlier stage disease<sup>(22)</sup>. An additional symptom campaign

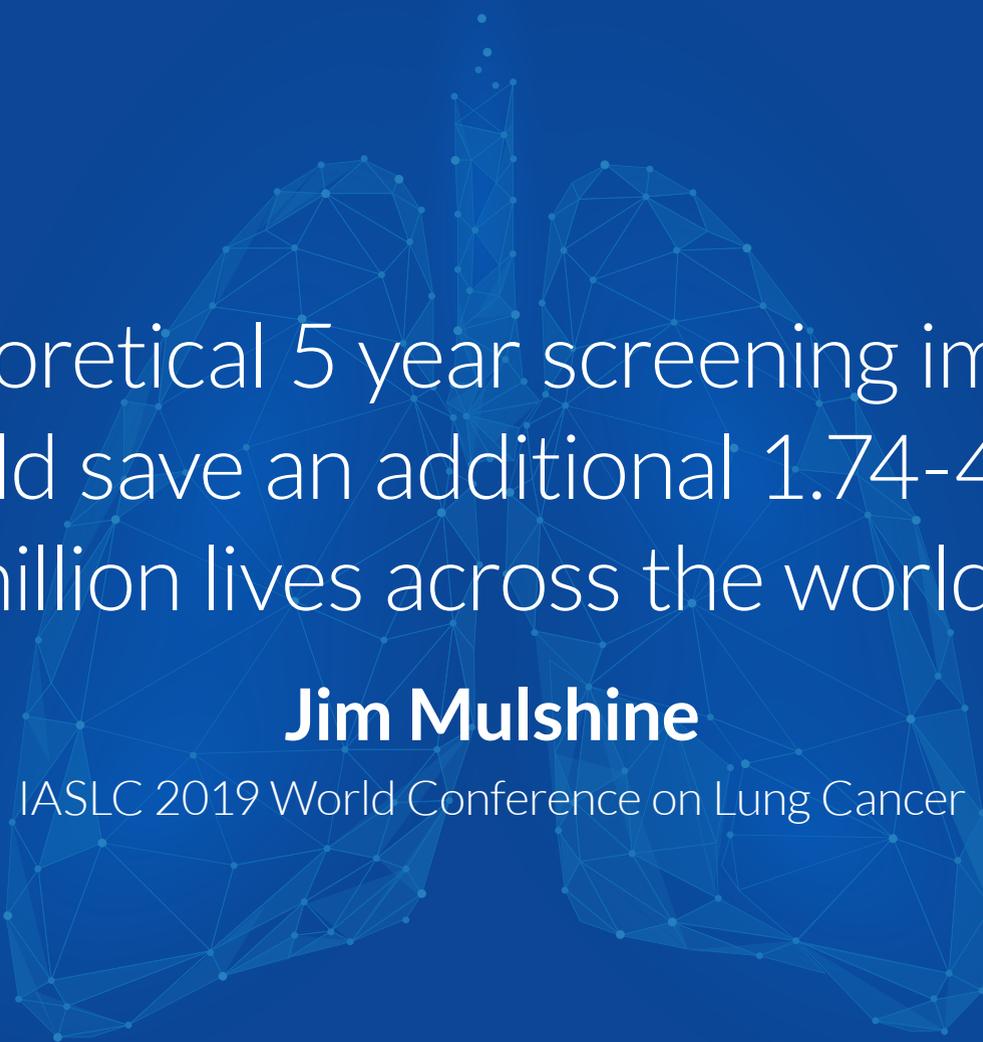
also reported plausible stage shifts<sup>(23)</sup>. There is also scope to include risk factor awareness within a campaign setting given the meaningful numbers of non-smokers who are diagnosed with this disease. Additionally, the way in which lung cancer is portrayed in the media, with language and images that perpetuate stigmatising people with this disease must be tackled.

## Conclusions

Delays in early diagnosis are multi-faceted at a patient and healthcare level. Patients can delay seeking help due to a lack of general lung cancer and symptom awareness; as well as the normalisation of worrisome symptoms. Additionally, some risk awareness programs concentrate solely on smoking which means that the public is not aware of other lung cancer risk factors such as radon exposure; and few realise that non-smokers are also at risk of this disease. The impact of the stigma associated with smoking cannot be underestimated and affects patient self-worth and critical interactions between patients and the healthcare service. At a healthcare level, some studies have shown that opportunities to identify lung cancer are being missed and this can contribute to late stage diagnosis. Improved primary health care strategies are needed to ensure that patients are identified in a timely manner and

seamlessly transitioned into patient centred diagnostic and treatment pathways. Patients and carers have the potential to play a huge role in defining a proper pathway to overcome early diagnostic barriers that result in improved outcomes for those impacted by lung cancer. Any future campaigns should be run in parallel with healthcare system improvements, and should encompass the key criteria set out in the WHO report on 'Guide to Cancer, Early Diagnosis):

*"Patients must be aware of specific cancer symptoms, understand the urgency of these symptoms, overcome fear or stigma associated with cancer and be able to access primary care. Thus, awareness has to be translated into appropriate health-seeking behaviour, and the health care they seek has to be accessible, affordable and culturally and gender appropriate."*



“Theoretical 5 year screening impact  
could save an additional 1.74-4.29  
million lives across the world.”

**Jim Mulshine**

IASLC 2019 World Conference on Lung Cancer

## LUNG CANCER SCREENING

One important tool in improving outcomes in any cancer is screening. Cancer screening programmes exist throughout most of Europe for cervical, breast and colorectal cancer but as of yet there are no national lung cancer screening programmes as it remains a controversial topic (as of October 20th 2019). While the terms screening and early diagnosis are often interchanged, it is important to note that there are differences between the two. The WHO (Cancer control: early detection. WHO Guide for effective programmes) defines screening as:

*“Cancer screening seeks to identify unrecognized (pre-clinical) cancer or pre-cancerous lesions in an apparently healthy target population.”*

Outside of Europe, annual screening using low dose CT (LDCT) has been recommended by the US Preventative Services Task Force (USPSTF) in a cohort of high-risk patients (based on age and cumulative tobacco smoke exposure) since 2013 (Final Recommendation Statement: Lung Cancer: Screening. U.S. Preventive Services Task Force). However, uptake to date has been extremely low and is a huge obstacle to successful implementation<sup>(24)</sup>.

### The Case for Lung Cancer Screening

In 2011, the results of the randomised National Lung Cancer Screening Trial (NLST) was published, which reported a significant 20% reduction

in lung cancer mortality in high risk current and former smokers screened (every year for three years) with LCDT as compared to chest x-rays<sup>(25)</sup>. In a subsequent report this year, the advantage of LDCT screening was still evident, with authors reporting that 303 patients would have to be screened to prevent one lung cancer death<sup>(26)</sup>. Data from the largest trial on screening in Europe, called the NELSON trial, was presented at the World Conference on Lung Cancer (WCLC) in 2018, which showed a 26% reduction in lung cancer mortality in men. While there were lower number of females in the trial, the mortality reduction varied between 39% to 61%. Data also demonstrated that a high percentage (69%) of cancers were detected at an early stage (Stage IA/IB) (International Association for the Study of Lung Cancer’s 2018 World Conference on Lung Cancer). The full study is expected to be published later this year. In addition, the Multicentric Italian Lung Detection (MILD) trial demonstrated that prolonged LDCT screening could achieve a 39% reduction in lung cancer mortality<sup>(27,28)</sup>. At the WCLC this year, the MILD trial also showed additional value of incorporating a blood test (for miRNA) into the screening programme (International Association for the Study of Lung Cancer’s 2019 World Conference on Lung Cancer). The Early Detection of Lung Cancer in Scotland (ECLS) also used a blood test to aid in the risk assessment and early detection of lung cancer (International Association for the Study of Lung Cancer’s 2019 World Conference on Lung Cancer). Other data presented at the 2019 meeting included the International Lung Cancer Screen Trial (ILST). The ILST showed screening benefit using a risk prediction tool called PLCom2012. The data suggested that this tool was better than the USPSTF criteria for selecting people for screening (International Association for the Study of Lung Cancer’s 2019 World Conference on Lung Cancer). This is a brief overview of the research in the screening field; however it should be noted that this is not exhaustive, and other trials and data exists.

## **Patient, HCPs and Healthcare system issues**

Many of the issues identified as barriers to early diagnosis, are also concerns for lung cancer screening and cover patients, HCPs and healthcare systems. Below are some of the issues which have been identified from multiple sources<sup>(29-40)</sup>:

- **Patient issues**

- i. Lack of understanding and information regarding screening
- ii. Issues with health literacy
- iii. Worry about perceived risk and harms (i.e. false positives and additional tests)
- iv. Uncertainty regarding benefits of screening
- v. Fear of finding something wrong
- vi. Socio-economic and practical issues (i.e. travel costs and time)
- vii. Emotional (i.e. anxiety related to waiting for scan results)
- viii. Lack of interest due to stigma associated with smoking
- ix. Competing needs and demands for health care (given that patient may have other health issues)
- x. Limited access to care

xi. Limited access to information

xii. Mistrust of doctors/health care system

xiii. Patient's feeling of nihilism

xiv. Worry regarding incidental findings

- **HCP issues**

- i. Lack of awareness of HCPs
- ii. Worry about high false positives and sufficient evidence for benefit
- iii. Patient resistance
- iv. No time to properly explain screening
- v. Patients presenting with other health care issues
- vi. Follow up issues
- vii. Limited information and training

- **Healthcare system**

- i. Inadequate infrastructure (Limited resources to support screening, including equipment, personnel and information technology resources)
- ii. Complexity of implementation
- iii. Conflicting information on screening recommendations

- iv. Lack of awareness
- v. Limited information and training
- vi. Nihilism related to treatment of lung cancer
- vii. Difficulties in identifying eligible patients (i.e. no electronic health record, incomplete smoking history)
- viii. Dealing with incidental findings

### **What can we do to address these issues?**

There is currently a call for an EU expert group on lung cancer screening<sup>(41)</sup> and a position paper has been published which encourages countries to plan for the implementation of lung cancer screening<sup>(42)</sup>. Additionally, a European Society of Radiology (ESR) - European Respiratory Society (ERS) Joint Paper on Lung Cancer Screening is expected in the next while. In addition, aside from the data provided here, other trial data and recommendations are reviewed in<sup>(43)</sup>. However, national publicly funded screening programs are likely to be a distant reality for those at risk in many countries across Europe. Although the UK are leading the way in terms of pilot and targeted screening programs (i.e. UKLS, Liverpool Health Lung Project, Leeds Lung Health Check, NHS Lung Health Check), other countries, such as Germany, Italy, Sweden and Poland, have also initiated pilot programs. Hopefully as more programs come online, and the NELSON study and others are published, this will encourage the EU to include Lung Cancer within their screening guidelines,

which has not been updated since 2003. Aside from the issues of implementation, a concerted effort must be made to educate both patients<sup>(39)</sup> and HCPs in an appropriate manner, as well as counteract the misinformation around lung cancer screening.

### **Conclusions**

The NLST and NELSON data have shown that LCDT lung cancer screening reduces mortality in high risk populations. Therefore, infrastructure and staffing must be put in place to implement a quality screening programme across Europe; as well as networks to ensure adherence to best practices and outcomes. The patient voice must be included in the creation of screening literature and pathways to aid in the successful uptake of a screening programme.

### **AIMS OF THIS REPORT**

This LuCE project will gather real-world data, which will help to identify obstacles in early diagnosis at both the patient and health care level; as well as improve our understanding of patient's knowledge and perceptions of lung cancer screening. This report will provide data, which will aid in the formation of action roadmaps for health care services, translating into a real impact at European, national and regional level.

## 2. METHODOLOGY

This report is divided into two main parts. The first covers challenges associated with the early diagnosis of lung cancer, while the second part is related to patient's knowledge and perceptions of lung cancer screening.

- **Literature review**

A literature review was conducted (See references, sources and further reading) in English, which included appropriate peer review publications, articles, and conference posters and presentations as of October 20th 2019. Key search words in the context of lung cancer were used to identify sources of information. This desk research was reviewed by the LuCE board, Fundación MÁS QUE IDEAS, and experts in the field.

- **Patient survey**

Following the review of the literature, a number of survey questions were drafted in conjunction with Fundación MÁS QUE IDEAS (Spain), and reviewed by experts in the field. Each question in the survey was intended to measure a specific construct: (i) socio-demographic profile (including general questions on age, gender etc.), (ii) lung cancer diagnosis (including questions on perception, experience and knowledge),

and (iii) lung cancer screening (including questions on perception and knowledge).

The technique used for data collection was a self-filled online survey through the "SurveyMonkey®" platform. The survey was confidential and was aimed at people diagnosed with lung cancer (both in remission and with active disease). The survey included open ended, as well as multiple choice and Likert scale questions. The survey was translated into seven languages (English, Spanish, Italian, German, French, Polish and Romanian), was active from August 5th to September 23rd, 2019 and was socialised through several communication channels: LuCE website and social media; LuCE full and individual members (websites, emails and social networks).

Survey questions can be accessed at this link:

[http://www.lungcancereurope.eu/wp-content/uploads/2019/10/4\\_luce\\_report\\_early\\_diagnosis\\_and\\_screening\\_patient\\_survey.pdf](http://www.lungcancereurope.eu/wp-content/uploads/2019/10/4_luce_report_early_diagnosis_and_screening_patient_survey.pdf)

- **HCP and advocate survey**

Using the same system as above, an additional survey was designed for HCPs and professional advocates. The majority of questions overlapped with the patient survey; however, it included additional questions relating to expert insights and potential solutions to improve early diagnosis and screening implementation.

The survey was provided in English only and provided online using the “SurveyMonkey®” platform. Participation in the online survey was by invitation only to eight HCPs, and eight professional advocates. Out of the eight advocate invites, six responses were received, which comprised of four women and two men; and included four people with lung cancer. The countries represented were Greece, Germany, Sweden, Italy, Ireland and the USA. In terms of the HCPs, responses were poor with only two responses received from two respiratory physicians covering Ireland and Greece. Due to the limited number of responses, the information gathered from these individuals will be given as insights only. These insights helped to bridge the data gathered from both the desk research and the patient survey.

Questionnaire can be accessed at this link: [http://www.lungcancereurope.eu/wp-content/uploads/2019/10/4\\_luce\\_report\\_hcp\\_advocates\\_questionnaire.pdf](http://www.lungcancereurope.eu/wp-content/uploads/2019/10/4_luce_report_hcp_advocates_questionnaire.pdf)

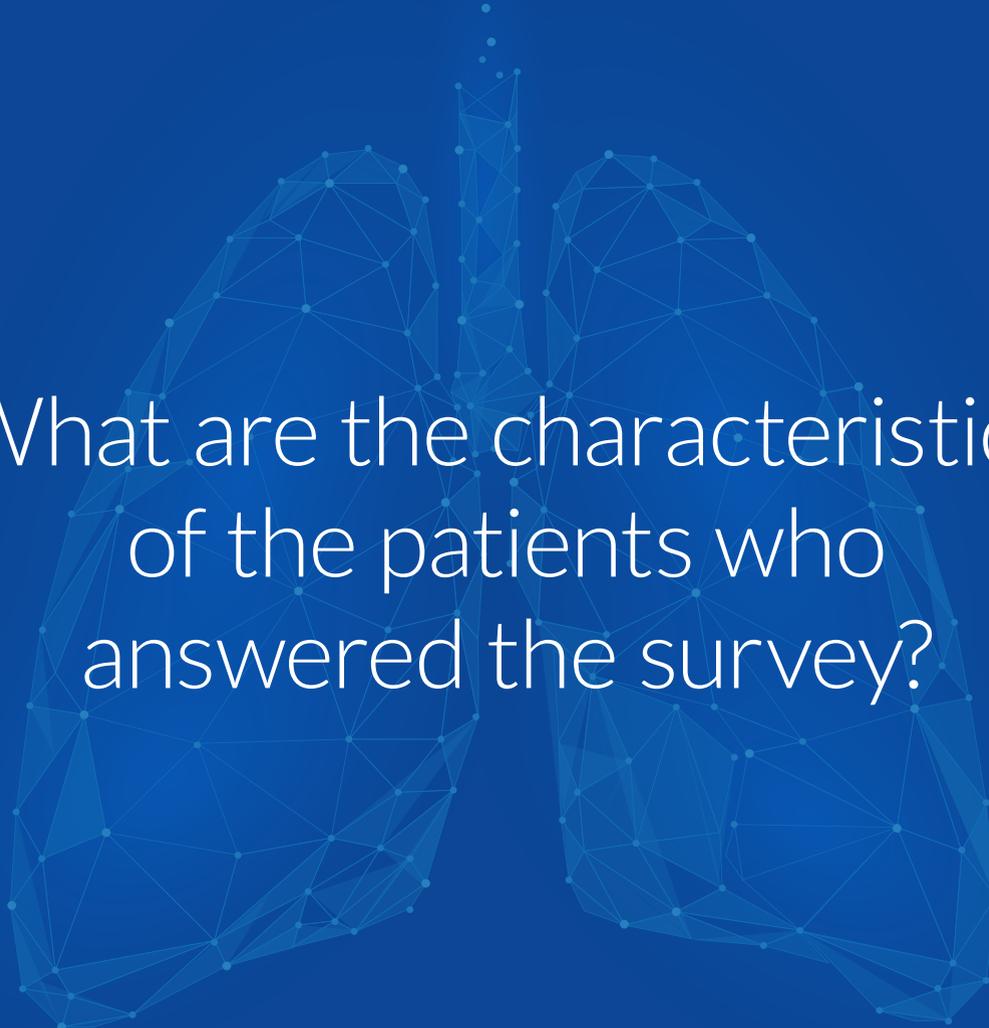
- **Data analysis**

The patient survey remained open for 8 weeks (August

5th to September 23rd 2019) and the HCP/advocates questionnaire remained open for 6 weeks (August 5th to September 13th). After this time, a quality control check of the data was performed. Data generated from the different language versions was integrated together using SurveyMonkey analytic tools. Open questions were translated into English, aggregated and standardised into a single tidied data set.

- **Report generation**

The literature review and survey data were combined to create a draft of this report. The final report was reviewed by the LuCE board, LuCE project manager and Fundación MÁS QUE IDEAS.

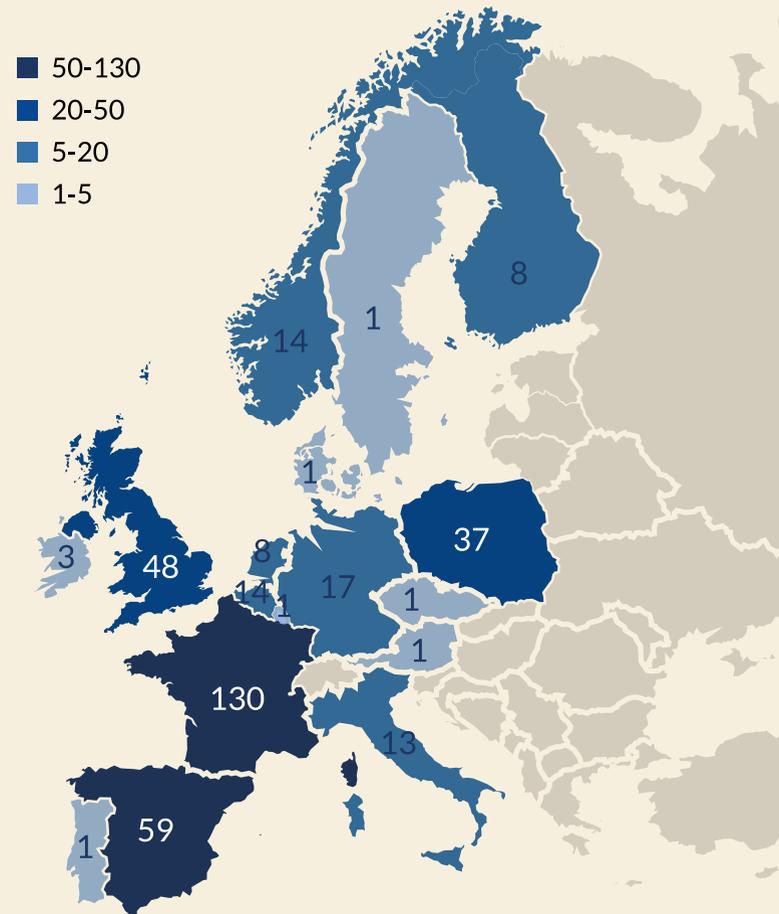


What are the characteristics  
of the patients who  
answered the survey?

# 3. GENERAL CHARACTERISTICS

## DEMOGRAPHICS

In total, 374 patients with lung cancer completed the online patient survey. Six responses were excluded as they were from outside of Europe (Australia, 2; Canada, 2; Equatorial Guinea, 1; USA, 1). Therefore, survey data is based on 368 responses unless stated otherwise. Respondents resided across 18 different countries, with the majority from France (35.33%), Spain (16.03%) and the UK (13.04%). Countries represented were mainly from Western (55.16%) and Southern (19.84%) Europe.



**FIGURE 1:**  
Number of survey responses from across Europe.  
*Total number of responses: 368*

Country	% of responses	Number of responses
Austria	0.27%	1
Belgium	3.74%	14
Czech Republic	0.27%	1
Denmark	0.27%	1
Finland	2.14%	8
France	34.76%	130
Germany	4.55%	17
Ireland	0.80%	3
Italy	3.48%	13
Luxembourg	0.27%	1
Netherlands	2.14%	8
Norway	3.74%	14
Poland	9.89%	37
Portugal	0.27%	1
Romania	2.94%	11
Spain	15.78%	59
Sweden	0.27%	1
United Kingdom of Great Britain and Northern Ireland	12.83%	48

Females were over-represented (66.58%), with only one third of respondents male (33.42%). Over half of respondents were in the 55-74 age bracket (59.24%). The majority of patients had either given up smoking before their diagnosis (36.68%) or were never smokers (27.98%). Nearly a third were smokers at the time of diagnosis (32.88%) and just over 2% preferred not to answer (2.44%)

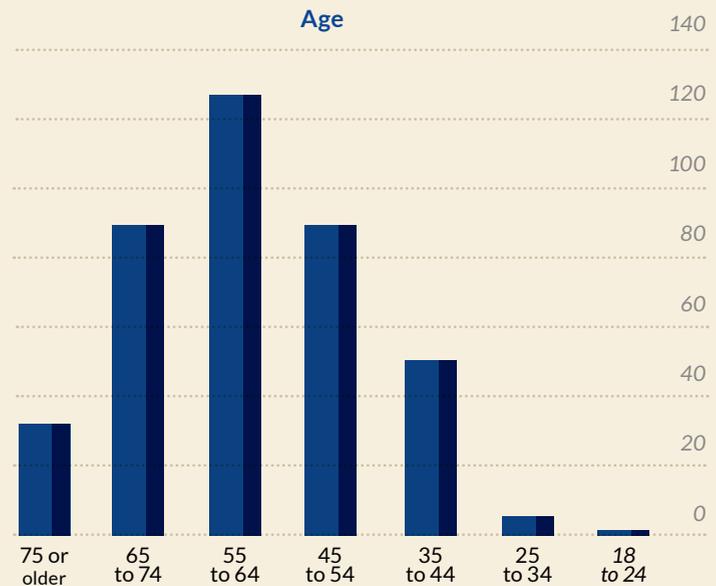
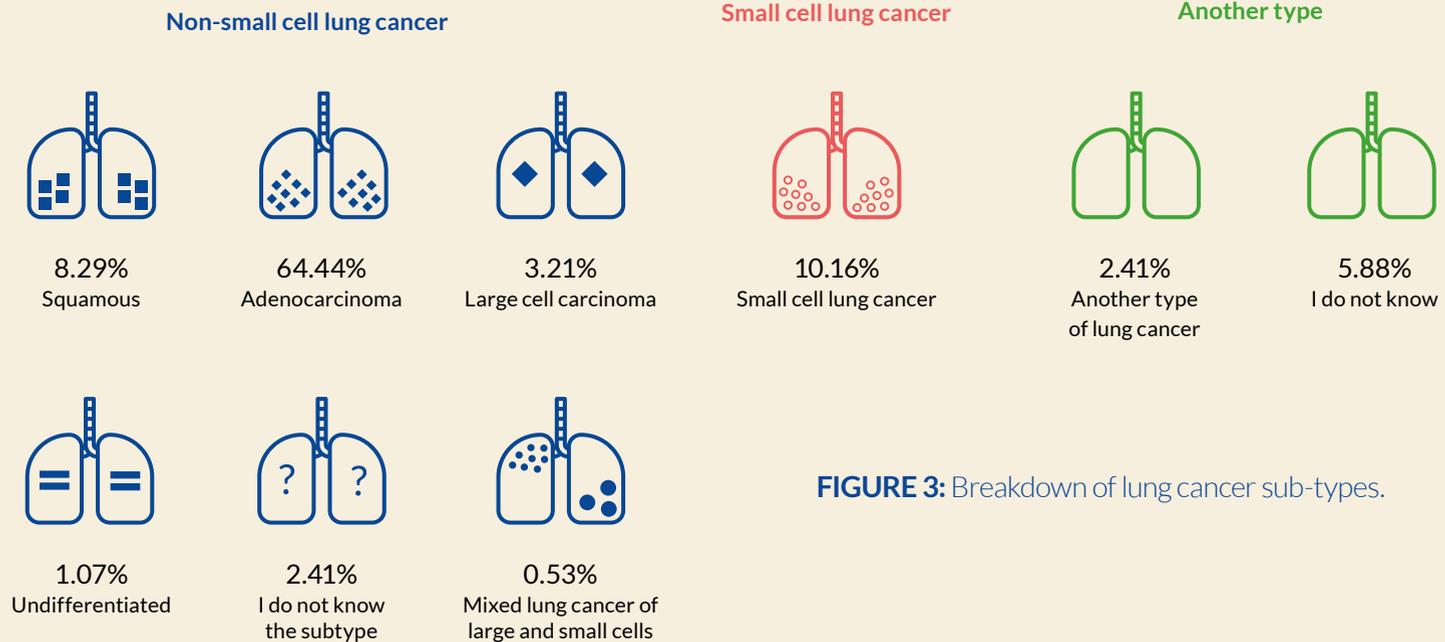


FIGURE 2: Age distribution of survey respondents.

## Lung cancer characteristics

In line with other data, the majority of patients were diagnosed with non-small cell lung cancer (81%), with adenocarcinoma the most common sub-type (81.14% of all NSCLC diagnoses). Our data concurs with that which is reported in most countries, which

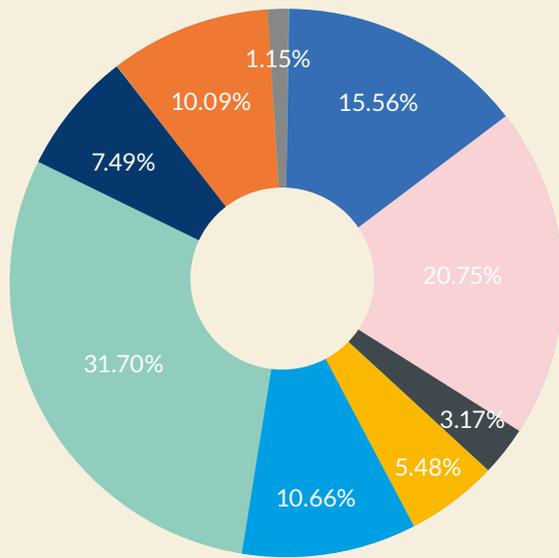
is that the majority of patients are diagnosed with advanced disease. Nearly 50% of our respondents were diagnosed with Stage IV (48.91%), followed by Stage III (15.22%) disease. Only one fifth were diagnosed at Stage II (10.60%) or Stage I (9.51%).



**FIGURE 3:** Breakdown of lung cancer sub-types.

In terms of molecular testing, a number of respondents had mutation positive lung cancer tumours. As per other genomic studies, EGFR (72 patients) was the most common alteration identified followed by ALK (54 patients) and ROS1 (11 patients), however KRAS was lower than expected (19 patients). About 7% (26 patients) stated that their tumour was tested but was negative. This may however mean that their tumour was only tested for the most common mutations and not a broader panel

to encompass those such as BRAF and RET; or it may mean that their tumour did not fit the criteria for testing. An additional 35 patients stated that their tumour was not tested; these patients may have had SCLC or squamous cell lung cancer, where molecular testing is not standard. In terms of an immunotherapy marker, only 10% stated that their tumour tissue was tested for PD-L1 expression (10.05%).



**FIGURE 4: Breakdown of tumour markers.**

- 15.56% · ALK
- 20.75% · EGFR
- 3.17% · ROS1
- 5.48% · KRAS
- 10.66% · PD-L1
- 31.70% · I do not know
- 7.49% · My tumour was tested but was negative
- 10.09% · My tumour was not tested
- 1.15% · Other

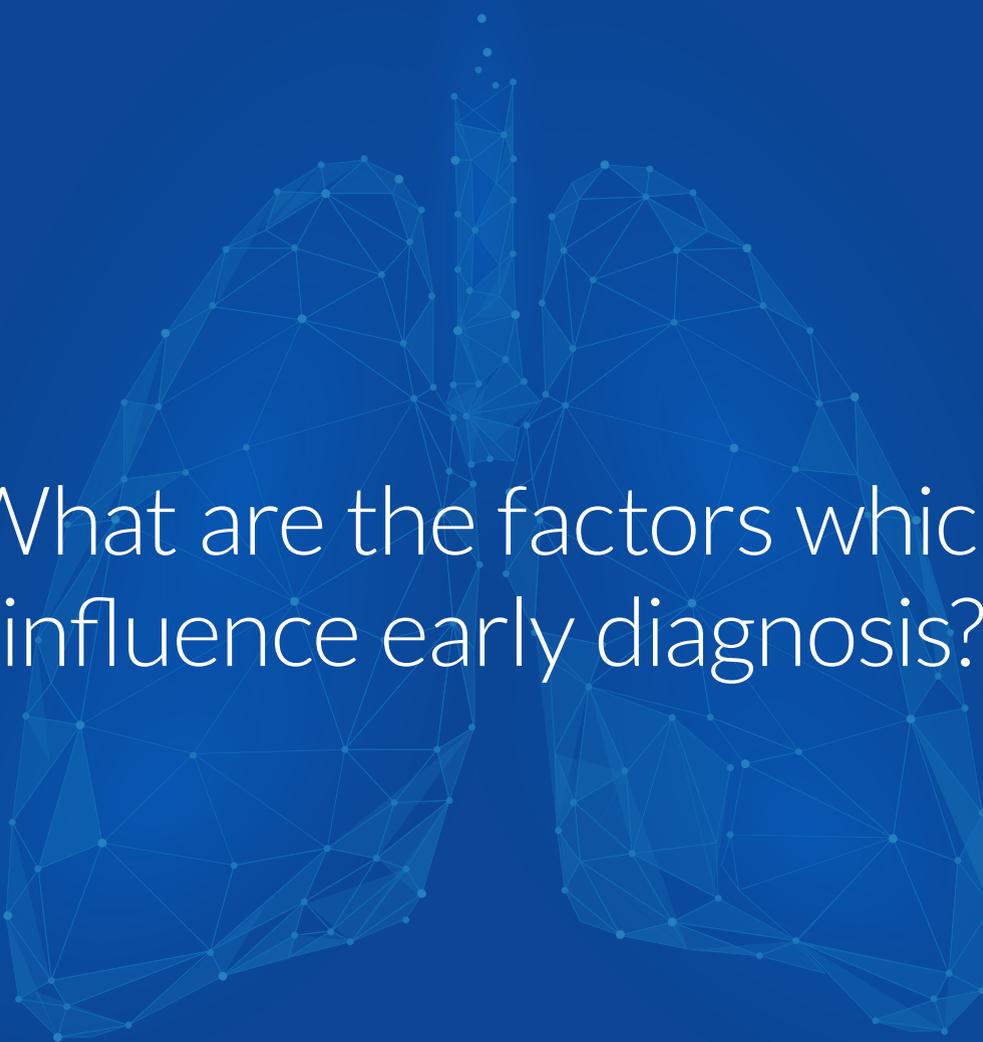


### KEY FINDINGS

Although not the main purpose of this study, we did identify that 6% of respondents did not know what type of lung cancer they had been diagnosed with; 1 in every 7 (15.76%) did not know the stage of their disease; and almost one third did not know if their tumour was tested for any of the common mutations or PD-L1.

### TAKE HOME MESSAGES

There is a need for better communication between clinicians and people impacted by lung cancer. This lack of clarity in the most basic of information (type, stage, molecular testing), could lead to further patient stress and uncertainty; hinder the patient's ability to research their disease; join patient groups; and most importantly serve as an obstacle to take part in shared decision making in their lung cancer journey.



What are the factors which influence early diagnosis?

## 4. DELAYS IN EARLY DIAGNOSIS

We are aware from other studies, that there appears to be a distinct lack of awareness around lung cancer in society in general, and a failure to identify symptoms associated with the disease. In the next parts of the study, we asked (i) patients with lung cancer and (ii) a number of HCPs and professional advocates a series of questions pertaining to early diagnosis and screening.

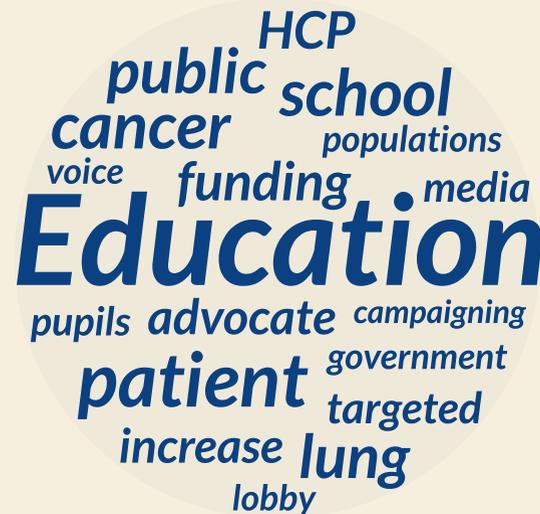
### Lung cancer awareness

As mentioned above, adequate awareness of lung cancer is lacking. Indeed, three quarters of HCPs/professional advocates surveyed (75%) felt that there was a lack of lung cancer awareness within their countries, and all agreed that their respective countries did not do enough to promote awareness. Although some countries undertook initiatives during lung cancer awareness month, there was an agreement that a need existed for the government to put national awareness campaigns in place; to provide appropriate information to the media; and to lobby the government to increase funding for lung cancer programmes. There was also a clear consensus for the need for an EU wide campaign, and a strong patient and advocate voice.

Overcoming this lack of awareness focussed on a number of key need areas:

1. Education for the public
2. Education for HCPs
3. Targeted education for school pupils
4. Outreach education programmes for 'hard to reach' populations

At a healthcare systems level, suggestions were made to introduce a 'prompt' system in medical records; develop and



maintain patient databases; implement national cancer plans; increase collaborative opportunities for research; and closer interaction between patients and clinicians. Issues were also raised in terms of specialist staffing; access to innovative diagnostics and therapies; and a lack of specialised centres. Although, we received only 8 HCPs and professional advocate responses - their answers identified a diverse array of issues for public, patients and HCPs, centring on education and awareness, and investment in health services.

### Risk factors

To begin with we asked patients, what risk factor, if any, they identified with lung cancer before their diagnosis. Not surprisingly smoking was identified by most (72,19%) as a risk factor for the disease. Other known risk factors were less readily recognized such as family history of the disease, exposure to second-hand smoke, and environmental pollutants such as asbestos exposure. More respondents believed that a lack of exercise was more of a risk factor for the disease than radon or radiation exposure. In Europe, data indicates that nearly 10% of all lung cancer cases are associated with radon exposure and is one of the leading causes of lung cancer in never smokers<sup>(44-46)</sup>. It is imperative that awareness campaigns focus on all risk factors for the disease, not solely on smoking.



**FIGURE 1:** Risk factors identified from patient responses.

## Symptom identification

While the identification of risk factors was good, worryingly symptom recognition was poor. In fact, 7 out of every 10 respondents did not know any potential symptoms of lung cancer or had only a slight knowledge (Not at all - 45.38%; Slightly - 27.17%). This is in contrast to the 2017 data from The Global Lung Cancer Coalition (GLCC) on symptom awareness, where 4 out of every 10 people were unable to name any symptoms of the disease. In our survey, less than 10% felt that they knew the symptoms potentially associated with the disease.

Given the responses to the question above, it is perhaps not surprising that so many patients did not notice any symptoms before being diagnosed with lung cancer. Shockingly, three quarters of all those diagnosed did not notice any symptoms and were instead diagnosed during a medical follow-up or at a routine consultation (61.95%). This may indicate that the survey respondents were in general more health conscious, and therefore attended routine check-ups more regularly; or it may indicate that people had other co-morbidities that required follow up and thus lung cancer may have been an incidental finding. However, these are just postulations as the survey question did not require a breakdown of reasons for doctor attendance. Although a large number of respondents stated that they did not know any potential symptoms of the disease; nearly 4 in every 10 (38.04%) stated that they noticed symptoms that may have suggested lung cancer. This may be due to smoking history rather than any specific symptom recognition.

## Knowledge about potential symptoms

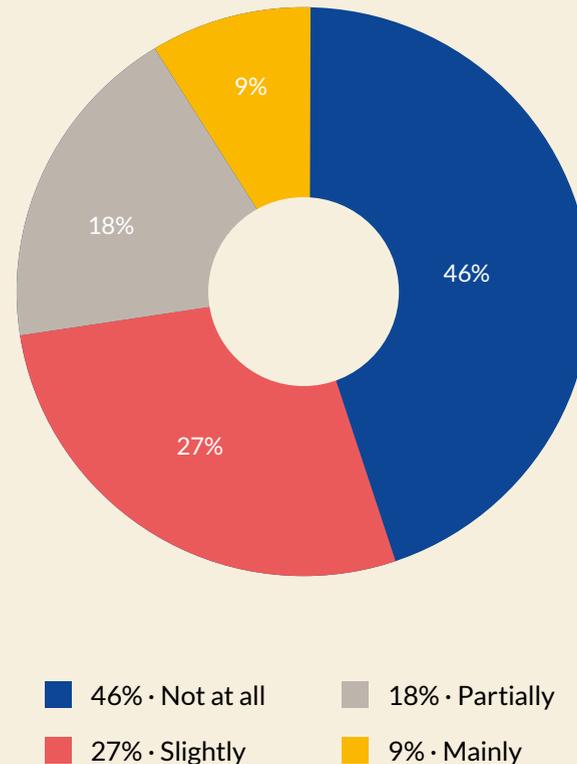
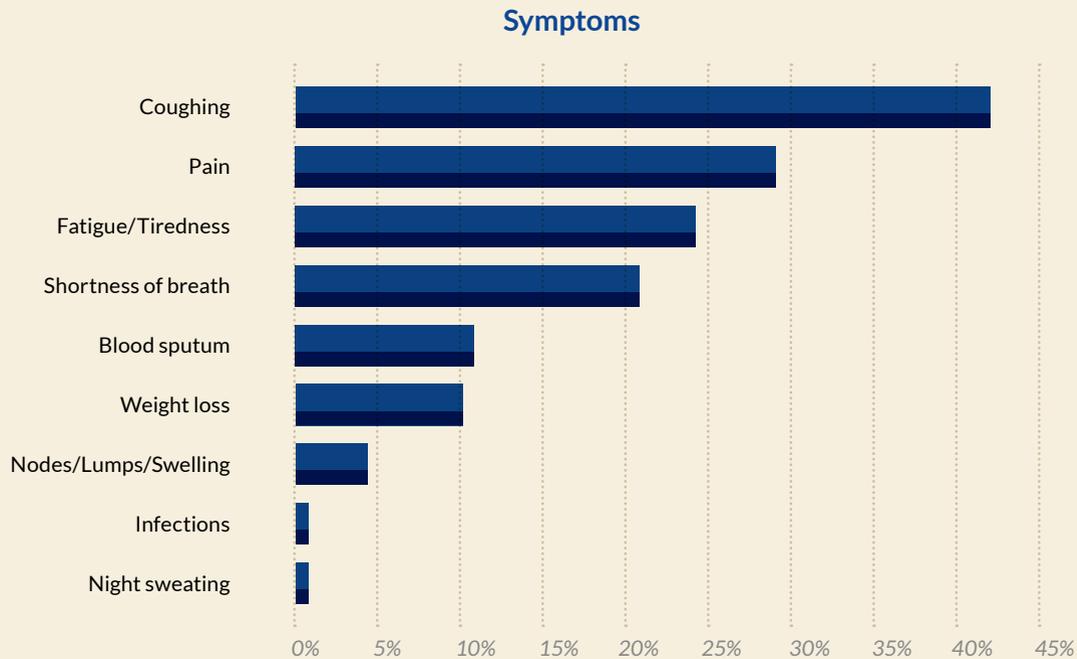


FIGURE 2: Knowledge of potential symptoms.

## Symptom presentation

The main symptoms associated with lung cancer at presentation tend to be a persistent cough and/or breathlessness. Our survey data was in line with this, given that 40% experienced a cough and 20.71% presented with breathlessness. Other common, albeit non-specific symptoms at presentation, were pain (28.57%) and fatigue/tiredness (24.28%). Figure 4 outlines a chart of signs and symptoms of lung cancer.



**FIGURE 3:** Chart of presenting symptoms.

Please note that only 140 people responded to this question.

## SYMPTOMS IN THE CHEST

## SYMPTOMS ELSEWHERE IN THE BODY

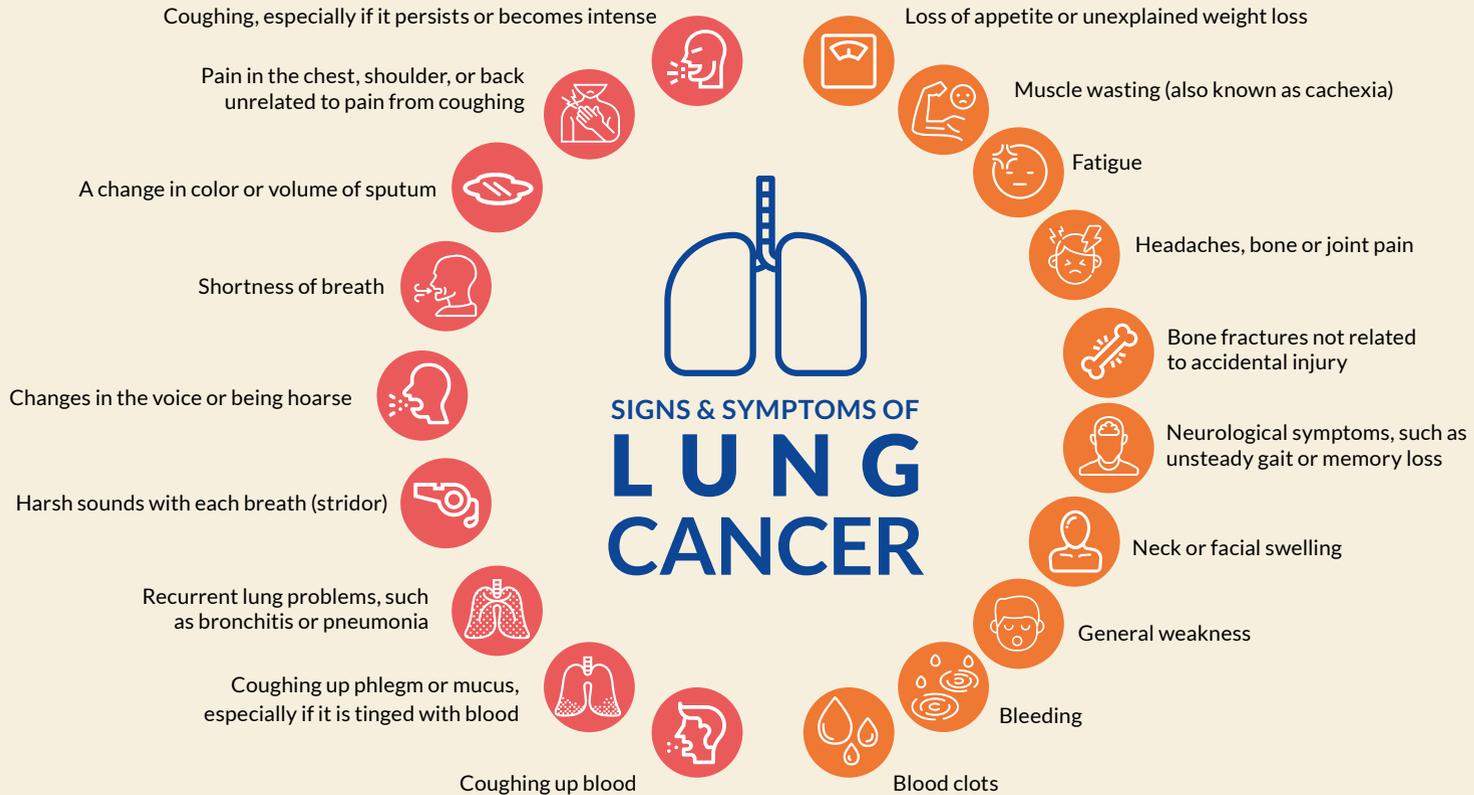


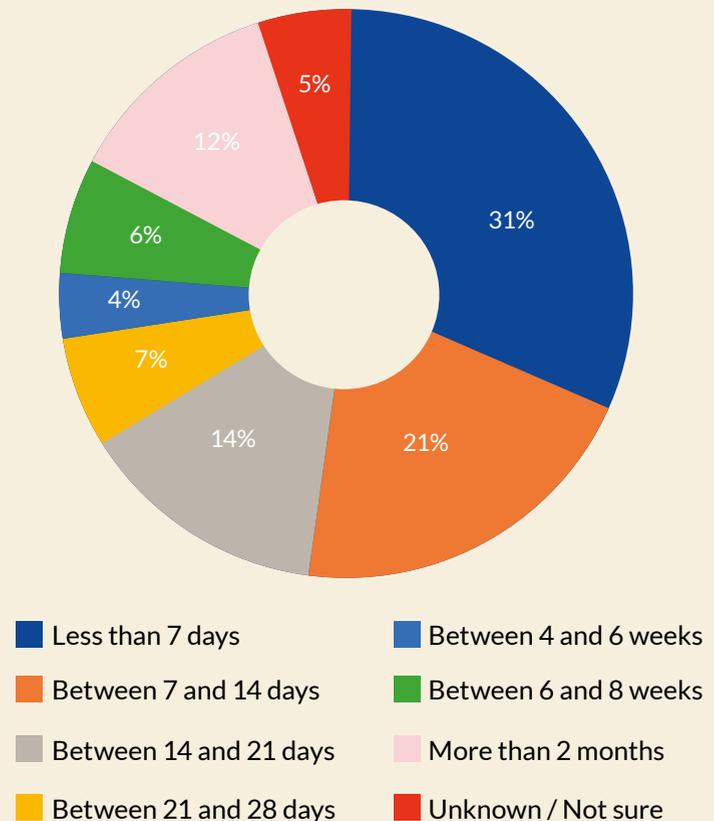
FIGURE 4: Lung cancer symptoms.

## Engagement with the healthcare system

Our next set of questions revolved around time to a visit to the doctor, number of visits, and delays in reporting symptoms. From other studies in the literature, delays in engaging with the healthcare system are complex and multi-factorial. Overall, over 50% of patients contacted their doctor within 14 days when they identified a symptom that may have indicated serious disease (52.14%), with 2 in 10 waiting between 14 and 28 days (20.71%) and 10% waiting between 4 and 8 weeks.

However, over 10% waited over 2 months before going to their doctor (12.14%). While the vast majority went quickly to the doctor, which is somewhat different from the literature, the data does not reflect the time that patients experienced the symptom, before identifying it as a possible sign of serious disease. It may indicate that patients experienced a symptom for a long period of time before identifying it as an 'alert' symptom, and once identified as a worrying symptom, they then proceeded quickly to their doctor. It may also mean that normalisation of symptoms was a factor, as this is something that has been identified in other studies (Reviewed in<sup>(5)</sup>). In general, wait time for an appointment was less than 14 days for the vast majority of respondents (77.86%), with 12.86% waiting between 2 and 8 weeks, and 5% waiting for more than 2 months.

## Knowledge about potential symptoms



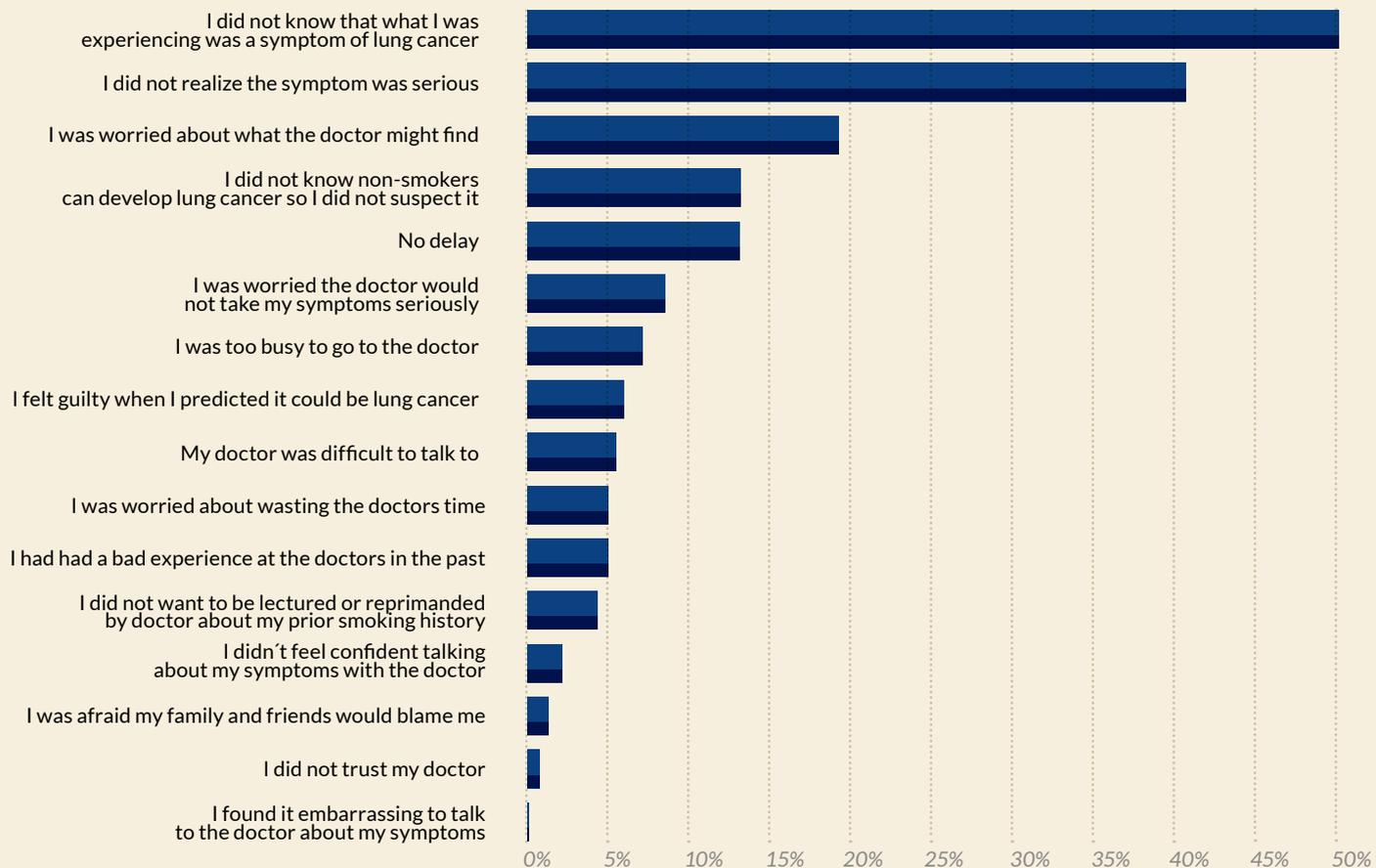
**FIGURE 5:** Delay from first symptoms to doctor consultation.

Please note that only 140 people responded to this question.

Although for the most part, patients appeared to attend their doctor rapidly, our next question focused on delays in attending doctor after experiencing first symptoms. It is difficult to say at this point whether this delay was interpreted as the delay from the very first sign of a symptom (after patients were aware it was a symptom), or whether it was understood as the delay in contacting the doctor when the patient realised the symptom they were experiencing was serious. The main causes for delay are those which have been identified as part of other studies on this subject (Reviewed in<sup>(5)</sup>). Half of the respondents stated that they did not know what they were experiencing was a sign of lung cancer, while 4 in 10 did not realise that the symptom was serious. These were also identified as the main issues according to HCPs and professional advocates. An interesting finding was that over 10% did not realise that non-smokers could develop lung cancer (13.85%), while all HCPs and professional advocates identified this as a barrier to early diagnosis. This again underscores the need for awareness campaigns which do not solely concentrate on smoking as a risk factor for this disease. Fear was a cause of delay in nearly a fifth of all patients (18.46%). This factor ranked more highly with HCPs and professional advocates. Other delays centred on relationship with the doctor - from worrying that symptoms would not be taken seriously (9.23%) to the doctor being difficult to talk to (6.15%). While it

was assumed that worry around blame would feature prominently, only 1.5% felt that this was a reason for delay. An issue that ranked more highly with HCPs and professional advocates was the worry that patients didn't want to be lectured or reprimanded about their smoking habits (62.5%).

### Causes on delay in reporting symptoms



**FIGURE 6:** Reasons for delay in contacting a doctor.

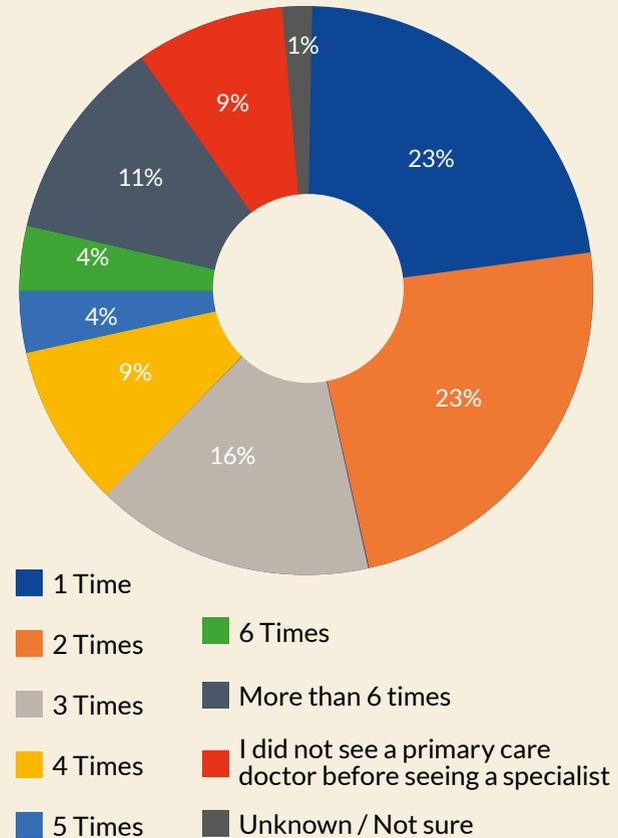
Patients were allowed to select multiple reasons and 130 responses were recorded in total.

## Findings on healthcare system challenges and barriers

Outside of patient delays, delays also existed within the health care systems. Worryingly almost half of patients who reported symptoms had 3 or more visits with a primary care doctor before being referred to a specialist (43.57%). Within this over 1 in every 10 visited their doctor 6 times or more with symptoms before referral to a specialist (15%). This is alarming, given that any delays can mean a greater chance of presenting with late stage disease. In addition, people with lung cancer can deteriorate rapidly, with their performance status impacting not only treatment options but possible clinical trial enrolment.

In addition, the time of presenting with symptoms at 'a specialist or primary care' to a diagnosis of lung cancer, was over 6 months for 1 in 10 (12.87%). Given the number of patients who experienced multiple visits to primary care before being referred on to a specialist, this data may be reflective of the time from the point of referral rather than the time for a first visit (if a patient experienced multiple visits). The point of referral from primary to hospital services, and within hospital services can cause a number of issues for patients. The HCPs/ professional advocates surveyed, felt that integration of rapid access clinics; digitised follow up; tumour boards

Visits to primary care doctor



**FIGURE 7:** Number of visits to primary care doctor.  
Please note that only 140 people responded to this question.

and multi-professional teams; and patient navigators could help with these transition phases. Additionally, all identified a need for greater educational opportunities for primary care doctors.

From a patient perspective, many issues were identified from a pre-populated list of situations which may have resulted in a delay in the diagnosis of lung cancer. Irrespective of reasoning, over half of all respondents, felt that their diagnosis could have been made earlier (Agree – 23.36%; Strongly agree –26.63%). Healthcare infrastructure was felt to contribute to a delay in diagnosis in terms of accessing scans (Agree – 12.5%; Strongly agree – 4.62%), accessing biopsy (Agree – 11.41%; Strongly agree –5.43%) and difficulties in making an appointment (Agree – 9.51%; Strongly agree – 4.35%). These also ranked highly for HCPs and professional advocates. Lack of knowledge

of healthcare professionals was also cited as a major issue (Agree – 14.40%; Strongly agree – 17.66%), and this was identified as an issue among HCPs and professional advocates (75%). These data both reflect the urgent need for more funding for adequate hospital infrastructure to ensure a timely diagnosis; as well as the need for better education for treating physicians around lung cancer itself. Socio-economic reasons did not rank so highly for delays, but this may be reflective of the survey population rather than a European wide perspective. HCPs and professional advocates both felt that socio-economic status (87.5%), as well as geographical location (100%) could contribute to delays. However, it must be noted that almost 1 in 10 of those surveyed experienced either stigma or blame from healthcare professionals. Stigma has no place in any healthcare setting and can contribute to delays in patients engaging with the health care systems<sup>(12)</sup>.

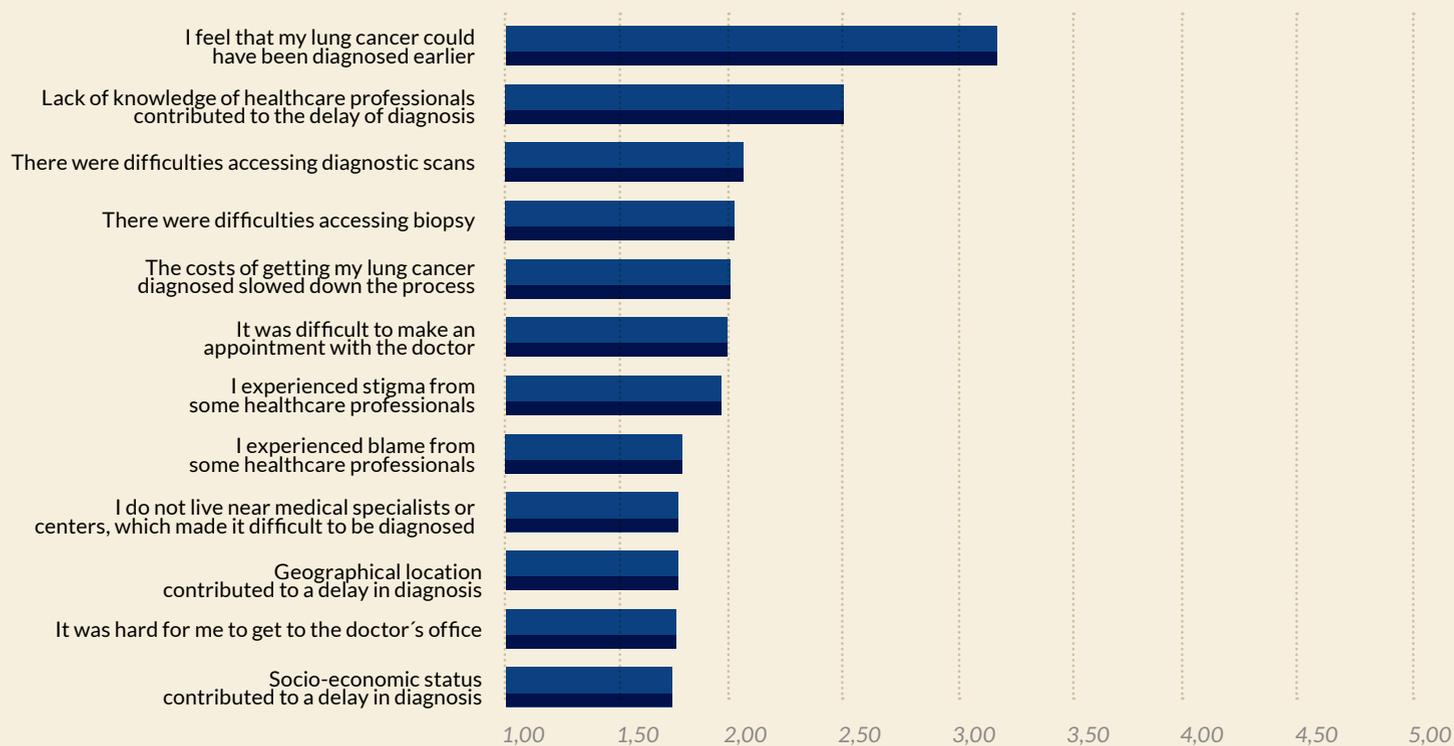


***In every 4 in 10 patients it took longer than 2 months to get a diagnosis.***

**FIGURE 8:** Time to diagnosis.

Please note that only 140 people responded to this question.

## Impact on diagnosis



**FIGURE 9:** Impact rate on diagnosis as perceived by patients.

Please note that all 368 people responded to this question.

## Stigma and nihilism

As outlined in the background to this report - other studies in the literature have identified patient and HCPs fatalistic and nihilistic attitudes to lung cancer as adding to delays in diagnosis. Additionally, stigma faced by patients, both from the public and HCPs also impacted early diagnosis rates. Although it was not something that featured prominently as an issue within the patient survey, stigma was something that the HCPs/professional advocates felt was a problem. Even though it comprised of just 8 responses, all but one felt that there was a nihilistic attitude towards lung cancer that did not exist for other cancers, and all believed that people impacted by lung cancer experience stigma. The reason for these attitudes centred across three main themes – low survival rate; the association of lung cancer with smoking; and the belief from society that lung cancer is a self-inflicted disease. Given these themes, media could play a central role in changing attitudes towards lung cancer.

*DUE TO THE CLOSE ASSOCIATION OF LUNG CANCER TO SMOKING AND THE SYSTEMATIC STIGMATIZING OF SMOKERS WITH GLOBAL TOBACCO CONTROL POLICIES.*

*ANDREA BORONDY-KITTS, USA*



*THE WAY THE DISEASE IS PORTRAYED IN THE MEDIA IS A HUGE ISSUE. PEOPLE FORGET THAT SMOKING IS AN ADDICTION.*

*ANNE-MARIE BAIRD, IRELAND*

*IN THE EYES OF MANY PEOPLE, LUNG CANCER IS A SELF-INFLICTED DISEASE.*

*GÜNTER KRANZ, GERMANY*



## KEY FINDINGS

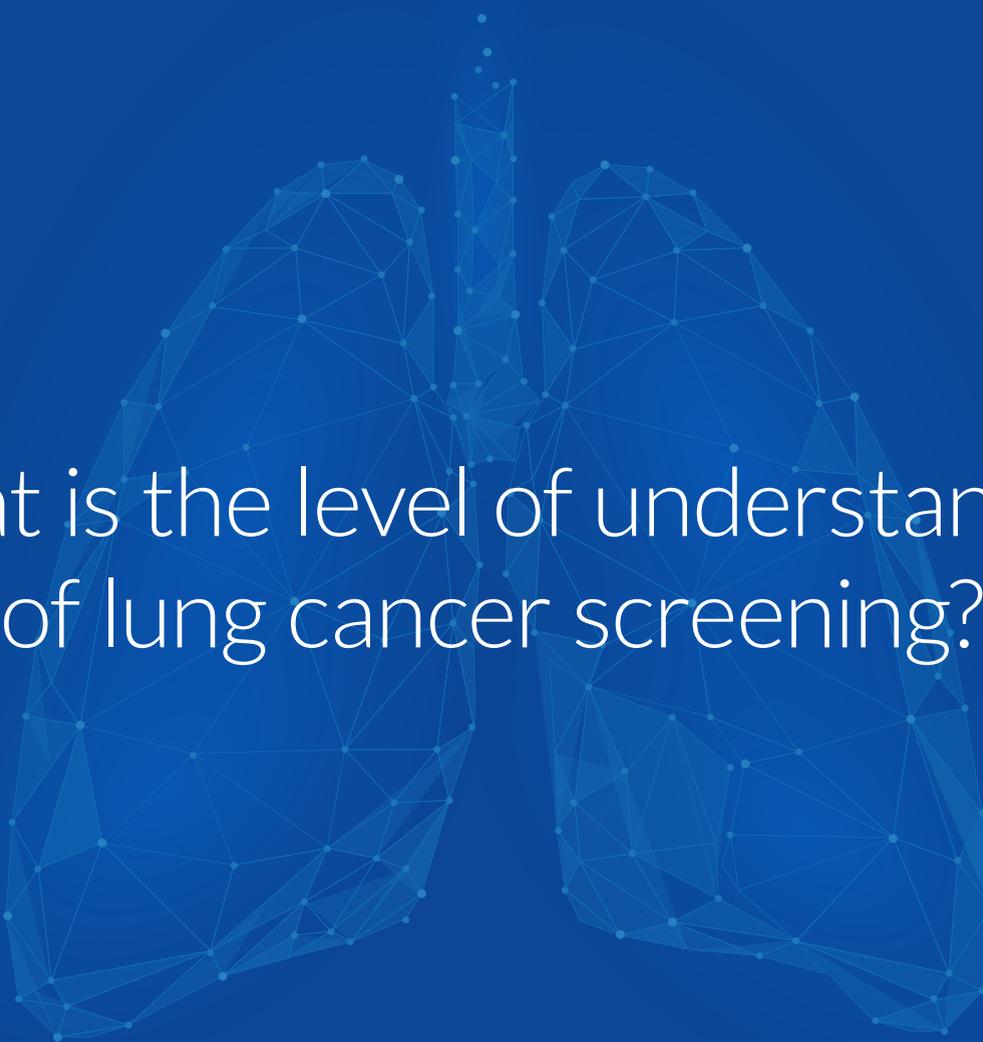
This survey overwhelming identified a need for improved education and awareness of lung cancer, both in terms of risk factors and symptom awareness.

This is in light of over 70% stating that they had no or only slight knowledge regarding lung cancer symptoms. Another, worrying finding was that only 4 in every 10 noticed symptoms that may have been associated with lung cancer before their diagnosis. Delays in diagnosis were also centred on not realising a symptom was serious or not knowing that the symptom was linked to lung cancer for 90% of people.

This again emphasizes the need for an adequate awareness campaign. Education is also needed for HCPs given that 15% of respondents needed to visit their doctor 6 or more times to secure a referral to a specialist, even when they were symptomatic. Additionally, over one third of patients either agreed/strongly agreed that a lack of knowledge of HCPs contributed to a delay in their diagnosis.

## TAKE HOME MESSAGES

**Adequate funding is required to ensure that patients have access to primary health care, specialists, diagnostic scans and biopsies in a timely fashion. Most importantly, a European wide campaign is needed to improve awareness of this disease (risk factors and symptoms), with targeted campaigns for the public and HCPs. Education campaigns must be done so in a non-stigmatising fashion and focus on more than smoking. Symptom recognition could take the form of an 'ALERT' system, to help people identify a worrisome symptom quickly and hopefully prevent them from normalising it.**



What is the level of understanding  
of lung cancer screening?

# 5. LUNG CANCER SCREENING

Although there are some pilot lung cancer screening programmes being undertaken in a number of European countries, it is not something that is part of the standard of care or has been implemented widely in any part of Europe at the time of this report. Therefore, we included this section within our survey as outside of the USA, there is little European data available on patients' knowledge and perceptions of lung cancer screening. The overwhelming consensus from the HCPs and professional advocates is that lung cancer screening should be introduced. To make lung cancer screening a reality they feel there is a need to invest in a number of areas

1. Education for the public and HCPs
2. Investment in healthcare systems
3. Proper training for HCPs
4. Introduction of electronic health records
5. More staff
6. Additional and suitable equipment

In terms, of the actions required to ensure that screening is accepted into the healthcare system - a number of key themes emerged:

1. Get politicians and policy makers on board
2. Get lung cancer onto national and European screening agendas
3. Provide adequate information to dispel misinformation regarding false positive and overdiagnosis rates
4. Increase the number of screening trials
5. Provide cost-effectiveness data
6. Collaborate with government organisations

The role that patient organisations could play centred around putting a human face on the disease; ensuring patients are aware of screening trial data; providing education relating to the benefits of screening; and bringing multiple stakeholders together to influence policy makers.

When the HCPs and professional advocates were asked to agree or disagree with the following statement:

***“THE BUDGET NEEDED FOR A LUNG CANCER SCREENING PROGRAM SHOULD BE DEVOTED TO PREVENTION PROGRAMMES (ESPECIALLY IN THE FIELD OF TOBACCO PREVENTION)”***

All bar one respondent disagreed with the statement; however, there was a consensus that separate budgets should be available for both programmes.

## LUNG CANCER SCREENING

Our section on screening started with a general question relating to the availability of lung cancer screening within the respondent's countries. Surprisingly, nearly 9% believed that there was a national public screening programme in their country. These responses came from France, Spain, UK, Norway, The Netherlands, Belgium, Germany, Italy, Poland and Denmark. To our knowledge no public national programme exists in Europe which fit these criteria. The confusion either lies with a lack of knowledge or a lack of understanding regarding pilot, regional or private programmes. Nearly 1 in 10 did state that some form of a programme was available to them either privately or in some regional places (9.51%), this may be reflective of pilot trial studies, or the availability of accessing paid screening services. It is worrying though, that over one third did not know if a screening programme existed (36.68%). Following from this, less than 3% (2.71%) had responded that they had 'excellent' knowledge of lung cancer screening. Nearly two thirds of people had either poor (29.34%) or very poor (32.06%) knowledge relating to screening. This underpins the need for greater awareness and education regarding lung cancer screening.

Screening knowledge

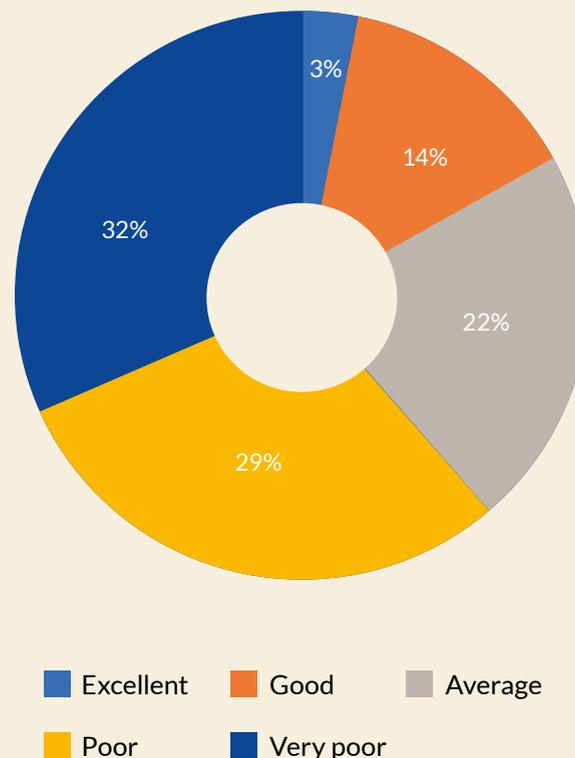
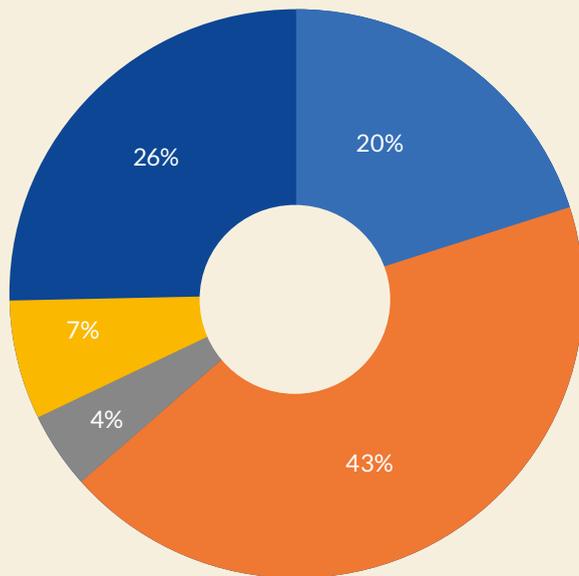


FIGURE 1: Knowledge of lung cancer screening.

In terms of defining screening, only 4 in every 10 (43.34%) identified correctly that screening is a test for people with specific risk factors for lung cancer to detect the disease before they have symptoms. A quarter could not define what

the purpose of lung cancer screening was (25.39%), and one fifth thought that it was for a symptomatic general population to find lung cancer at an early stage (20.12%). This further identifies the lack of knowledge as a significant unmet need.

### Best definition of screening



- It is a test for the general population with symptoms to find lung cancer at an early stage
- It is a test for people with specific risk factors for lung cancer to detect disease before they have symptoms
- It is a diagnostic procedure to determine whether lung cancer has spread to other parts of the body
- It is a test to check for certain changes in a gene or chromosome that may cause or affect the chance of developing lung cancer
- I do not know

**FIGURE 2:** Definitions of lung cancer screening. Please note that 323 respondents answered this question.



## Perceived benefits of lung cancer screening

Just over 6 in 10 respondents would participate in a screening programme if it was available before their diagnosis (65.48%). A quarter felt that they would need more information before taking part (25.81%). Therefore, should screening be implemented in any country there is an essential need for an information programme to be undertaken in parallel. Only 5% would not have taken part in a screening programme (5.16%).

In terms of perceived benefits from screening, the majority indicated the increased chance of finding lung cancer early (88.57%), and reducing the chance of dying from lung cancer (60%). Other highly ranked benefits were increased eligibility for surgery (47.86%) and improvement of quality of life due to better treatment options (45.71%). These data indicate the necessity for accurate information regarding screening and the



*6 in 10 patients asked would have participated in a screening programme before their diagnosis.*

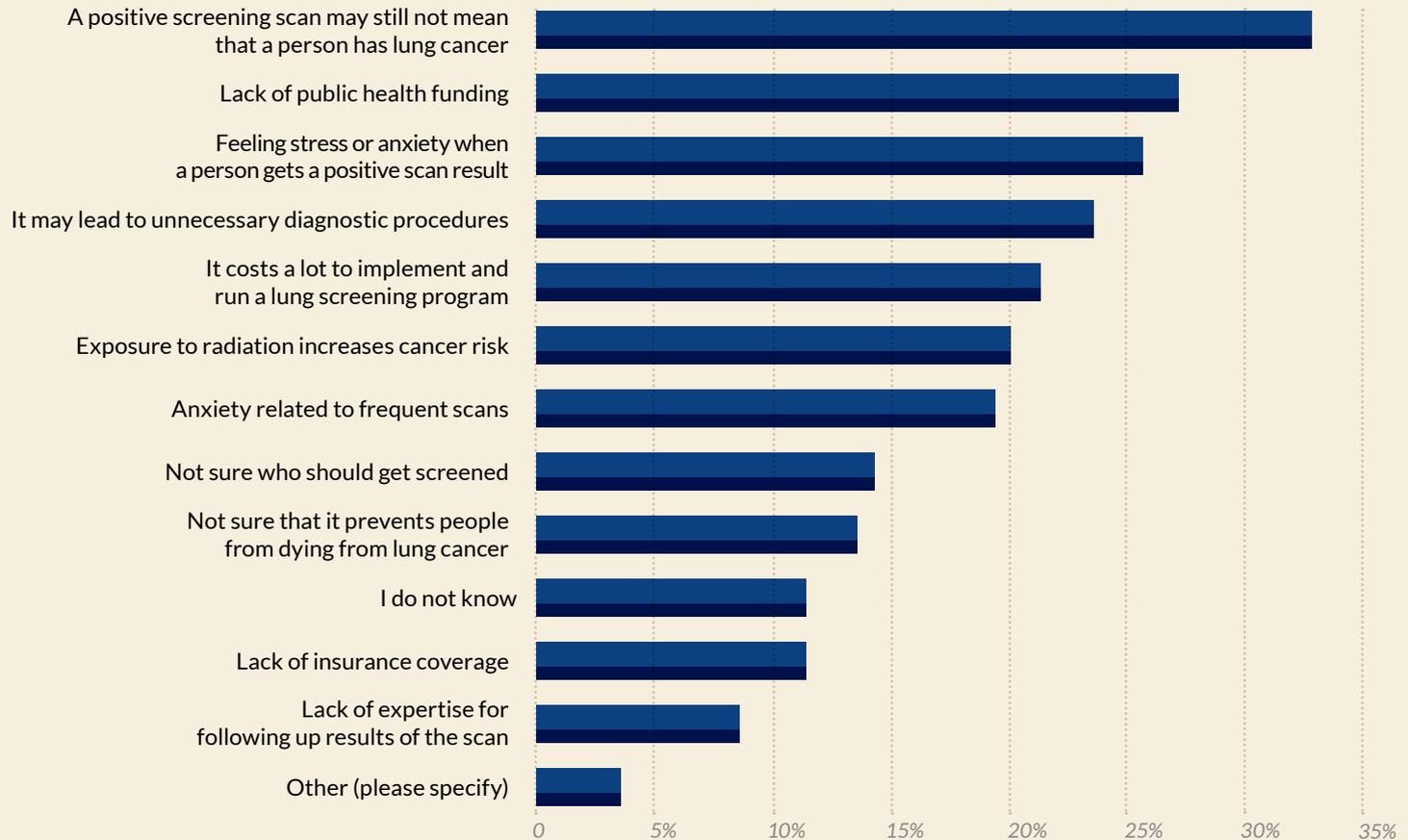
**FIGURE 3:** Screening participation rates.

need to adequately manage expectations in patients partaking in a screening programme. Just over 20% felt that screening would help motivate people to quit smoking, therefore indicating a willingness to accept the integration of a 'help to quit smoking' element into screening programmes (21.43%).

When asked about potential harms, issues were raised regarding false positives, with nearly a third indicating it as a potential harm (32.86%). Anxiety relating to a positive scan result (25.71%), and unnecessary diagnostic procedures (23.57%) also ranked highly as potential harms. About a fifth identified scanxiety as an issue (19.29%). Scanxiety describes the apprehension felt by people with cancer as they wait for their next scan. However, data from the UK lung screening (UKLS) reported no clinically significant long-term psychosocial impact on high-risk participants partaking in their screening trial<sup>(47)</sup>. Nevertheless, any programme must have adequate psycho-social support in place for patients to help them through any lung cancer screening programme.

Outside of perceived personal harms, a number of patients were concerned about funding for such a programme. Over a quarter felt there was a lack of public funding (27.14%), this ranked second on the scale of potential harms. Additionally, 2 in every 10 were concerned about the cost to implement and run a screening programme (21.43%). It is unusual for a patient population to identify these as issues within a screening programme, and we can only speculate that it may be due to

### Potential harms of screening



**FIGURE 4:** Perceived screening harms.

Please note that only 140 respondents answered this question.

underlying feelings of being undeserving of a screening programme; or the way in which screening costs is portrayed to them.

Irrespective of the perceived benefits or harms, 9 in 10 believed that the benefits outweighed any harms (89.28%) with 8.5% unsure.

### Perception of lung cancer screening

In the last section of our survey we ended with two questions relating to screening benefit and implementation. Nearly 9 out of every 10 believe that lung cancer screening can save lives (88.04%), with only less than 11% unsure (10.87%) and very few responding that did it not save lives (1.09%). Ultimately, 90% feel that lung cancer screening should be available in their country (91.03%), with less than 1 in 10 unsure (7.34%).

Do you think lung cancer screening can save lives?

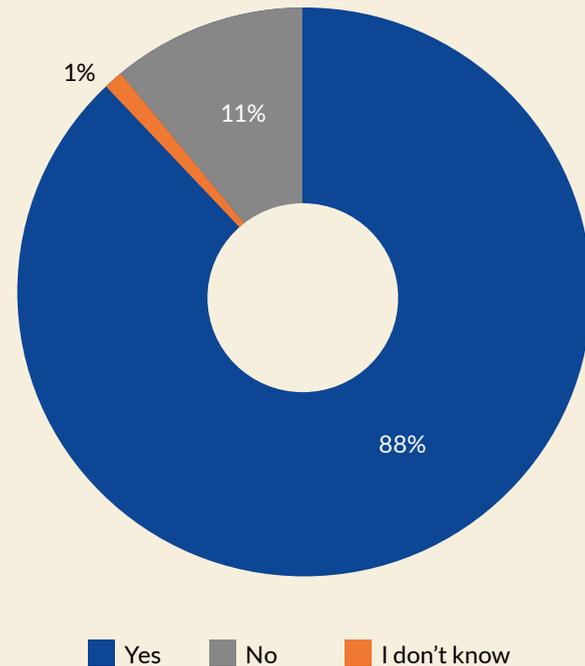


FIGURE 5: Combination of saving lives and implementation.



## KEY FINDINGS

There is a clear lack of understanding of not only what defines lung cancer screening but also general awareness around it from the vast majority of respondents. This has a great impact on how patients judge benefits, harms and screening expectations.

## TAKE HOME MESSAGES

There is a need for a proper screening information campaign throughout Europe, only then will this increase awareness and understanding of lung cancer screening. This will also help to create a stronger patient voice to lobby for the implementation of screening across Europe. Patients believe that the benefits outweigh the harms; they would participate in a programme; that lung cancer screening saves lives; and they believe that screening should be implemented. These data provide a concrete platform on which to advocate for screening at a personal, organisational and political level.



LuCE calls on all stakeholders to take action in order to improve lung cancer early diagnosis and screening implementation across Europe

# 6. CALL TO ACTION

Given the data that was generated from this survey, we now ask you to work with us as we make the following Call to Action.

## 1. Early diagnosis

We call on all stakeholders to work together as a community to design and drive an education and awareness campaign around lung cancer risk factors and symptom recognition; with unified messaging in non-stigmatising language that can be translated into multiple languages and used across Europe.

## 2. Lung Cancer Screening

We urge everyone in the lung cancer community to come together to lobby for lung cancer screening to be included in the EU cancer screening guidelines; and in parallel work collectively to promote education and awareness of screening across Europe.

# 7. HOW CAN YOU USE THIS REPORT?

We wish to thank everyone who has contributed to this report, especially to all the people with lung cancer who took the time to respond to our survey. With this fourth report, LuCE has produced a unique piece of work which provides a comprehensive collection of evidence based data, including patient preferences, needs and views on early diagnosis and screening challenges across Europe. This report is a powerful tool, which will help the lung community advocate for improvements in healthcare systems; increase education so as to remove barriers to early diagnosis; and advocate for the implementation of screening programmes. This will result in the earlier diagnosis of the disease and improve the outcomes for people living with lung cancer.

This report is distributed together with an executive summary, which contains the most relevant highlights of this work and an infographic which displays the main outcomes of this study. LuCE encourages you to use these materials to strengthen and sustain your advocacy efforts for the benefit of the entire lung cancer community.

## So, what can I do?

Below there are some ideas that you could use this report:

- Generate content based on the outcomes and conclusions of the report
- Use data and images in your presentations, talks and letters
- Use it as a start off point for background desk research and surveys
- Organise a webinar or an information talk for your members
- Use it as scope for a funding application
- Build on the report for awareness days (i.e. World Lung Cancer Day, Lung Cancer Awareness Month, etc.)
- Translate it into your language
- Share the link to the full report on your organisation's website and social media channels
- Provide printed copies for your members

## **Where can I get the materials and templates?**

If you are interested in printed copies or require the report templates, please contact us on [luce@etop-eu.org](mailto:luce@etop-eu.org).

Please, reference “IV LuCE REPORT ON LUNG CANCER -Early diagnosis and screening challenges in lung cancer (2019)” if you use data or images from this report.



## 8. ACKNOWLEDGEMENTS

We would like to thank Amgen, AstraZeneca, Bayer, Blueprint Medicines, Boehringer Ingelheim, Bristol-Myers Squibb, Celgene, Lilly, Merck, MSD, Novartis, Pfizer, Roche and Takeda for their kind support to LuCE. We are very grateful for the interest they have shown in our organisation.

We would also like to thank the 368 patients with lung cancer who completed our survey. Thanks to them, we have better insights on unmet needs for lung cancer diagnosis and screening.

A special thanks goes to our members for their support. Their advocacy work inspires us to grow and to keep working to overcome our shared challenges.

Lastly, we would like to thank the following people who have shared their knowledge, experience and opinions on this body of work. Teamwork, now more than ever, has made this report possible.

### **Medical and scientific collaborators:**

- Dr Lisa Carter-Harris (PhD, APRN, ANP-C, FAAN), Associate Attending Behavioral Scientist; Associate

Research Director, Tobacco Research, Training & Treatment Lab, Department of Psychiatry & Behavioral Sciences, Memorial Sloan Kettering Cancer Center, USA

- Dr Marcus Kennedy (MB, BAO BCh), Consultant Respiratory Physician, Interventional Pulmonologist, Cork University Hospital; Senior Lecturer, School of Medicine, University College Cork, Ireland
- Dr Mina Gaga (MD, PhD, FCCP) Pulmonologist; European Respiratory Society (ERS) President 2017-2018; Medical Director, Athens Chest Hospital, Greece

### **Individual collaborators from industry:**

- Dr Lizzie Barclay, Medical Associate, Aidence
- Paul Naish, Global Director, Oncology Advocacy and Government Affairs, AstraZeneca

### **Lung cancer patient advocates:**

- Alfonso Aguarón, Lung Cancer Europe (LuCE), Spain

- Dr Anne-Marie Baird, Senior research fellow, Trinity College Dublin, Ireland and Board member of Lung Cancer Europe (LuCE)
- Tommy Björk, Lungcancerförening, Sweden and Board member of Lung Cancer Europe (LuCE)
- Andrea Borondy-Kitts, Lung Cancer and Patient Advocate, Consultant, Patient Outreach & Research Specialist, Lahey Hospital & Medical Center, United States
- Cinzia Borreri, Associazione Insieme per i pazienti di Oncologia Polmonare IPOPOP ONLUS, Italy
- Alina Comanescu, Community Health Association, Romania
- Regine Deniel Ihlen, Treasurer of Lung Cancer Europe (LuCE), Norway/France
- George Kapetanakis, The Hellenic Cancer Federation, Greece
- Günter Kranz, Bundesverband Selbsthilfe Lungenkrebs e.V., Germany
- Leine Persson, LungcancerförbundetStödet, Sweden
- Christian Schmitt Plank, BundesverbandSelbsthilfeLungenkrebse.V., Germany and Board member of Lung Cancer Europe (LuCE)
- Ewelina Szmytke, StowarzyszenieWalki z RakiemPłuca, Poland and Vicepresident of Lung Cancer Europe (LuCE)
- Stefania Vallone, Women Against Lung Cancer in Europe, Italy and President of Lung Cancer Europe (LuCE)
- Diego Villalón, Fundación MÁS QUE IDEAS, Spain

## 9. ABOUT LuCE

Lung Cancer Europe (LuCE) is the voice of people affected by lung cancer, striving to make lung cancer an EU health priority and supporting its members to be effective and sustainable organisations. 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.

Our vision is to be an equal stakeholder in the community so nobody dies from lung cancer anymore. To reach this goal, our organisation relies on five fundamental values:

- Representativeness
- Commitment
- Reliability
- Trust
- Uniqueness

Our strategic objectives are:

- Contribute to improve early diagnosis of lung cancer
- Enhancing our network by improving internal communication and engage potential new members
- Advocate for equality of access to treatment and care across Europe
- Improve the skills and build capacity among our community to increase the presence and relevance of lung cancer patient advocates
- Reduce the stigma in lung cancer

In order ensure and grant the governance and accountability of the organisation, LuCE has a Board made up by:



**Stefania Vallone**  
Italy  
President



**Ewelina Szymtke**  
Poland  
Vice-President



**Regine Deniel Ihlen**  
Norway  
Treasurer



**Christian Schmitt Plank**  
Germany  
Board member



**Dr Anne-Marie Baird**  
Ireland  
Board Member



**Tommy Björke**  
Sweden  
Board member

LuCE has two staff members which take care of the daily work to ensure the operational functioning of the organisation:



**Alfonso Aguarón**  
Spain  
Project Manager



**Charles Bisailon**  
Switzerland  
Communications  
Manager

## ABOUT OUR MEMBERS

LuCE gathers its strength from the combined action of different national patient organisations across Europe. These organisations give support to patients with lung cancer, 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 contributions.

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

### FULL MEMBERS



**Patientforeningen Lungekræft**  
[www.lungekraeft.com](http://www.lungekraeft.com)



**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)



**Women Against Lung Cancer in Europe**  
[www.womenagainstlungcancer.eu](http://www.womenagainstlungcancer.eu)



**Associazione Insieme per i pazienti di  
Oncologia Polmonare IPOPOP ONLUS**  
[www.associazione-ipop.org](http://www.associazione-ipop.org)



**Longkanker Nederland**  
[www.longkankernederland.nl](http://www.longkankernederland.nl)



**Lungkreftforeningen**  
[www.lungkreftforeningen.no](http://www.lungkreftforeningen.no)



**Stowarzyszenie Walki z Rakiem Płuca**  
[www.rakpluca.org.pl](http://www.rakpluca.org.pl)  
[www.rakpluca.szczecin.pl](http://www.rakpluca.szczecin.pl)



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



**Asociación Española de Afectados  
de Cáncer de Pulmón**  
[www.afectadoscancerdepulmon.com](http://www.afectadoscancerdepulmon.com)



**Lungcancerförening**  
[www.lungcancerforeningen.se](http://www.lungcancerforeningen.se)



**National Lung Cancer Forum for  
Nurses (NLCFN)**  
[www.nlcfn.org.uk](http://www.nlcfn.org.uk)

## ASSOCIATE MEMBERS



Jedra

[jedra.toraks.hr](http://jedra.toraks.hr)



SuomenSyöpäpotilaat

[www.syopapotilaat.fi](http://www.syopapotilaat.fi)



De L'air

[www.assodelair.fr](http://www.assodelair.fr)



Patients en Réseau/Mon  
Réseau Cancer du Poumon

[www.monreseau-cancerdupoumon.com](http://www.monreseau-cancerdupoumon.com)



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

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



K.E.F.I. of Athens – Association  
of Cancer Patients of Athens

[www.anticancerath.gr](http://www.anticancerath.gr)



European School of Oncology (ESO)

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



Dzīvības Koks

[www.dzivibaskoks.lv](http://www.dzivibaskoks.lv)



Community Health Association

[www.facebook.com/pg/SanatatepentruComunitate](https://www.facebook.com/pg/SanatatepentruComunitate)



DRUŠTVO  
ONKOLOŠKIH  
BOLNIKOV  
SLOVENIJE

**Društvo onkoloških bolnikov Slovenije**

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



Juntos sumamos en salud

**Fundación MÁS QUE IDEAS**

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



**European Thoracic Oncology Platform (ETOP)**

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



**Pembe Hanım**

[www.pembehanım.com.tr](http://www.pembehanım.com.tr)

## INDIVIDUAL MEMBERS



**Regine Deniel Ihlen**



**Anne-Marie Baird**



**Nicoleta Mitrea**

# 10. BECOME A LuCE MEMBER

The purpose of LuCE is to be the voice of people impacted by lung cancer at a European level. We are a non-profit association that provides a platform for organisations supporting people affected by lung cancer. We advocate and network to improve outcomes for the community and our vision is to be an equal stakeholder in the community so nobody dies from lung cancer. LuCE represents their members' voice at the European level.

## LuCE membership benefits:

- Become part of a strong collaborative network of patient advocates
- Access our capacity building and educational programs, and patient materials to increase your organisation's outreach and sustainability
- Share our network of partners and stakeholders
- Access evidence-based reports and position papers to improve your advocacy efforts at a national and regional level

- Access and contribute expertise for the benefit people impacted by lung cancer

## Is my organisation eligible for LuCE membership?

LuCE offers two types of membership:

- Full membership is open to non-profit lung cancer specific groups, which (i) have a focus on patients from countries in the WHO region of Europe and (ii) must be registered and active on a national level. Full Members are eligible to vote, nominate and elect the members of the Board. Further, full members may submit proposals for projects and activities to the Board for consideration.
- Associate membership is open to non-profit groups with an interest in lung cancer, which do not meet the criteria for full membership. Associate Members are not eligible to vote, nominate or elect the members of the Executive Board. However, Associated Members are entitled to attend the General Assembly and may submit proposals for projects and activities to the Executive Board for consideration.

There is a membership fee of 100€ per year for Full Members and 10€ per year for Associate Members.

Further information on LuCE membership and its' constitution can be found here: <https://www.lungcancereurope.eu/wp-content/uploads/2017/01/LuCE-Articles-of-Association-signed.pdf>

## **How can I apply for LuCE membership?**

If your organization meets the membership criteria, LuCE will require the following:

- Completed application form (available on our website - [www.lungcancereurope.eu](http://www.lungcancereurope.eu))
- Application letter stating that your organisation would like to join LuCE and accepts its' Constitution
- A registered copy of your Constitution/Statutes
- An official Registry document of your organisation

All applications are reviewed by the Executive Board and you will receive a response within 8 weeks.

ALONE WE CAN

**DO SO LITTLE,**

TOGETHER

WE CAN

**DO SO MUCH.**

## CONTACT INFORMATION

Lung Cancer Europe (LuCE)

Effingerstrasse 40

3008 Bern

Switzerland

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

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

Follow us on Facebook: [www.facebook.com/LungCancerEurope](https://www.facebook.com/LungCancerEurope)

Follow us on Twitter: [@LungCancerEu](https://twitter.com/LungCancerEu)



# 11. REFERENCES AND FURTHER READING

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Press release: NELSON Study Shows CT Screening for Nodule Volume

Management Reduces Lung Cancer Mortality by 26 Percent in Men. Study presented by Harry de Koning at the 2018 World Conference on Lung Cancer (<https://wclc2018.iaslc.org/media/2018%20WCLC%20Press%20Program%20Press%20Release%20De%20Koning%209.25%20FINAL%20.pdf>)

Press release: Lung cancer screening model favored in Europe detects more cancers than one preferred in the United States. Study presented by Stephen Lam at the 2019 World Conference on Lung Cancer (<https://wclc2019.iaslc.org/wp-content/uploads/2019/09/ILST-News-Release-AO-approved-816bbbedits.pdf>)

Press release: BioMILD Trial Demonstrates Lung Cancer Screening Using MicroRNA Blood Test Enhances Prevention Effort. Study presented by Ugo Pastorino at the 2019 World Conference on Lung Cancer (<https://wclc2019.iaslc.org/wp-content/uploads/2019/09/BioMILD-Trial.pdf>)

Press release: Scottish Study Demonstrates that Autoantibody Test Followed By CT Imaging May Reduce Lung Cancer Mortality. Study presented by Frank Sullivan at the 2019 World Conference on Lung Cancer ([https://wclc2019.iaslc.org/wp-content/uploads/2019/09/ECLS-Scottish-news-release\\_SSfs-8-16bbbedits.pdf](https://wclc2019.iaslc.org/wp-content/uploads/2019/09/ECLS-Scottish-news-release_SSfs-8-16bbbedits.pdf))

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Lung Cancer Europe

**Many faces. One voice**

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

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

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

