

November 2024

9th LUCE REPORT ON LUNG CANCER



Lung Cancer Europe

Empowering voices:

Knowledge and decision-making among people impacted by lung cancer in Europe

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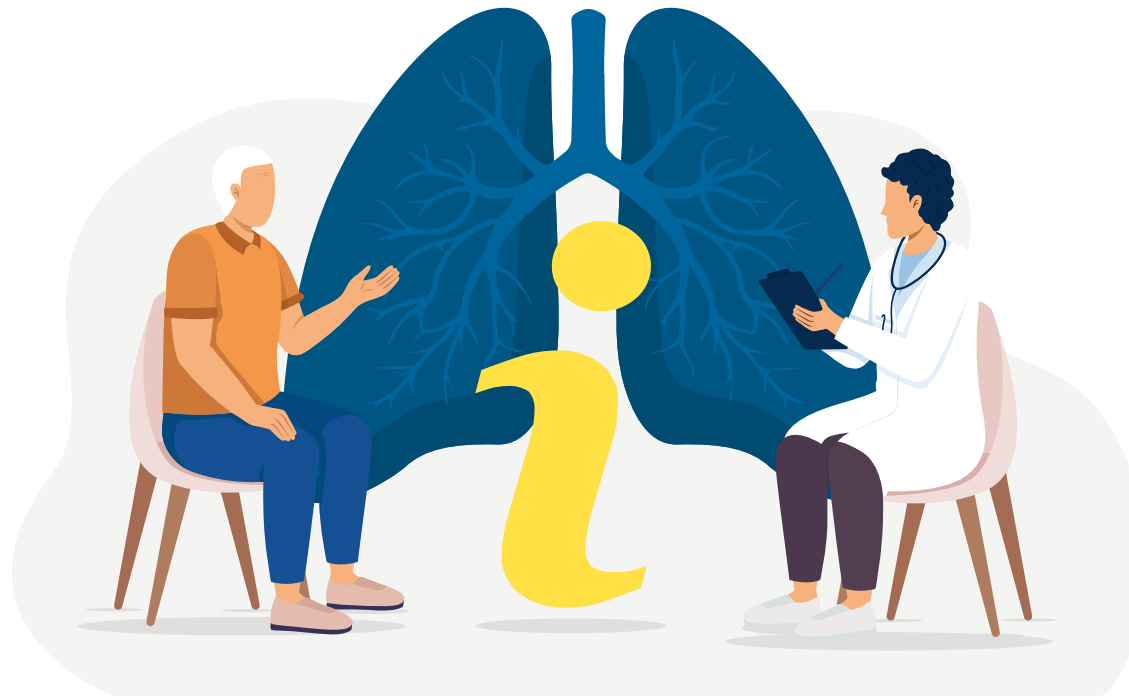
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are accessible here:



Empowering voices:
Knowledge and decision-making among
people impacted by lung cancer in Europe





This is an annual initiative led by Lung Cancer Europe (LuCE) with the purpose of raising awareness relating to the main challenges faced by people impacted by this disease.

Lung Cancer Europe

This 9th edition of the LuCE Report has been developed with the support of:

Organisations



Individuals

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Since 2013, Lung Cancer Europe (LuCE) has been advocating for the rights of Europeans impacted by or at risk of lung cancer. This need is growing, given the lung cancer landscape is constantly evolving, with a rising need for new therapies, innovative technologies, care and supportive services.

In recent years, LuCE has provided an overview of the barriers that we need to overcome in the lung cancer community in Europe. With its current 9th report, LuCE has focused on the **importance of education and shared decision-making**, as we believe there is room for improvement in this field. Placing individuals at the centre of the care process is essential. When those impacted by lung cancer are empowered to take an active role in managing their disease, they are in the best position to understand what works for them. With the right information, they can make more informed decisions about their treatment options and ensure that it is aligned with their treatment goals.

Some key findings from our report highlight several areas of importance. First, the need for increased knowledge about lung cancer remains crucial, particularly regarding **early detection**. Accelerating early detection campaigns could save lives, as treating lung cancer at an early stage significantly improves survival rates. However, disparities persist across European countries in terms of access to low-dose CT screening (LDCT) for lung cancer and addressing these differences could lead to better outcomes across the region.

Another important area is **access to information** throughout the lung cancer journey. A gold standard has not yet been achieved, especially in informing caregivers about their rights and available support services. Caregivers often feel isolated and unsupported in navigating the administrative complexities they face. Individuals with lung cancer also continue to report insufficient information about therapy side effects, a

lack of awareness about psychological support, and limited knowledge of clinical trials.

Shared decision-making is another key issue. This report highlights that most people impacted by lung cancer wish for their opinions to be acknowledged by healthcare providers; however, fewer feel that their perspectives are genuinely valued. This gap must be addressed. Physicians should clearly explain the rationale behind the treatment choices, even if it requires additional time. Documenting available treatment options is also important, so **individuals can work collaboratively with their physicians** to decide on the best course of action, considering factors like side effects, drug toxicity, and the balance between quality and length of life. Additionally, the right to seek a second opinion should be standard practice and readily accessible in every European country.

LuCE looks forward to your continued support in improving lung cancer awareness in society, as well as enhancing the education and involvement of those affected by the disease.

**Together, we can make a difference:
we shall unleash our collective strength!**



Alexandre Brutti

Board member of Lung Cancer Europe (LuCE)



Lung Cancer Europe

Empowering voices:

Knowledge and decision-making among
people impacted by lung cancer in Europe

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1. About this report

DESCRIPTION

Lung Cancer Europe (LuCE) is an independent not-for-profit organisation, committed to making lung cancer a European healthcare priority. LuCE, as the voice of Europeans impacted by or at risk of lung cancer, works to ensure that people living with this disease get the care they need to achieve the best possible outcomes.

Since its establishment, LuCE has continually developed a range of reports tackling relevant challenges for the lung cancer community. Through a systematic process based on desk research and surveys, LuCE has been able to provide evidence-based reports that provide insights around patients and caregivers needs.

This 9th report titled **‘Empowering voices: Knowledge and decision-making among people impacted by lung cancer in Europe’** is a descriptive research analysis that explores the level of information, knowledge and decision-making involvement among those impacted by lung cancer in Europe.

Over the years, individuals with lung cancer and their caregivers have shared challenges related to accessing information, involvement in shared decision-making, and improving their quality of life. The purpose of this 9th LuCE Report is to gain a deeper understanding of their preferences and needs, and to explore how knowledge and information can influence individuals’ decisions regarding the disease, diagnosis, treatment, and care.

OBJECTIVES



To explore the level of knowledge among people impacted by lung cancer regarding the disease, diagnosis, treatment, and care



To analyse experiences and preferences concerning access to information



To identify barriers to accessing information



To explore the level of involvement in treatment and care decision-making and identify challenges to active engagement



To identify relevant interventions to improve education and enable shared decision-making

METHODOLOGY



LITERATURE REVIEW

February - March 2024

Objective: To design an online survey about the level of information, knowledge and decision-making involvement among people impacted by lung cancer.

Method: Search of online databases. Publications were limited to the English language.

References are provided at the end of this report.



ONLINE SURVEY: DESIGN

March - May 2024

Designed by MÁŠ QUE IDEAS Foundation and reviewed by the LuCE Report Working Group.

Self-filled online survey via the SurveyMonkey[®] platform.

Anonymous survey with no questions relating to personal or identifiable information.

Survey was made available in 20 languages. Bulgarian, Croatian, Danish, Dutch, English, Finnish, French, German, Greek, Hebrew, Hungarian, Italian, Latvian, Polish, Portuguese, Romanian, Serbian, Slovenian, Spanish and Ukrainian.



ONLINE SURVEY: DISSEMINATION

May - July 2024

The survey was active from May 24th until July 7th, 2024.

It was disseminated through the communication channels of LuCE and its members.

Number of responses: 2,040 (1,432 people with lung cancer and 608 caregivers).



DATA ANALYSIS

July - October 2024

A quality control check of the data was performed to identify and remove incomplete surveys and responses from outside the WHO European region.

A survey was considered valid when the participant had completed, at least, the first two series of questions (21 questions).

Data generated from the different language versions were integrated together using SurveyMonkey[®] analytic tools.

All data were combined to create a draft of this report, which was reviewed and finalised by the LuCE Report Working Group.

PARTICIPANT CHARACTERISTICS: OVERVIEW

The total number of survey participants was 2,040. This consisted of 1,432 people diagnosed with lung cancer (70.2%) and 608 caregivers* (29.8%) from 34 WHO European Region countries. The number of responses per question varies as most questions were not mandatory. The most relevant research limitations are female over-representation (78.6%), and the under-representation of those older than 64 (28.8%). A brief snapshot of the participant characteristics is provided below. Complete survey participant characteristic can be found in Annex I.

		All participants (n=2,040)	People with lung cancer (n=1,432)	Caregivers (n=608)
GENDER	Women	78.6%	77.0%	82.2%
	Men	21.2%	22.7%	17.6%
AGE	45-54	21.7%	19.5%	26.9%
	55-64	33.0%	37.1%	23.2%
	65-74	23.6%	28.7%	11.5%
LEVEL OF EDUCATION	Primary/Lower secondary	8.3%	9.4%	5.8%
	Upper secondary	37.8%	39.5%	33.8%
	Tertiary	53.5%	50.5%	60.4%
COUNTRY OF RESIDENCE	Countries with the highest number of survey responses	France: 13.9% United Kingdom: 11.4% Spain: 9.9% Greece: 8.4%	France: 17.3% United Kingdom: 13.1% Germany: 9.4% Spain: 8.3%	Greece: 17.9% Spain: 13.7% Ukraine: 10.0% United Kingdom: 7.4%
TYPE OF LUNG CANCER	Non-small cell lung cancer (adenocarcinoma)	67.1%	73.8%	51.4%
BIOMARKER		Unknown: 22.2% EGFR: 21.7% ALK: 20.9%	Unknown: 18.6% EGFR: 24.7% ALK: 23.7%	Unknown: 30.8% EGFR: 14.8% ALK: 14.1%
STAGE OF LUNG CANCER	Stage IV	52.9%	52.2%	54.5%
	Stage I-II	26.4%	28.3%	22.1%
	Stage III	17.7%	16.3%	21.1%
TYPE OF HOSPITAL	3 rd level hospital (university)	60.5%	59.3%	63.3%
	2 nd level hospital (regional)	26.1%	25.9%	26.7%
	1 st level hospital (local)	18.5%	19.2%	17.0%

* For the purpose of this report, the term `caregiver` refers to informal caregivers: people caring for someone with lung cancer, as family, friends or partners (not healthcare professionals).

2. Summary: Main findings

KNOWLEDGE ABOUT LUNG CANCER: Early detection, diagnosis and treatment

55.3% of those diagnosed with lung cancer did not know they were at risk of developing the disease (not at all/a little bit). Similarly, 58.3% of caregivers were also unaware about the risk of their loved one developing lung cancer.

Smoking was the only and main factor that most participants identified as a risk factor for lung cancer (82.8%). Only a minority were aware that exposure to radon (17.1%), radiation (21.5%), asbestos (34.8%) and environmental pollutants (38.5%) could increase the risk of lung cancer.

Most symptoms were largely unknown to people impacted by lung cancer before their diagnosis. Participants identified a persistent cough (72.5%) and shortness of breath (52.6%) as possible lung cancer symptoms. It is notable that of the seven lung cancer symptoms listed, less than 15% of respondents recognised that all symptoms could be associated with a possible lung cancer diagnosis.

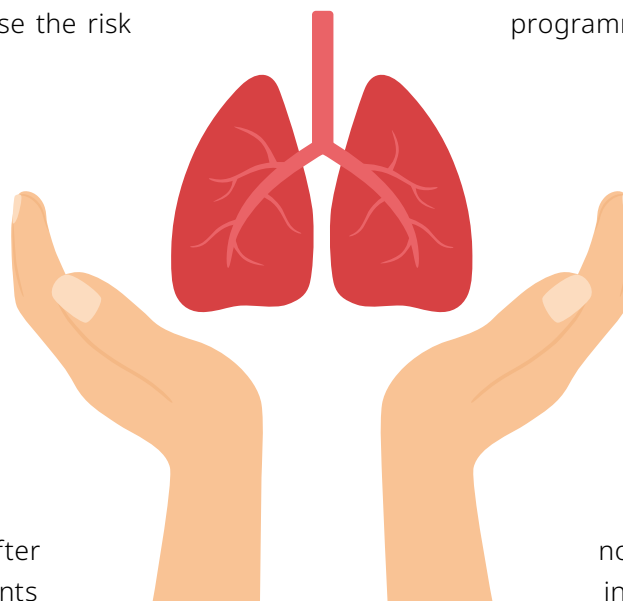
65.1% delayed seeking medical advice after experiencing symptoms. Nearly half of the participants

(46.5%) attributed this delay to not recognising the symptoms associated with lung cancer. Additionally, 4 out of 10 did not recognise their symptoms due to perceiving them as being related to other diseases or conditions.

Most people impacted by lung cancer were not familiar with lung cancer screening. Only 4 out of 10 knew what lung cancer screening was. In addition, 44.9% did not know if there was a lung cancer screening programme in their country.

Three out of 10 stated they did not have a good level of knowledge about their disease. A significant proportion of respondents indicated that they were not aware of biomarkers (22.2%) and did not fully understand the disease prognosis (24.2%).

Only 1 out of 5 people with lung cancer surveyed reported having a good knowledge about clinical trials. In addition, half wrongly believed that trials are only available for people without alternative treatment options, and 1 in 4 did not know that participation in a trial is voluntary and that individuals can leave at any time.



ACCESS TO INFORMATION: Experience, preferences and needs

About half of the survey respondents received full information from, and had good access to, their healthcare team throughout the diagnostic pathway. Better access was more commonly reported by people with lung cancer (compared to caregivers), men, older patients, and those treated at university hospitals.

89.2% considered that information was extremely important. However, 40.2% did not receive enough information and 28.9% stated that they did not fully understand the information received. Lack of information was reported more commonly by caregivers and by women.

The main information barriers cited were difficulties in processing the information (39.0%), insufficient information (32.9%), and unclear information (32.5%).

Only 47.1% of all respondents received and understood all the information they needed before signing the informed consent document (55.5% among men and 44.9% among women).

Half of participants did not receive any information about alternative treatment options. In addition, only 51.8% were informed about potential side effects or risks, 53.6% about expected outcomes and benefits, and 59.6% about how the treatment worked.

85.5% reported lacking some form of support or information. The most frequently identified information needs related to side effects (38.5%), followed by psychological counselling (36.8%).

Clinical trials were the most frequently cited information gap among those with stage IV lung cancer (34.9%).

Caregivers reported a much greater lack of information than patients, especially about psychological counselling (48.2% vs. 32.1%) and medical information (39.9% vs. 28.8%).

Half of those with lung cancer stated that they did not feel equipped enough to manage symptoms and side effects. Among caregivers, 43.2% received little or no information on how to help their loved one cope with side effects.

33.5% did not positively value their communication with their healthcare team, with lower satisfaction among caregivers and women.

Limited time for the consultation (50.9%), poor communication skills (41.7%), and the use of complex information (25.3%) were cited as the most common factors that influenced the exchange of information with healthcare professionals.

Nine out of 10 sought health information outside the healthcare system. However, 1 out of 4 either did not find the information or, if they did, the information was not accurate enough.

The internet was the most frequently used source of information (83.0%), with physicians being the second most frequent source. Only 54.6% sought information through their physicians, a very similar proportion from patient organisations (49.6%) and other people impacted by lung cancer (48.9%).



SHARED DECISION-MAKING: Experience, challenges and recommendations

Almost all people with lung cancer surveyed (98.0%) believed their opinions should be considered in the decision-making process. Similarly, 91.5% of caregivers also stated that their opinions should be included in the discussions.

Despite these priorities, only 49.3% reported being highly involved in decision-making, and only 55.9% felt that their opinion was being considered.

Among caregivers, 37.6% reported some doubts as to whether their loved one was offered the best possible treatment and care.

Only 6 out of 10 of all participants felt that the treatment and care plan aligned with patient preferences.

1 out of 4 reported having disagreed with their physician about treatment or care decisions. However, 21.9% of them did not raise their disagreement with their clinician.

Only 59.5% of respondents positively valued their involvement in the decision-making process. Satisfaction was positively influenced by the level of involvement, with greater patient involvement leading to higher decision satisfaction.

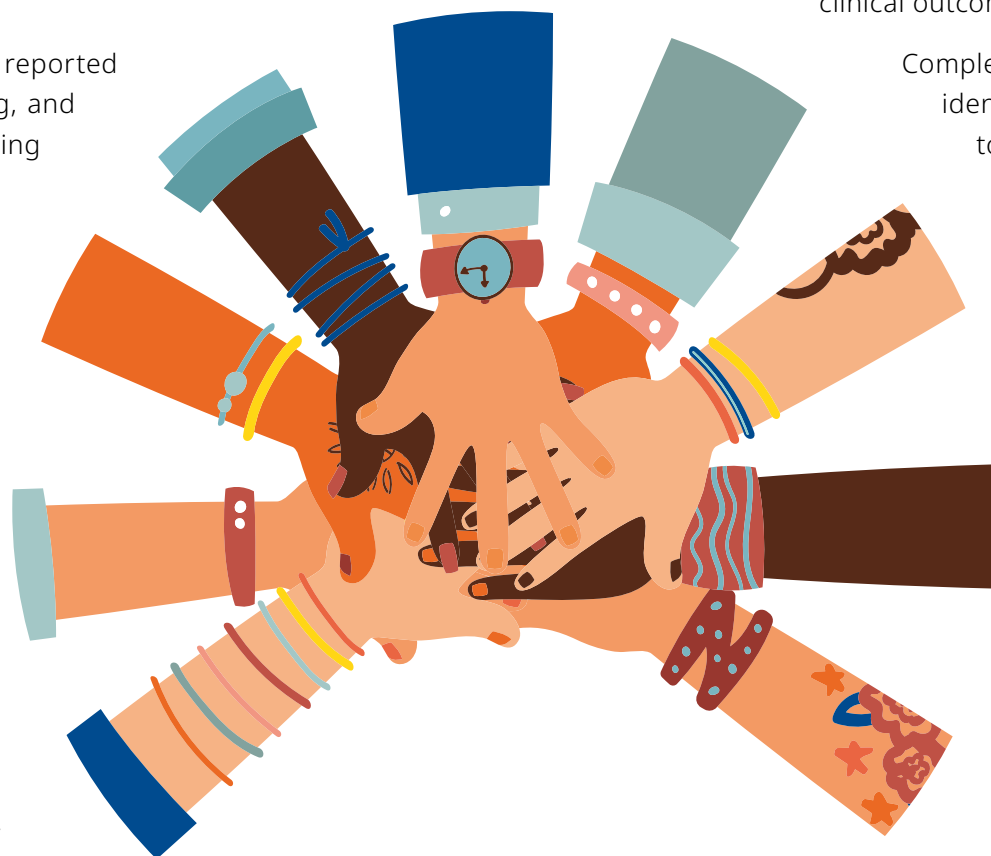
When deciding on treatment, 3 out of 4 followed their physician's recommendations. Far fewer participants chose the options 'had no choice' (27.8%) and the 'expectations of positive clinical outcomes' (26.1%).

Complex information (49.2%) was identified as the main obstacle to meaningful participation in decision-making, followed by poor communication with their healthcare team (37.6%).

While most participants highlighted that both quality of life and length of life were equally important (63.7%), it is notable that around 1 in 3 participants prioritised quality over length of life.

65.6% identified pain as the main concern when making decisions about treatment.

Face-to-face consultations (42.8%) were cited as the main aid in making the best treatment decision, followed by a question prompt sheet (16.6%).



3. Results

3.1. KNOWLEDGE ABOUT LUNG CANCER: EARLY DETECTION, DIAGNOSIS AND TREATMENT

Awareness of lung cancer risk factors

Early diagnosis is essential for better outcomes in lung cancer. However, previous research has shown that people may delay reporting symptoms due to factors such as a lack of awareness about potential risk factors and lung cancer symptoms and the belief that the disease only affects those with a history of smoking¹.

Understanding the level of knowledge about lung cancer risk factors and general risks can help in designing and implementing **effective public health interventions**², such as mass media campaigns to educate the public or cost-covered and population-wide support for risk reduction³. However, the majority of people with lung cancer were not aware of the risk of developing lung cancer before diagnosis (Figure 1).

A total of 55.3% of those diagnosed with lung cancer did not know they were at risk of developing the disease (not at all / a little bit).

It is important to remember that **anyone can develop lung cancer**, and this possibility increases if exposed to specific risk factors.

“*Being a non-smoker, I would never have imagined having lung cancer.*
(Person with lung cancer from France)

To what extent were you aware of the risk of developing lung cancer before the diagnosis?

People with LC (n=1,424)

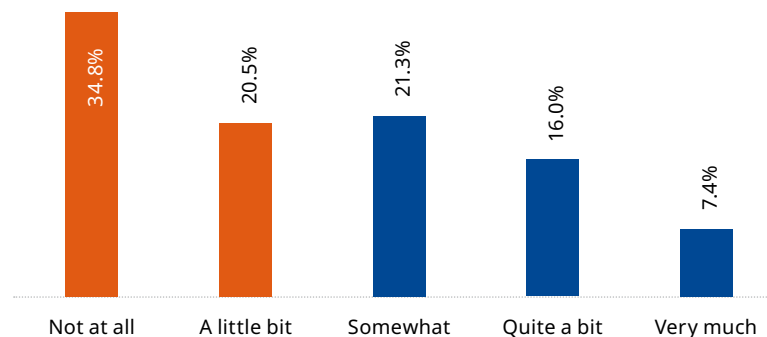


Figure 1. Lung cancer risk awareness.

	People with LC* (n=1,424)	Caregivers (n=603)
Not at all	34.8%	41.5%
A little bit	20.5%	16.8%
Somewhat	21.3%	18.6%
Quite a bit	16.0%	15.9%
Very much	7.4%	7.3%

Table 1. Lung cancer risk awareness (patients vs. caregivers).

* LC: lung cancer



LUCE
Lung Cancer Europe

Get
checked!
Anyone
with lungs
can get
lung cancer

Don't wait
get checked!
The earlier the disease is diagnosed
the better the outcome

lungcancereurope.eu

Caregivers were also asked if they were aware of the risk of their loved one developing lung cancer before the diagnosis. Table 1 shows that there were no large differences in responses collected by people with lung cancer and caregivers. **Caregivers reported a little bit less risk perception than patients (2.3 vs. 2.4*).**

Age is an important risk factor in lung cancer, as well as in other types of cancer. Therefore, risk perception is usually higher among older people. Among those diagnosed with lung cancer, our findings show that **younger participants had much lower awareness about the risks than older groups.** For example, 46.6% of people between 35 and 44 were not aware of any risks, while this percentage was 31.4% for those between 65 and 74.

While the average age for a lung cancer diagnosis is around 70 years⁴, this disease also affects younger people. Approximately 10% of lung cancers are diagnosed in people under the age of 55⁵, highlighting the importance of raising public awareness across all age groups.

“

No specific factor suggested that my loved one could be at risk of having lung cancer.
(Caregiver from Italy)

Education is vital for families impacted by lung cancer. Be sure to visit LuCE Get Checked! campaign website. This resource aims to increase public awareness of the signs, symptoms and not so well-known risk factors associated with lung cancer.

WWW.GETCHECKED.EU

* Scale from 1 (Not at all) to 5 (Very much)

Our research suggests that a low perception of risk is associated with a limited understanding of risk factors. **Patients with a high awareness of lung cancer risks (Figure 1) were more likely to identify specific risk factors (Figure 2),** such as a family history of lung cancer (44.8% vs. 27.4% in those with low awareness), a history of smoking (83.5% vs. 70.3%), environmental pollution (48.6% vs. 36.8%), and radon exposure (25.7% vs. 15.1%).

As Figure 2 shows, **smoking is the only and main factor that most participants identified as a risk of lung cancer (82.8%).**

Although smoking is a key risk factor for developing lung cancer, there are other contributing factors, such as environmental pollution and radon exposure⁶⁻⁷. However, only a minority of respondents were aware that **exposure to radon (17.1%), radiation (21.5%), asbestos (34.8%) and environmental pollutants (38.5%)** are risk factors for this type of cancer.

Even though smoking is a well-known risk factor, we observe that 17.2% did not know that it is a risk factor for lung cancer. Additionally, more than half of the respondents (57.5%) did not know that exposure to second-hand smoke is also a risk factor.

Therefore, Figures 1 and 2 show **a lack of knowledge about lung cancer risk factors and a low perception of the associated risks.**

However, compared to data collected in 2019, we observe an increase in knowledge across all risk factors, except for the lack of exercise. Public education on lung cancer risk factors in recent years may explain this improvement, particularly in awareness of asbestos exposure (19.2% vs. 34.8%, 2019 vs. 2024), environmental pollutants (27.0% vs. 38.5%) and radiation exposure (9.4% vs. 21.5%).

Before diagnosis, which factors did you identify as a risk factor for lung cancer?

Comparison of data collected in 2019 and 2024

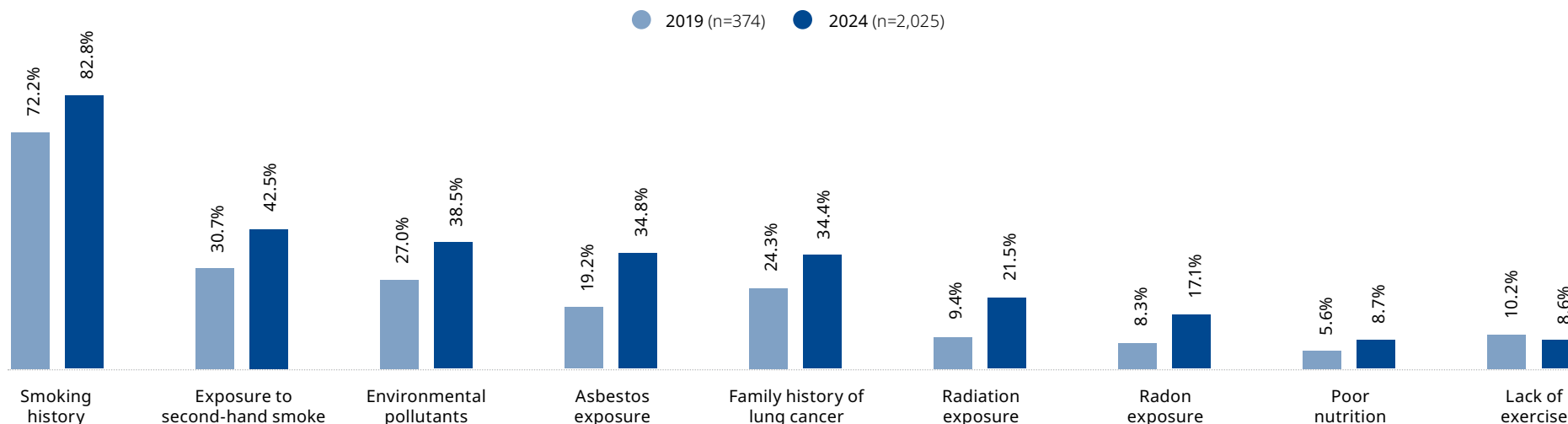


Figure 2. Lung cancer risk factors awareness (2019 vs. 2024).

Knowledge of lung cancer symptoms

Before diagnosis, which signs did you identify as a symptom of lung cancer?*

	All participants (n=1,958)	People with LC (n=1,367)	Caregivers (n=591)
Persistent cough	72.5%	69.6%	79.2%
Shortness of breath	52.6%	53.8%	49.6%
Blood in sputum	44.6%	43.7%	46.7%
Unexplained weight loss	38.4%	35.7%	44.5%
Wheezing and stridor	25.9%	25.2%	27.6%
Chest pain	25.4%	23.1%	30.8%
Weakness	20.0%	17.0%	26.9%
Night sweats	14.1%	13.5%	15.6%
Nodes/Lumps/Swellings	12.7%	11.5%	15.6%
Bone pain	8.6%	7.4%	11.3%
Fever	5.7%	4.8%	7.8%
Dysphagia**	5.5%	4.8%	7.3%
Finger clubbing	5.4%	4.7%	7.1%
SVCO***	2.6%	1.8%	4.4%

Table 2. Lung cancer risk awareness (patients vs. caregivers).

* The survey specified that the question did not pertain to the symptoms experienced, but rather to the knowledge of lung cancer symptoms before diagnosis.

** Difficulty or discomfort in swallowing.

In lung cancer, there is usually an initial a symptom-free period, followed by the onset of nonspecific symptoms such as cough, pain, or weakness. Seeking help when experiencing symptoms is key for timely and early diagnosis and improved survivorship⁸. However, according to our 2022 survey (7th LuCE Report), 4 out of 10 patients waited more than a month from the time they first experienced symptoms until they contacted their doctor⁹.

Lack of knowledge is a major barrier to early lung cancer diagnosis¹⁰. Recognising lung cancer symptoms is crucial for seeking medical advice as soon as possible. However, as illustrated in Table 2, **most symptoms were largely unknown to people impacted by lung cancer** before their diagnosis.

Both people with lung cancer and caregivers identified **persistent cough** (72.5%) and **shortness of breath** (52.6%) as the most known possible signs of lung cancer. **Only these two symptoms were selected by more than half of the participants.** The next most known signs were blood in sputum (44.6%), unexplained weight loss (38.4%), and wheezing and stridor (25.9%).

It is notable that **of the 14 possible symptoms (Table 2), only 7 were selected by less than 15%** of respondents, highlighting the urgent need to raise public awareness about lung cancer symptom recognition.

Caregivers identified more signs as possible lung cancer symptoms than people with lung cancer. The only sign that was selected by people with lung cancer more frequently than caregivers was shortness of breath.

*** Superior vena cava obstruction (SVCO) is a group of problems caused when blood flow through the superior vena cava (SVC) is slowed down. The SVC is a large vein that drains blood away from the head, neck, arms, and upper chest and into the heart.

Delay in seeking medical advice after the initial recognition of symptoms is a factor in late diagnosis of the disease. However, **65.1% of people affected by lung cancer delayed seeking medical advice after experiencing symptoms** (Figure 3). Nearly half of the participants (46.5%) attributed this delay to not recognising the symptoms associated with lung cancer. Additionally, 4 out of 10 did not recognise their symptoms as signs of lung cancer, instead perceiving them as related to other diseases or conditions.

Analysis of the participants who were diagnosed with lung cancer shows that **those who recognised the symptoms of lung cancer and promptly sought**

medical consultation were more likely to receive an earlier diagnosis of the disease. Delay in contacting a doctor was more common among participants diagnosed with stage IV lung cancer than in those diagnosed with stage I-II (67.3% vs. 54.8%). In addition, people with stage IV lung cancer more frequently reported not knowing that their symptoms were indicative of lung cancer (53.7% vs. 39.9%), not realising that the symptoms were serious (30.5% vs. 18.9%), not being aware that people without a smoking history are also at risk (23.8% vs. 15.5%) and perceiving that the symptoms were related to other conditions (46.6% vs. 31.8%).

After experiencing symptoms, if you (or your loved one) delayed contacting your doctor, did any of the following impact your decision?

All participants (n=1,991)

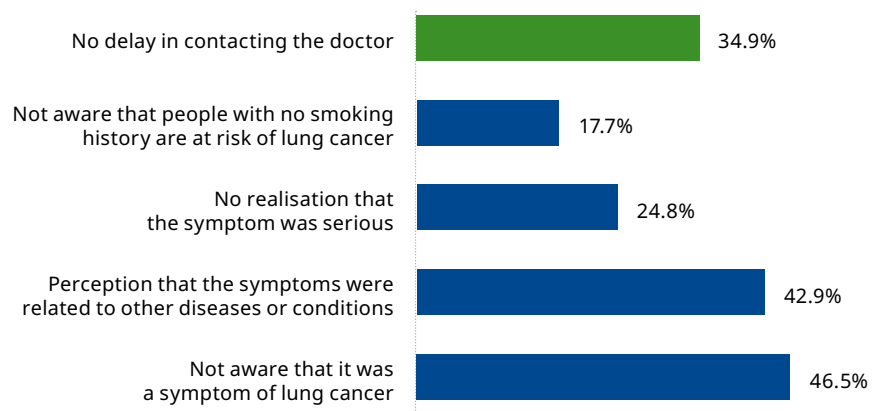


Figure 3. Reasons for delaying contacting a doctor after experiencing symptoms.

	People with LC (n=1,358)	Caregivers (n=550)
Not aware that it was a symptom of lung cancer	48.0%	43.0%
Perception that the symptoms were related to other diseases or conditions	41.2%	46.8%
No realisation that the symptom was serious	26.1%	21.8%
Not aware that people with no smoking history are also at risk of lung cancer	19.4%	14.0%
No delay in contacting the doctor	36.1%	32.2%

Table 3. Reasons for delaying contacting a doctor after experiencing symptoms (patients vs. caregivers).

Knowledge of lung cancer screening

Lung cancer is the leading cause of cancer-related deaths worldwide, accounting for the highest mortality rates among both men and women¹¹. The two most effective ways to reduce lung cancer mortality are awareness of primary risk factors and earlier diagnosis in individuals at risk for lung cancer through screening programmes¹².

Lung cancer screening is currently a test for people with specific risk factors for lung cancer to detect the disease before they have symptoms. Lung cancer screening via low-dose CT (LDCT*) scan has been shown **to be effective in reducing lung cancer mortality** in asymptomatic people¹³ by at least 20%¹⁴. This screening helps to identify lung cancer in an apparently healthy target population.

According to survey respondents from the 7th LuCE report (2022), the implementation of screening programmes is the **key priority to improve the lung cancer diagnostic pathway**⁹. However, our current study suggests that most people impacted by lung cancer were not familiar with this test. **Only 4 out of 10 selected the correct definition of screening**. As Figure 4 shows, 20.6% responded that they did not know what screening was and 27.4% thought that screening was for people who already were experiencing symptoms.

Select the option that you think best defines lung cancer screening.

All participants (n=2,034)

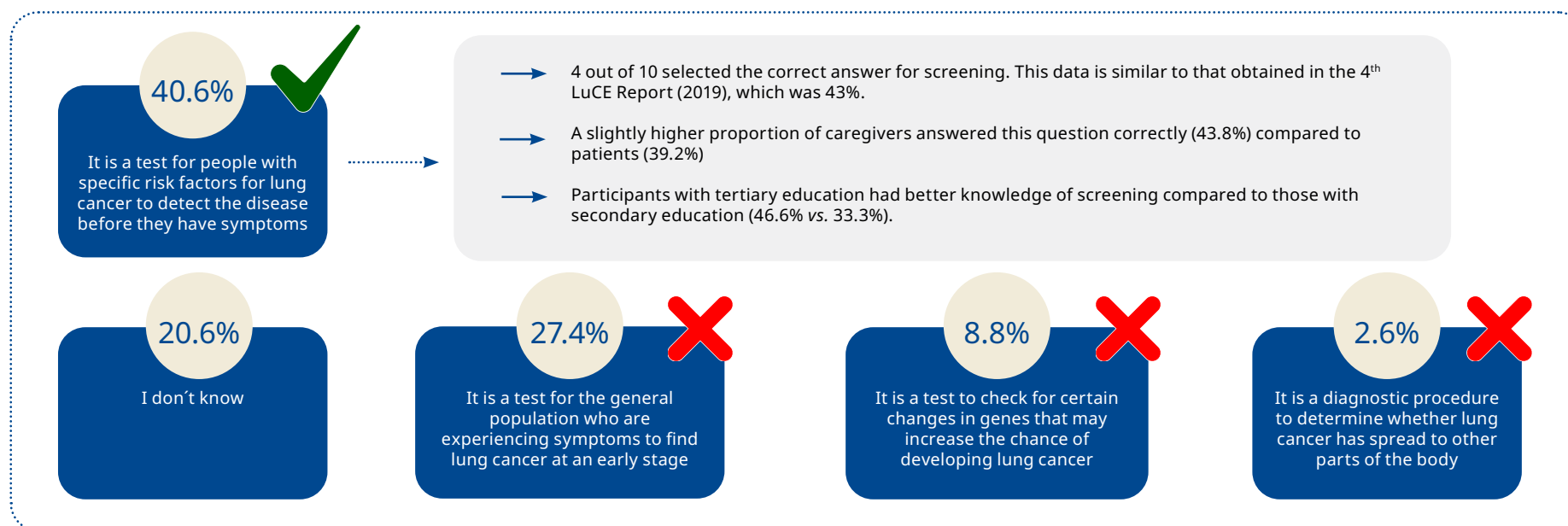


Figure 4. Definition of lung cancer screening.

* LDCT: Low dose computed tomography

Another challenge identified is that **44.9% of survey participants did not know if there was a lung cancer screening programme** in their countries (Figure 5).

Lung cancer screening programmes have started to be implemented across Europe in recent years. However, the proportion of people unaware of the availability of screening programmes in their countries has increased from 36.7% in 2019¹⁰ to 44.9% in 2024.

LuCE urges everyone in the lung cancer community to unite in advocating for the development of targeted screening programmes across Europe to facilitate earlier diagnosis of the disease. Given the concerning data around current knowledge of screening, it is crucial **to work together to enhance education and awareness of lung cancer screening** throughout Europe.



I went for a lung screening about every year/every two years on my own, even though it was not mandatory and no longer free.

(Person with lung cancer from Hungary)

Do you know if there is a lung cancer screening programme in your country?

All participants (n=2,038)

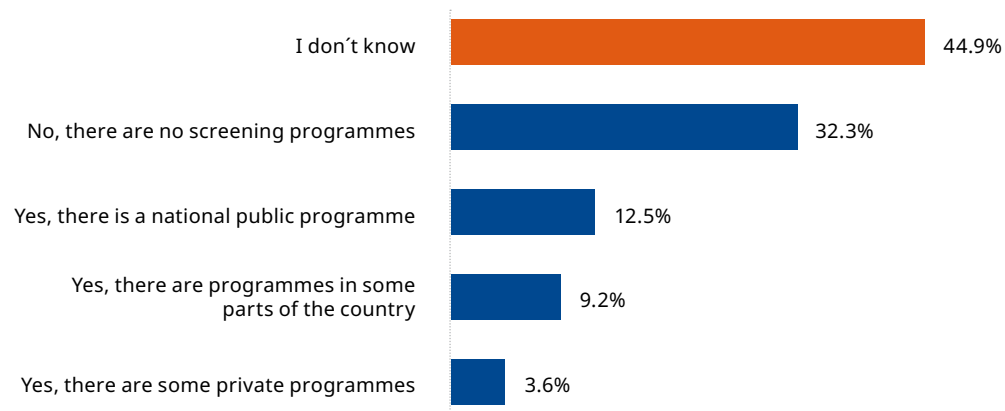


Figure 5. National lung cancer screening programmes.

Poor knowledge of lung cancer screening can be also observed through the results presented in Table 4. From a series of statements (some true, others false), it is evident that a significant percentage of individuals did not know the correct answer, while a smaller proportion provided the incorrect answer.

It is remarkable that **38.4% wrongly thought that screening lowers the chances of getting lung cancer** and **29.3% wrongly believed that screening can cure the disease**. In addition, **29.8% did not know if screening may result in exposure to dangerous radiation**. Previous literature has identified the fear of radiation exposure as an important barrier to lung cancer screening¹⁵.

In response to this data, it is important to note that while screening can reduce the risk of dying from lung cancer by detecting it at an earlier stage, it does not prevent the disease itself. Although radiation exposure is a valid concern, lung cancer screening uses a low-dose CT scan, which involves only a small amount of radiation. This machine uses about one-fifth the amount of ionising radiation compared to a standard chest CT scan, resulting in minimal risk from radiation exposure¹⁶.

Please select True or False for each of the next statements relating to lung cancer screening.

All participants (n=2,036)

	True	False	I don't know
Screening can cure cancer	29.3%	58.1%	12.6%
Screening may show findings that are not related to lung cancer	66.4%	9.3%	24.3%
Screening lowers your chances of dying from lung cancer	81.6%	7.6%	10.8%
After screening, you may need to get an extra test which can cause complications	37.5%	26.4%	36.1%
Screening may result in exposure to dangerous radiation	14.3%	55.9%	29.8%
There is no harm in undergoing screening	64.6%	11.7%	23.7%
Screening lowers your chances of getting lung cancer	38.4%	47.1%	14.6%

Table 4. Statements relating to lung cancer screening.

Knowledge of lung cancer diagnosis

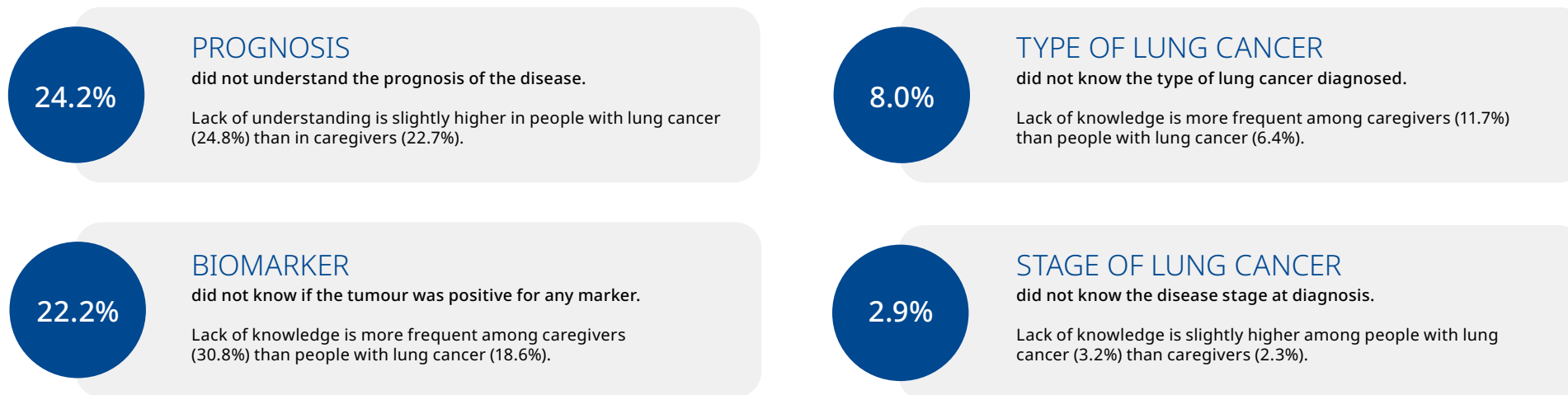


Figure 6. Knowledge about lung cancer diagnosis.

Understanding a lung cancer diagnosis is essential for effective shared decision-making. A majority of participants reported being well-informed about the type of lung cancer (92.0%) and the stage of the disease at diagnosis (97.1%).

However, as Figure 6 shows, **a significant proportion of respondents indicated that they were not aware of biomarkers (22.2%) nor did they fully understand the disease prognosis (24.2%).**

Our research suggests that a higher level of education is associated with greater knowledge regarding the diagnosis. For example, 28.4% of participants with primary or lower secondary education did not know if the tumour was positive for any biomarker. However, there was slightly more knowledge among respondents with upper secondary or post-secondary education (22.9%) and tertiary education (14.6%). **Educational level was found to have an influence on awareness of disease prognosis.** People with tertiary education reported to understand very well the prognosis more frequently than people with primary or lower secondary education (38.5% vs. 22.9%).

“*The tumour has mutations, but I don't know which ones.*
(Person with lung cancer from Spain)

“*It is important to provide clear information tailored to the patient's level of understanding.*
(Person with lung cancer from France)

Regarding prognosis, participants with advanced disease reported having significantly more information than those with earlier stage disease. Specifically, 40.2% of participants with stage IV (or their loved ones) felt very well informed about the prognosis, compared to 30.5% of those with stage III and 27.7% of those with stages I-II.

This study also finds differing levels of knowledge of the diagnosis between men and women diagnosed with lung cancer. **Men reported a greater lack of knowledge regarding the type of lung cancer** (10.5% vs. 5.2% in women) and **biomarker** information (23.8% vs. 17.0%).



They performed a biopsy after removing the metastasis from the bones, but I don't know which markers were tested.

(Person with lung cancer from Serbia)

To explore whether the level of lung cancer knowledge of those impacted has increased in recent years, data collected was compared to data from previous LuCE surveys. This comparison only used data from those diagnosed with lung cancer, as some prior LuCE surveys were not aimed at caregivers.

In Figures 7 and 8, we observe that there are no differences in the levels of knowledge about staging at diagnosis and the type of lung cancer*. However, we find a much **more or deeper knowledge about molecular markers (biomarkers)**. While 28.6% of people with lung cancer did not know if their tumour was positive for a biomarker in 2020, this percentage decreased to 18.6% in 2024 (Figure 9).

There may be several reasons to explain this improved knowledge regarding biomarkers, such as better access to biomarker testing or educational activities in recent years.

People with lung cancer who stated they did not know their diagnosis stage.

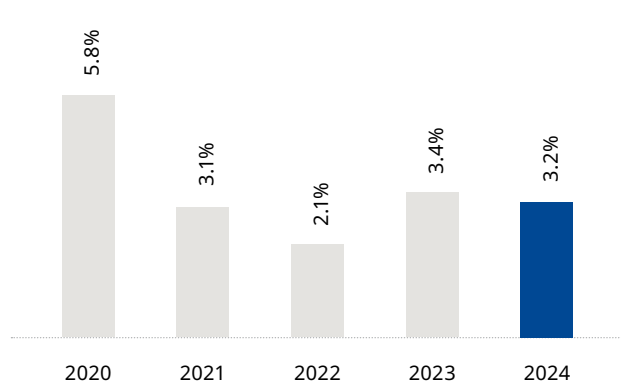


Figure 7. Lack of knowledge about diagnosis stage in people with LC: yearly comparison.

People with lung cancer who stated they did not know their type of lung cancer.

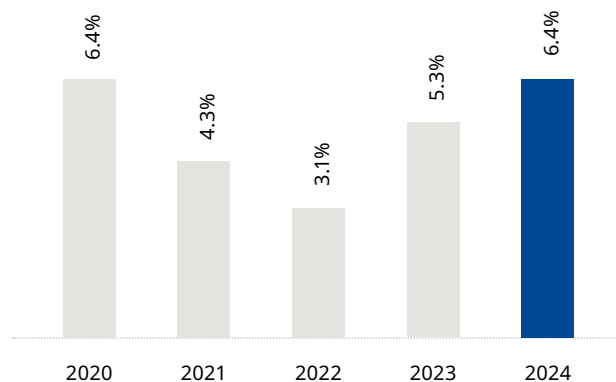


Figure 8. Lack of knowledge about type of lung cancer in people with LC: yearly comparison.

People with lung cancer who stated they did not know if the tumour was positive for a biomarker.

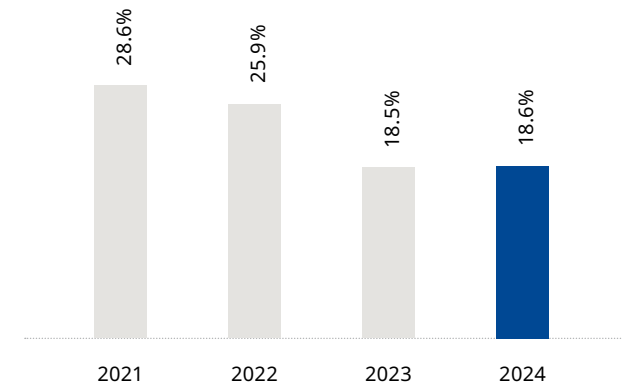


Figure 9. Lack of knowledge about biomarker positivity in people with LC: yearly comparison

* No questions about prognosis were asked in previous LuCE surveys.

How would you rate your level of understanding about the disease?

1 is 'very limited understanding' and 5 is 'full understanding'
All participants (n=2,033)

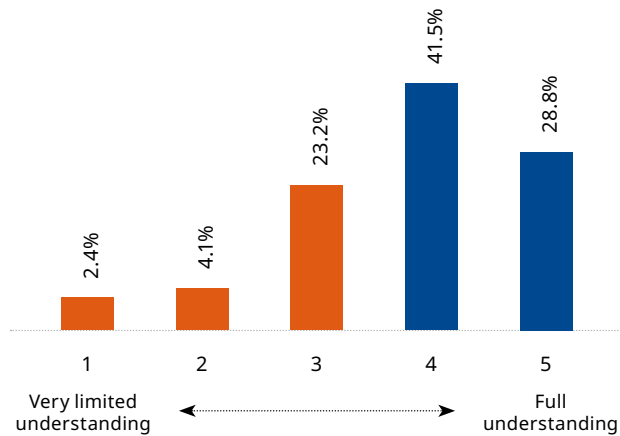


Figure 10. Level of understanding about the disease.

It is important to involve people impacted by lung cancer in the decision-making process as this allows for a better psychological adjustment and an overall improvement in quality of life¹⁷. The effectiveness of this involvement is influenced by the level of information and knowledge that individuals have.

In this regard, our survey shows that most participants (70.3%) reported having good understanding of the disease (Figure 10). However, we still find a significant number of participants – **3 out of 10** – who **did not have a good level of knowledge about their disease**.

Both people with lung cancer and caregivers reported similar levels of understanding of the disease (Table 5). The average score obtained in both groups was 3.9*.

	People with LC (n=1,427)	Caregivers (n=606)
1	1.8%	3.8%
2	3.8%	5.0%
3	23.1%	23.4%
4	43.3%	37.3%
5	28.1%	30.5%

Table 5. Level of understanding about the disease (patients vs. caregivers).*

“No information at all. Only information from the patient group, after which I learned the maximum amount of information.”
(Caregiver from Ukraine)

“Especially at the time of diagnosis, I was missing much information because I simply did not know where to obtain it.”
(Person with lung cancer from Germany)

“The main difficulty in participating is a lack of sufficient knowledge and skills.”
(Caregiver from Italy)

“Partial denial can make it difficult for the patient to absorb information.”
(Caregiver from Germany)

“We need better explanation from the oncologist about the nature of the treatment, type of treatment, side effects, etc.”
(Person with lung cancer from Israel)

* Scale from 1 (very limited understanding) to 5 (full understanding)

Knowledge of clinical trials and treatment options

An initial step in shared decision-making involves understanding the available options and clearly grasping the benefits and risks associated with each choice. Having information about the diagnosis is just as important as having knowledge about the different treatment options for lung cancer. As Figure 11 shows, **targeted therapy, chemotherapy and surgery were the treatments most known to participants.** The high awareness of targeted treatments may be due to the large proportion of respondents with oncogene-driven* lung cancer who participated in this survey (53.5%).

It is surprising to find that **4 out of 10 participants reported having low or no knowledge about clinical trials (46.9%), biomarkers (45.1%) and palliative care (43.8%).** These three items were identified as the areas of least knowledge by people impacted by lung cancer, while these are issues of interest for any individual, regardless of their clinical situation.

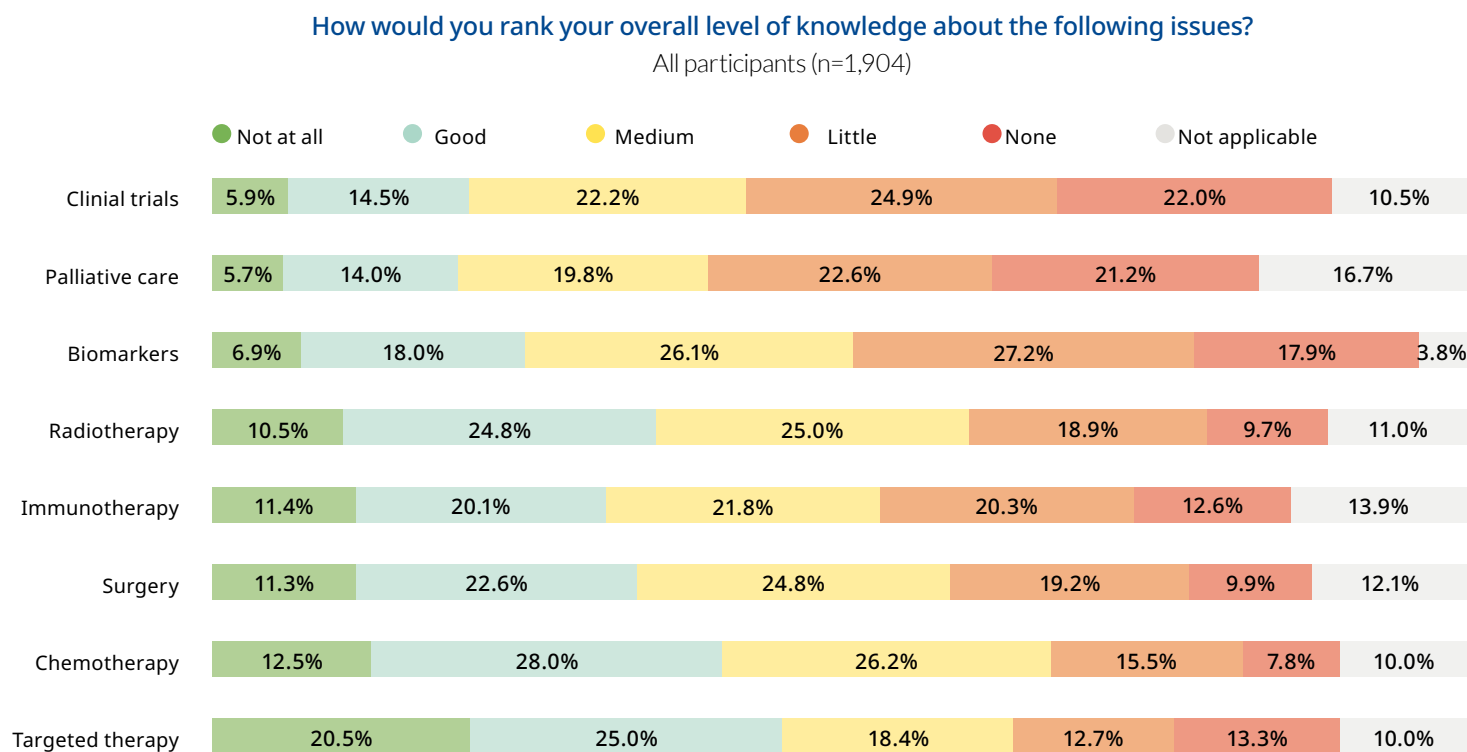


Figure 11. Level of knowledge about issues related to treatments, diagnosis and care.

* *Oncogene-driven: where a biomarker has been identified that can be targeted with specific treatments.

Clinical trials play a pivotal role in advancing treatment for lung cancer. They not only have the potential to benefit future patients but can also enhance the health and wellness journey of those participating. Trials, as care options, offer hope for many participants who may have access to the possible newest treatments. However, only **1 out of 5 people with lung cancer in our survey reported having good knowledge about clinical trials**. It is very worrisome that around half of respondents (46.5%) reported having little to no information about clinical trials.

Figure 12 shows the comparison between the level of knowledge of clinical trials reported by people with lung cancer in 2018 and 2024*. The findings show that there is a **decrease in knowledge**. This year, 22.6% reported having no knowledge of clinical trials, an increase of 12 percentage points compared to six years ago. In 2018, 62.2% stated having medium to good knowledge, whereas this year, this percentage has dropped to 42.4%.

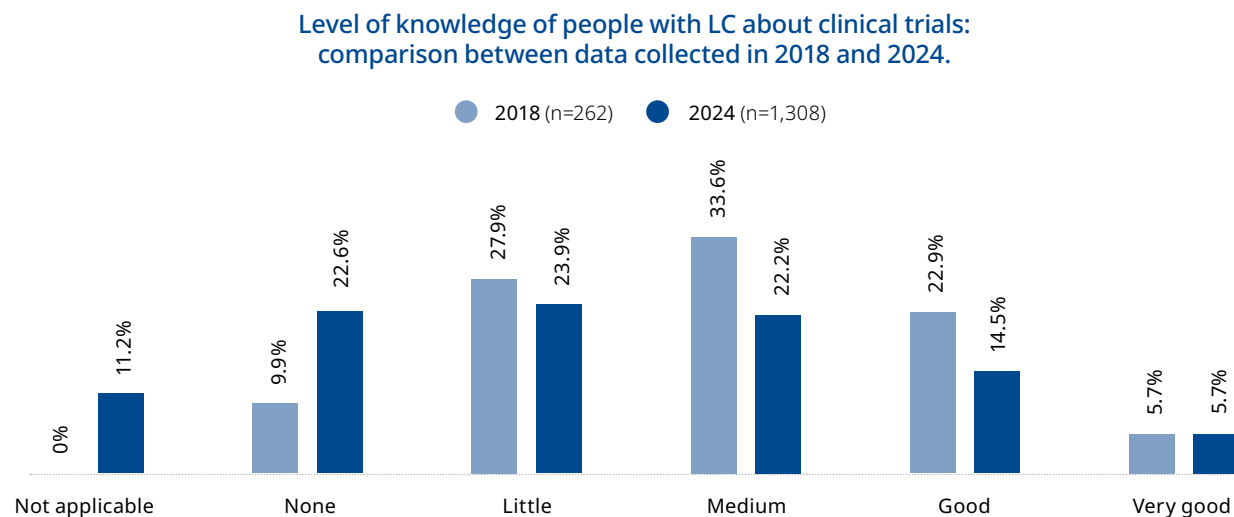


Figure 12. Level of knowledge of people with LC about clinical trials: yearly comparison.

* Responses from caregivers were not collected in 2018.

Figures 11 and 12 illustrate that clinical trials are largely unfamiliar to people impacted by lung cancer. **Only 20.4% reported having good level of knowledge about clinical trials.**

Given the amount of misinformation and myths regarding clinical trials, the survey explored awareness among people impacted by lung cancer.

Table 6 highlights that the most common myth among survey respondents was that clinical trials are only for individuals with no other treatment options. In fact, **only 52.6% knew that trials are also suitable for people with alternative treatment options.**

Only a minority of participants selected the false option that clinical trials guarantee a cure. However, the survey finds a significant percentage of respondents still lack basic knowledge about clinical trials. For example, it is concerning that **1 in 4 respondents did not know that participation in a trial is voluntary** and that individuals can leave at any time.

The results from both people with lung cancer and caregivers were very similar, with no large differences observed.

Please select True or False for each of the next statements relating to clinical trials.

All participants (n=1,905)

	True	False	I don't know
Clinical trials help find if new treatments work and are safe	85.9%	1.9%	12.2%
People in clinical trials might get new treatments before others	73.7%	7.4%	18.9%
Clinical trials guarantee a cure for participants	8.4%	74.1%	17.5%
Joining a clinical trial is voluntary and you can leave at any time	72.9%	4.1%	23.0%
Clinical trials are only for individuals with no other treatment options	16.0%	52.6%	31.5%

Table 6. Statements about clinical trials.

“After being diagnosed at a local hospital, I sought treatment at another facility. By chance, I met an exceptional oncologist and began a trial with a drug targeting the mutation. It's been 10 years since the diagnosis, and I'm truly grateful to the oncologist.”

(Person with lung cancer from Italy)

“I would really like to see as many clinical trials for lung cancer as possible. Patients need to have a chance and hope that remission is achievable”

(Person with lung cancer from Ukraine)

Clinical trials are essential to confirm the efficacy and safety of novel treatments. However, only 3% to 5% of eligible adults with cancer participate in clinical trials¹⁸. Consequently, approximately 20% of cancer clinical trials stop due to insufficient participant enrolment¹⁹.

Although the rate of clinical trial participation has not improved significantly in recent years²⁰, our findings show that **most people impacted by lung cancer (68.1%) expressed willingness to participate in a clinical trial** (Figure 13), with slightly higher interest among people with lung cancer than caregivers (Table 7). Figure 14 shows that 69.7% of people with lung cancer would participate in a clinical trial, which is 16.5 percentage points higher than the data from 2018, as shown in the 3rd LuCE Report (2018).

According to literature, the lack of knowledge and awareness of clinical trials is a significant barrier to participation²¹. Indeed, our findings suggest an

association between the level of education and willingness to participate in clinical trials. Participants with tertiary education showed greater interest in clinical trials compared to those with secondary or primary education, with willingness rates of 71.4%, 65.7% and 58.4%, respectively.

In addition, we find that **the greater the perceived knowledge about the disease, the greater the interest in participating in clinical trials**. Among patients who reported a good level of understanding of their disease*, 73.4% expressed willingness to participate in a clinical trial. In contrast, only 54.8% of patients who reported a low level of understanding indicated a willingness to participate.

Finally, it is important to note that **people with advanced lung cancer reported more interest in participating in a trial than those with earlier stage disease** (75.5% of people in stage IV, 66.2% in stage III and 63.4% in stage I-II).

Would you personally participate in a clinical trial?

All participants (n=1,903)

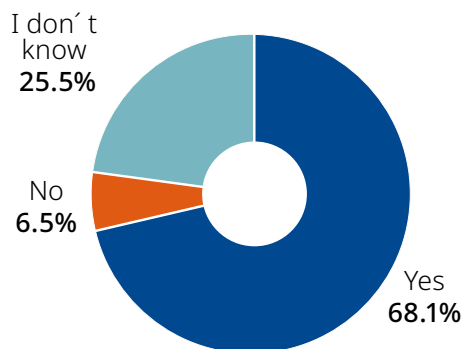


Figure 13. Willingness to participate in a clinical trial.

Willingness of people with LC to participate in a clinical trial.

Comparison between data collected in 2018 and 2024

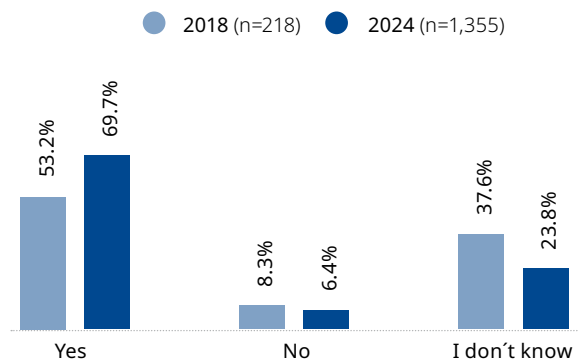


Figure 14. Willingness of people with LC to participate in a clinical trial: year comparison.

	People with LC (n=1,355)	Caregivers (n=548)
Yes	69.7%	63.9%
No	6.4%	6.6%
I don't know	23.8%	29.6%

Table 7. Willingness to participate in a clinical trial (patients vs. caregivers).

* As reported in question 'How would you rate your level of understanding about the disease?' (see Figure 10)

3.2. ACCESS TO INFORMATION: EXPERIENCE, PREFERENCES AND NEEDS

Experience with access to information in healthcare

The diagnostic pathway can be an emotionally intense time for people impacted by lung cancer, especially in the moment of receiving bad news, such as the initial lung cancer diagnosis. During challenging times, receiving information and empathy are crucial both physically and psychologically for diagnosis and treatment.

It is surprising to find that only about half of the survey respondents received full diagnostic information and had good access to their healthcare team throughout the diagnostic pathway (Figure 15). In these moments, people value accessibility and clear information most⁹. However, around **half of respondents reported having insufficient information or lack of access to the healthcare team during these challenging times.**

I need a more detailed description of the findings. My molecular biology report lists the breakpoints of the ALK-EML4 fusion but does not specify which variant it is. I have not yet received a response to my written inquiry.

(Person with lung cancer from Germany)

It is essential longer conversations, more time, and psychological training for doctors treating young patients with metastatic disease.

(Caregiver from Germany)

We didn't have a phone number to call to know if the patient should go to the emergency room based on their symptoms.

(Caregiver from Spain)



Select the option which best describes your experience regarding the information you received along the diagnostic pathway.

All participants (n=2,036)

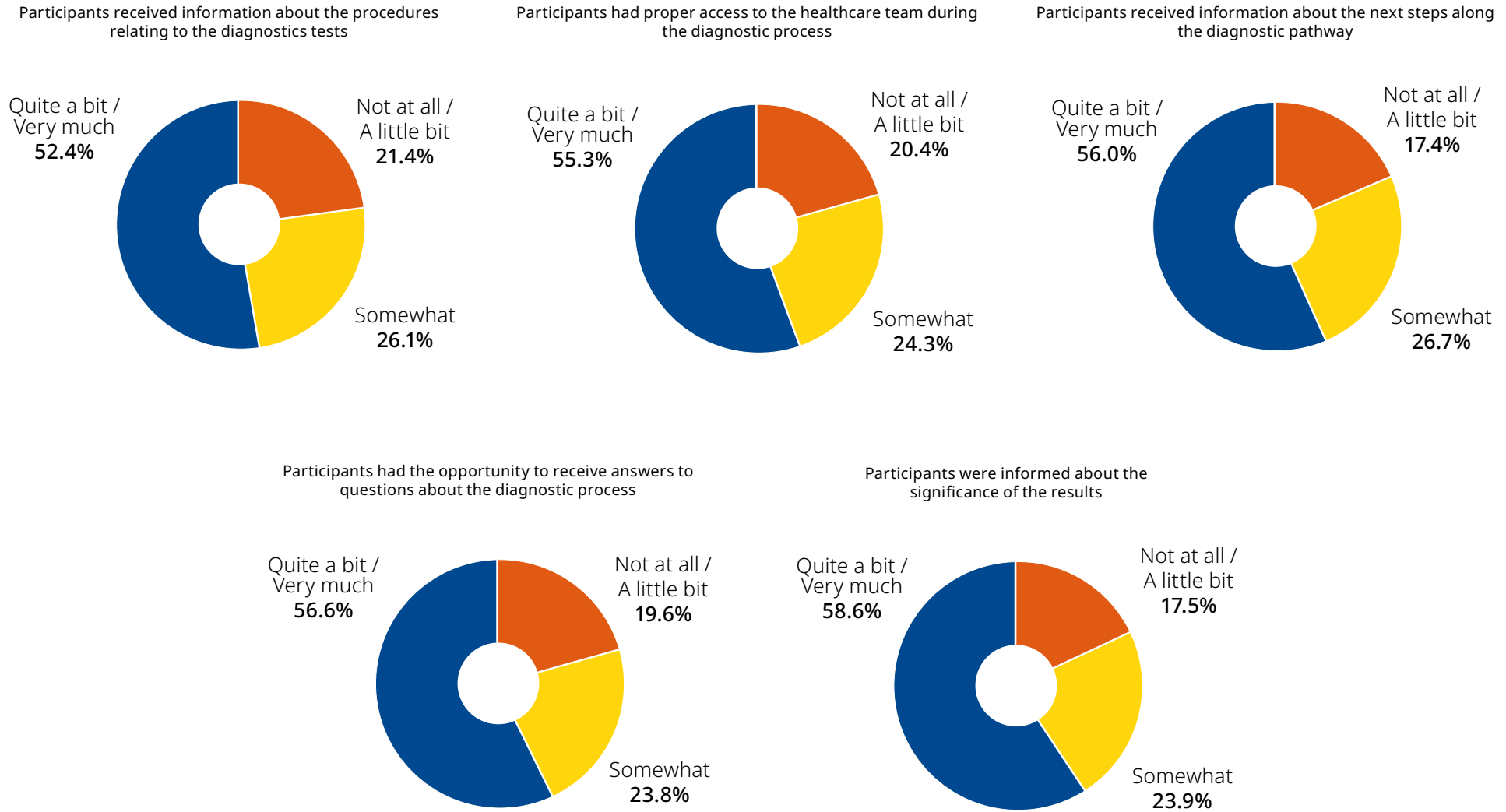


Figure 15. Experience regarding the information along the diagnostic pathway.

Access to information along the diagnostic pathway: Differences per gender.

All participants (n=2,031)

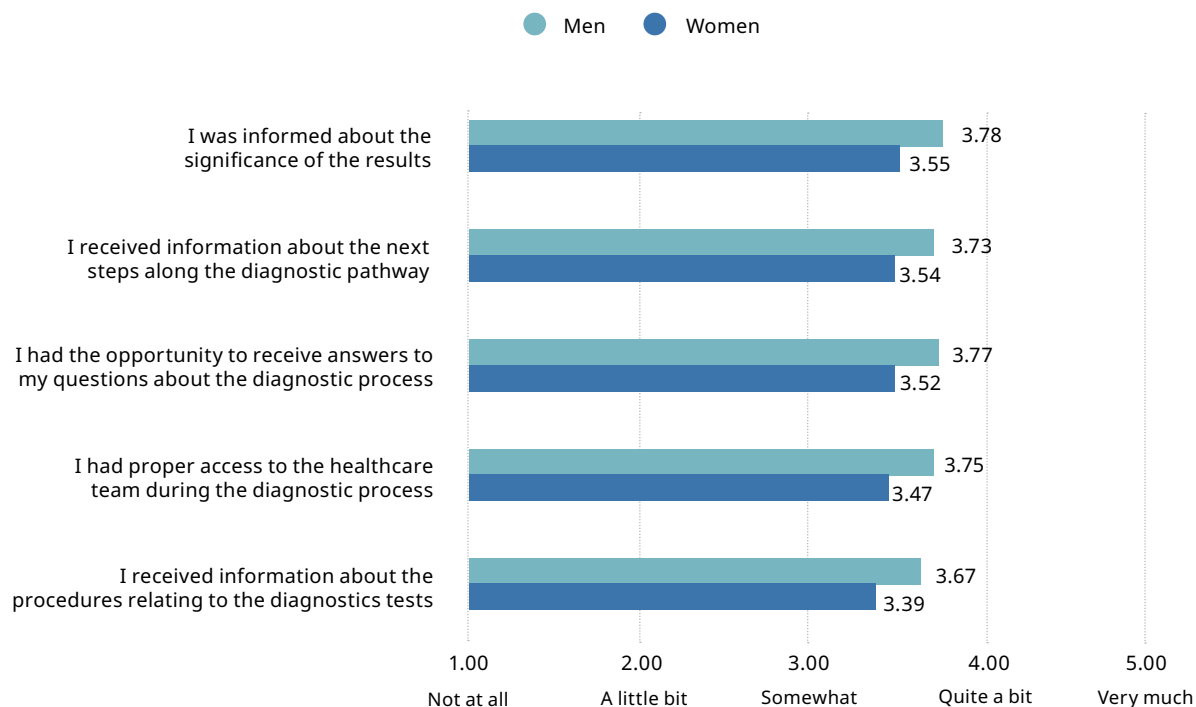


Figure 16. Experience regarding the information along the diagnostic pathway (women vs. men).

The data from women on their experience receiving information along the diagnostic pathway is even more concerning (Figure 16).

Female participants reported worse experiences across all measures, particularly in access to the healthcare team and information about diagnostic procedures.

A total of 21.7% of women reported having no or limited access to their healthcare team (compared to 15.8% of men)*, and 23.2% of women stated they were not informed or were barely informed about the procedures (compared to 15.1% of men)*.

* Reported as 'Not at all' or 'A little bit'

According to our research, **older individuals with lung cancer are more likely to feel that they received information during the diagnostic process.** For example, among people over 64, 59.5% reported having received a lot of information* about diagnostic procedures and about the next steps in the diagnostic process (58.6%). In contrast, these percentages dropped to 45.8% and 48.4%, respectively, among those aged 45 to 54.

Another relevant finding is that **individuals with lung cancer treated at university hospitals reported better experiences across all access measures** (Figure 17). The most notable difference was in the provision of information about the significance of diagnostic results. Specifically, 65.0% of patients in university hospitals reported receiving comprehensive information about their results, compared with only 50.7% of patients in local hospitals.

Patients reported receiving a greater amount of information than caregivers across all areas (Table 8). Notably, 1 in 4 caregivers either did not receive or barely received information about procedures, access to the healthcare team, or time to get answers to their questions.

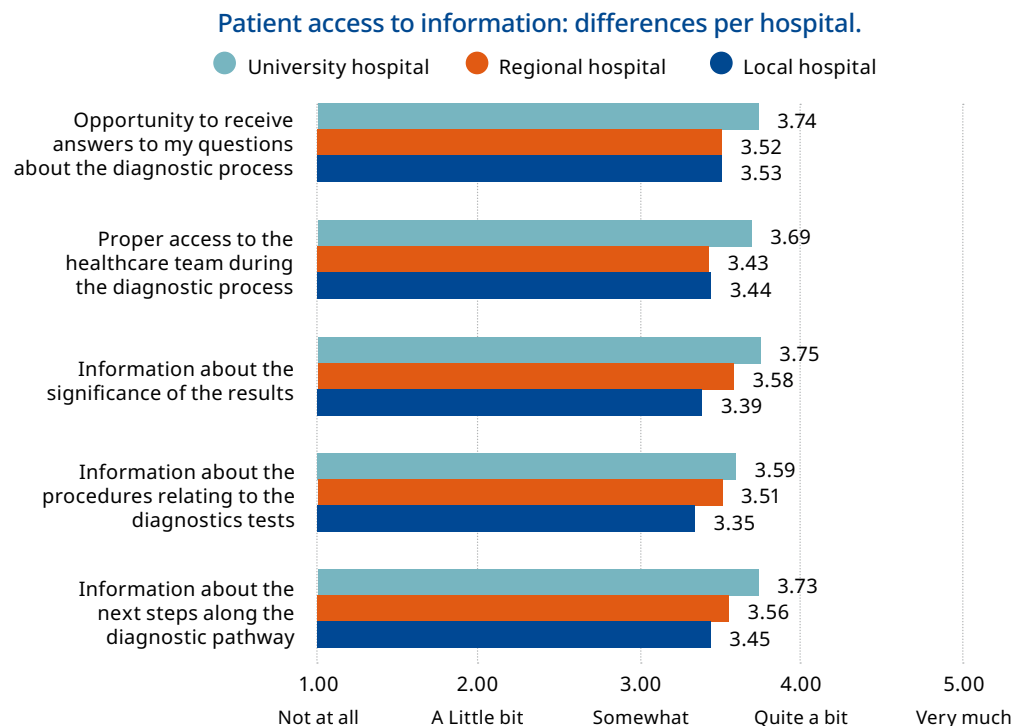


Figure 17. Patient access to information: Differences per hospital.

	People with LC (n=1,430)			Caregivers (n=606)		
	Not at all / A little bit	Somewhat	Quite a bit / Very much	Not at all / A little bit	Somewhat	Quite a bit / Very much
Information about the next steps along the diagnostic pathway	15.5%	25.9%	58.6%	21.8%	28.4%	49.8%
Information about the procedures relating to the diagnostics tests	19.9%	25.9%	54.2%	25.0%	26.6%	48.4%
Information about the significance of the results	16.3%	23.6%	60.1%	20.3%	24.7%	54.9%
Access to the healthcare team during the diagnostic process	19.1%	24.1%	56.8%	23.5%	24.8%	51.7%
Opportunity to receive answers to my questions about the diagnostic process	17.7%	23.7%	58.6%	24.0%	24.0%	52.0%

Table 8. Experience regarding the information along the diagnostic pathway (patients vs. caregivers).

* Reported as 'quite a bit' or 'very much'

Information about the disease is a key element to a better quality of life. Results from our research show high interest among people impacted by lung cancer in having access to medical and healthcare information. **A majority (89.2%) considered that information was extremely important** (Figure 18). However, as shown in the following results, participants reported significant barriers to getting information and being actively involved in their disease management.

The data illustrated in Table 9 does not show large differences between the groups of people with lung cancer and caregivers.

“ Knowledge is a survival advantage! Connect with other affected individuals, carefully assess whether you feel well cared for by your medical team and ask about anything you don't understand. (Caregiver from Germany)

How important is it for you to have access to information about the disease?

1 is 'not important at all' and 5 is 'extremely important'
All participants (n=2,030)

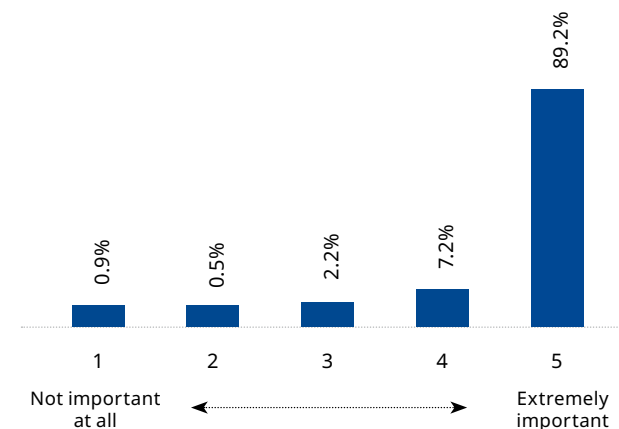


Figure 18. Importance of having information about the disease.

	People with LC (n=1,425)	Caregivers (n=605)
1	0.9%	0.8%
2	0.5%	0.5%
3	2.9%	0.7%
4	8.1%	5.1%
5	87.7%	92.9%

Table 9. Importance of having information about the disease (patients vs. caregivers).

Have you received all the information you need or needed about the diagnosis, treatment and care?

All participants (n=1,909)

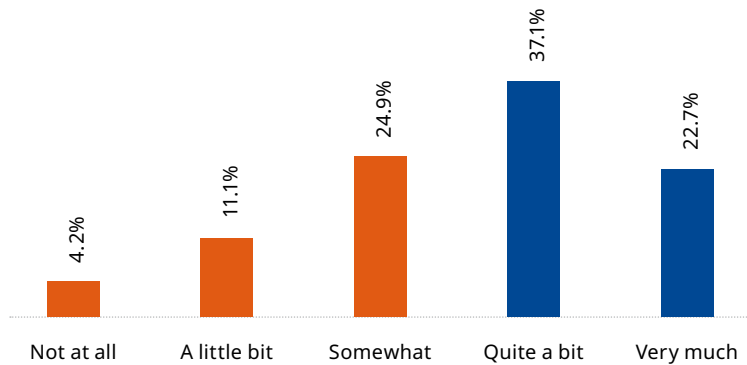


Figure 19. Level of information received.

Have you received all the information you need or needed about the diagnosis, treatment and care?

Comparison between data collected in 2021 and 2024

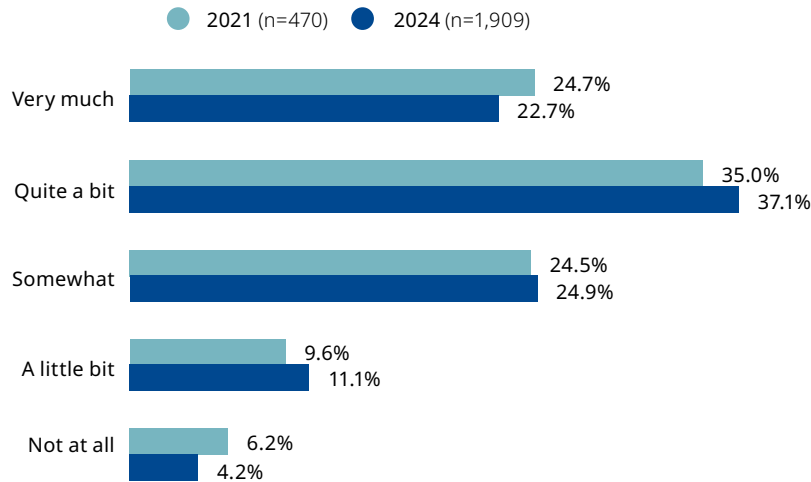


Figure 20. Level of information received: year comparison.

Appropriate information is one of the most important components in effective supportive cancer care²². **Adequate information provision is associated with improved metrics** such as quality of life, adherence to treatment, psychological well-being, and decision-making, whereas inadequate provision is associated with negative outcomes²³.

However, previous research has shown that many of those affected by cancer report that their information needs are not adequately met²⁴. Our research identifies relevant challenges in access to, and understanding of, information.

A total of **40.2% of participants highlighted that they did not receive enough information** about their diagnosis, treatment and care (Figure 19). Similar data was obtained in the 6th LuCE Report (2021), as shown in Figure 20. These results suggest that there is room for improvement in the information provided by healthcare professionals.

Lack of information was reported more commonly by caregivers than people with lung cancer (Table 10). Of note, 1 out of 4 caregivers reported not receiving, or barely receiving the information they needed.

	People with LC (n=1,358)	Caregivers (n=551)
Not at all	2.4%	8.7%
A little bit	9.0%	16.2%
Somewhat	23.5%	28.3%
Quite a bit	39.8%	30.5%
Very much	25.3%	16.3%

Table 10. Level of information received (patients vs. caregivers).

**Have you received all the information you need or needed about the diagnosis, treatment and care?
Differences per gender.**

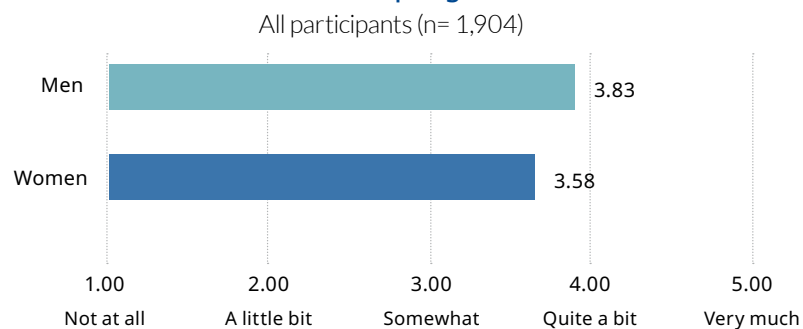


Figure 21. Level of information received (women vs. men).

Literature has reported gender differences in information needs²⁴, and this has also been identified in our research.

Women reported greater informational needs than men (Figure 21). Only 58.1% of female participants stated that they received all the information needed, compared to 66.5% of male participants.

“No information is received from the treatment team at all. I obtained information from the internet and then by asking the treatment team.
(Person with lung cancer from Finland)”

“Doctors and nurses need to have time for the patient. They should listen and understand their fears. Patients should not be sent back and forth in a hospital to take tests without understanding why.
(Caregiver from Norway)”

“I did not receive information about EGFR positive or detailed information about EGFR mutations for medics. I found it myself.
(Person with lung cancer from the United Kingdom)”

“The doctors are overwhelmed with work and have little time for patients.
(Person with lung cancer from Italy)”

Have you understood the information you received about the diagnosis, treatment and care?

All participants (n=1,908)

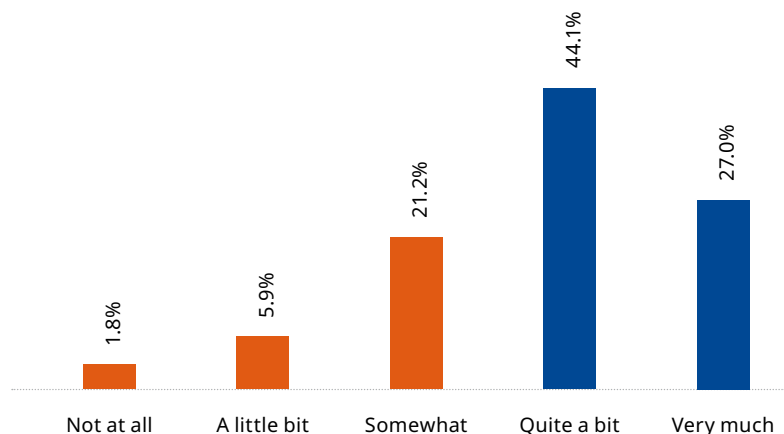


Figure 22. Level of understanding of the information.

	People with LC (n=1,358)	Caregivers (n=550)
Not at all	1.3%	3.1%
A little bit	5.0%	8.2%
Somewhat	20.7%	22.4%
Quite a bit	44.2%	43.8%
Very much	28.9%	22.6%

Table 11. Level of understanding of the information (patients vs. caregivers).

We observe in Figure 22 another significant challenge between healthcare providers, people with lung cancer and caregivers: **1 out of 4 participants stated that they did not fully understand the information** received.

Difficulties in understanding information were more commonly reported by caregivers (Table 11). A slightly higher proportion of people diagnosed with lung cancer stated that they understood the information properly, compared to caregivers (73.1% vs. 66.4%)

“ Good information encourages thoughtful decision-making throughout the healthcare process.
 (Person with lung cancer from Croatia)



“ I received a lot of conflicting information from various doctors and nurses, which made it very confusing.
 (Person with lung cancer from Norway)

Have you ever experienced any of the following during the disease journey?

All participants (n=1,673)



Figure 23. Barriers to accessing information.

Difficulties in accessing and understanding information can reduce an individual's confidence, increase misconceptions, and reduce their involvement in their own disease management²⁵⁻²⁶⁻²⁷. Survey participants identified different **barriers associated with accessing information** (Figure 23).

A total of 39.0% of respondents recognised **difficulties in processing the information**, followed by **insufficient information** (32.9%) and **unclear information** (32.5%). Poor communication with the healthcare team was also reported by 1 out of 4 participants. Information should be tailored to everyone, so it is important to respond to an individual's doubts and questions. However, our research shows that a significant proportion of people impacted by lung cancer did **not have enough time to ask questions** (28.8%) or stated that all **their questions were not answered** (27.7%).

Table 12 shows that **caregivers reported more difficulties compared to people with lung cancer**, especially relating to a lack of information (42.6% vs.

	People with LC (n=1,159)	Caregivers (n=514)
Difficulty processing and retaining information	40.1%	36.4%
Lack of information	28.7%	42.6%
Unclear information	30.5%	37.0%
Not enough time to ask questions	28.0%	30.5%
Poor communication with healthcare professionals	24.6%	36.4%
Not all my questions were answered	26.1%	31.1%
Contradictory information	20.4%	27.0%
Information not provided at the right time	19.2%	27.2%
Lack of trust in healthcare professionals	18.0%	27.6%
Excess information	5.4%	4.7%

Table 12. Barriers to accessing information (patients vs. caregivers).

28.7% in patients), poor communication with the healthcare team (26.4% vs. 24.6%), and not receiving information at the right time (27.2% vs. 19.2%).

Our survey identified **gender differences regarding the experience with health information**. Lack of information was more frequently reported by women (34.8% vs. 25.8%), while more men reported an excess of information compared to women (8.2% vs. 4.5%). It is also notable that female respondents expressed a greater lack of trust in healthcare professionals (22.6% vs. 14.2%) and poor communication with healthcare professionals (29.7% vs. 22.1%) than male participants.



Clinicians must provide more reliable information, allow time for patients to absorb the news, and then have a discussion.
(Person with lung cancer from the United Kingdom)

Informed consent is crucial for treatment decisions. This is defined as the process of communication between doctors and individuals regarding treatment options, resulting in the individual's authorisation or agreement to undergo a specific medical intervention²⁸.

In our survey, only 47.1% of respondents stated that they had received and understood all the information they needed before signing the informed consent document (Figure 24). This means that **30.2% of the participants did not receive or understand the information**, while the remaining respondents (22.7%) were unsure or did not know what informed consent was.

Informed consent involves patients and occasionally caregivers. Therefore, it is important to analyse data specifically among people diagnosed with lung cancer. Surprisingly, percentages did not differ by a great amount. **Only half of patients surveyed (50.6%) agreed to having received and understood all the information before signing the document.**

Similar data were obtained in the 7th LuCE Report (2022), which indicated that the **informed consent process is not working effectively** for many individuals impacted by lung cancer.

In the informed consent process, female participants again reported more difficulties in accessing information. While 55.5% of men stated that they had received and understood all the information, this percentage decreased to 44.9% among women. Additionally, women more frequently reported being barely informed before signing the informed consent document (9.0% vs. 3.8%).

The treatment often feels imposed rather than proposed to the patient. Although I did not question the doctors' decisions, I would have preferred a more thorough process for obtaining my consent, as if I were an active participant in the treatment plan.
 (Person with lung cancer from France)

Which of the following describes your experience (or your loved one) with informed consent?*

All participants (n=1,900)

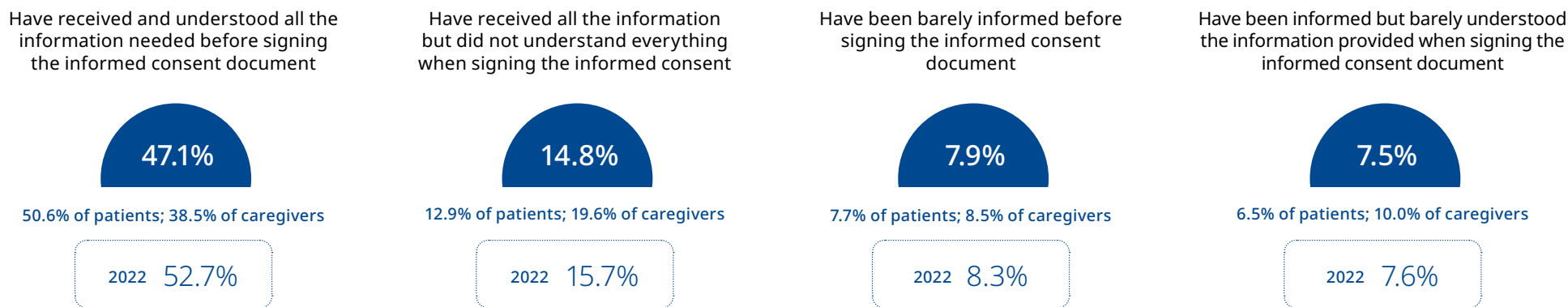


Figure 24. Experience with informed consent.

* 22.7% were unsure or did not know what informed consent was.

Specific needs for information

Informed consent is a basic principle that facilitates a shared decision-making model between patients and physicians²⁹. Through this process, individuals deliberately decide whether to accept or refuse the proposed treatment or intervention. However, patients' adequate understanding of the information is a major limitation for a truly informed consent²⁹.

Our survey shows that nearly **half of participants (47.5%) did not receive any information about other possible alternative treatment options** (Figure 25). Even accounting for cases where there may be no other treatment options, we still consider this percentage to be very high. This finding contradicts the very nature of the informed consent process, as individuals need to understand all available options beyond the one proposed. In addition, it is worrisome that **only**

51.8% were well informed about potential side effects or risks, 53.6% about expected outcomes and benefits, and 59.6% about how the treatment worked.

We also observe limitations in accessing supportive services. Our 7th LuCE Report (2022) highlighted that people with lung cancer experienced difficulties accessing care⁹. Results from that year showed that 1 out of 3 people surveyed recognised that their overall needs were not addressed enough. As Figure 25 shows, in this year's survey, **only 35.1% reported being well informed about supportive services**. People affected by lung cancer should be informed of the available healthcare services, and healthcare professionals should offer or refer to services based on individual needs and preferences³⁰. Additionally, information on supportive services should be provided before the start of treatment⁹.

Which of the following describes your experience (or your loved one) with informed consent?

All participants (n=1,909)

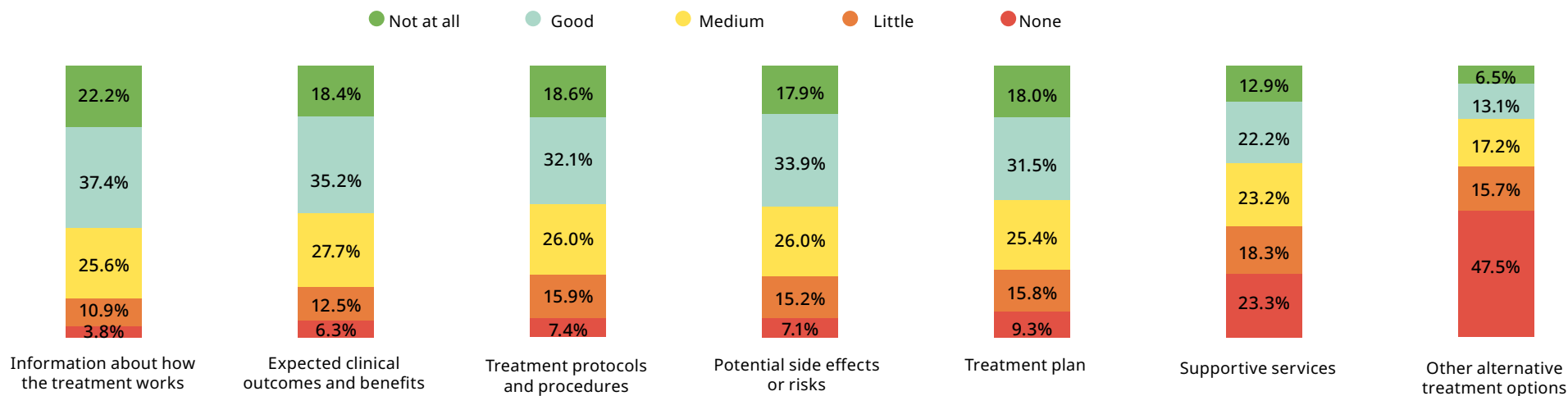


Figure 25. Level of information about issues related to treatments.

Table 13 illustrates some differences between people with lung cancer and caregivers. According to ‘Patients’ Rights in the European Union’ report by the European Commission (2016), **patients have the right to information about treatment options**. Therefore, it was expected that patients should have had more access to information than caregivers. Indeed, people with lung cancer reported more frequently being better informed about the various options, compared with caregivers.

However, it is worth noting that, **in most cases, the right to be completely informed about treatments was not fully met**. Specifically, 63.5% of people

with lung cancer reported receiving no information or barely being informed about alternative options, and 23.6% reported insufficient information on the treatment plan.

Among caregivers, it is worrying that **half reported having received little or no information about supportive services**. In addition, 1 in 4 had received very limited information on critical aspects of their loved one’s treatment, such as the treatment plan (28.9%), the treatment protocol (28.8%), potential side effects (26.8%) and expected outcomes (25.4%).

To what degree have you been informed about the following issues related to the treatments received?	People with LC (n=1,359)			Caregivers (n=550)		
	Not at all / A little bit	Somewhat	Quite a bit / Very much	Not at all / A little bit	Somewhat	Quite a bit / Very much
Information about how the treatment works	12.6%	24.4%	63.1%	20.2%	28.8%	51.0%
Expected clinical outcomes and benefits	16.1%	26.9%	57.0%	25.4%	29.7%	44.9%
Potential side effects or risks	21.8%	25.4%	52.8%	26.8%	27.4%	45.8%
Treatment protocols and procedures	19.6%	25.6%	54.8%	28.8%	26.9%	44.3%
Treatment plan: duration, combinations with other treatments, etc.	23.6%	23.4%	53.0%	28.9%	30.2%	40.8%
Supportive services	38.6%	22.8%	38.7%	49.0%	24.4%	26.6%
Other alternative treatment options	63.5%	15.8%	20.8%	62.6%	20.7%	16.7%

Table 13. Level of information about issues related to treatments (patients vs. caregivers).

“ We would have needed information about alternatives when the treatment wasn’t working.
 (Caregiver from Spain)

“ Patient involvement requires greater access to information about alternative treatments.
 (Person with lung cancer from Norway)

“ I lack a treatment plan, and it is not satisfactory to receive the image description of the follow-up CT scan over the phone from a busy doctor.
 (Person with lung cancer from Denmark)

Information and support throughout the disease journey are crucial for appropriate care and well-being. However, it is surprising to find that **85.5% of respondents impacted by lung cancer reported lacking some form of support or information** (Figure 26).

The most frequently reported **informational gaps** are related to **side effects** and their management (38.5%), followed by **psychological counselling** (36.8%). Participants also reported a lack of information about clinical trials (32.2%) and medical details (32.0%).

Notably, **clinical trials were the most frequently cited information gap among those with stage IV lung cancer (34.9%)**. In contrast, participants with stage III disease most commonly lacked information about side effects (43.5%) and nutrition and exercise (35.7%).

Table 14 shows that **caregivers reported a much higher lack of information than people with lung cancer**, especially about psychological counselling

	People with LC (n=1,358)	Caregivers (n=551)
Side effects (and how to manage)	37.3%	41.4%
Psychological counselling	32.1%	48.2%
Clinical trials	30.1%	37.6%
Medical information	28.8%	39.9%
Nutrition and exercise	30.4%	35.0%
Social resources and rights	26.1%	29.3%
Patient organisations and NGOs*	24.5%	30.4%
Health system navigation	17.5%	25.8%
Palliative care	11.8%	25.8%
Sexuality	13.0%	10.4%
Fertility	3.1%	2.8%
None	17.2%	11.4%

Table 14. Information missing since diagnosis (patients vs. caregivers).

* NGOs: Non-governmental organisation

(48.2% vs. 32.1%), medical information (39.9% vs. 28.8%) and palliative care (25.8% vs. 11.8%).

Female caregivers overwhelmingly reported not receiving information about side effects management compared with male caregivers (25.6% vs. 5.8%).

Since diagnosis, what type of information or support have you lacked?

Comparison between data collected in 2021 and 2024

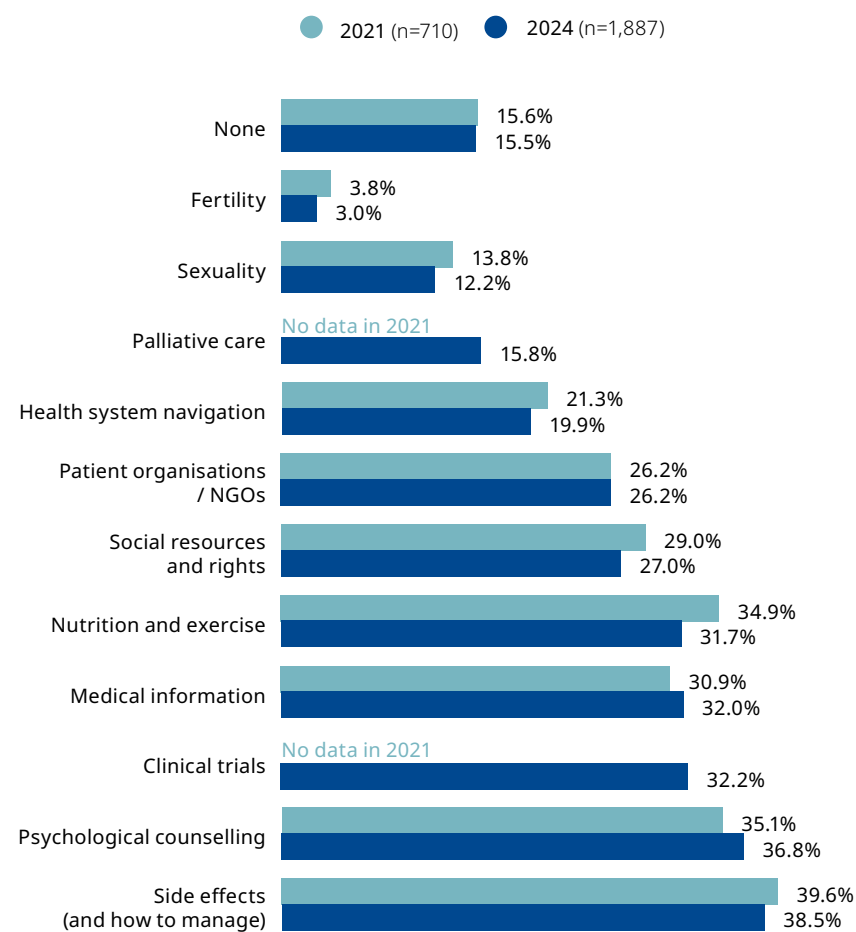


Figure 26. Information missing since diagnosis: year comparison.

Education about side effects and how to manage them is a priority for both people with lung cancer and caregivers³¹. Worryingly, survey participants reported very limited information about this important need.

Therefore, it is unsurprising to find that a significant proportion of **patients** (52.5%) surveyed reported **not feeling well equipped to manage symptoms and side effects** (Figure 27). It is even more concerning to find that 1 out of 4 (22.7%) reported being either not equipped or only minimally equipped to deal with side effects. Similar data were obtained in the 6th LuCE Report (2021), which emphasised the need for better support for people with lung cancer to self-manage side effects.

Importantly, caregivers play a key role in enhancing their loved one's quality of life. According to the 6th LuCE Report (2021), 7 out of 10 caregivers provided support in managing patient symptoms and side effects. Proper education is essential for caregivers to offer the best possible support.

However, only 29.2% responded that they had received complete information on managing side effects (Figure 28). It is notable that **43.2% received little or no information on how to help their loved one manage side effects**.

Have you felt equipped to manage the symptoms and side effects?

Comparison between data collected in 2021 and 2024

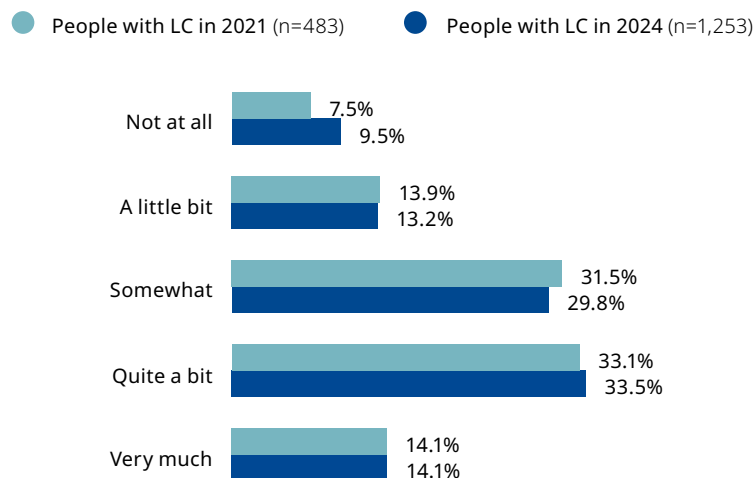


Figure 27. Extent of equipment for managing side effects: year comparison.

Have you received information and support to help your loved one to manage the symptoms and side effects?

Caregivers (n=493)

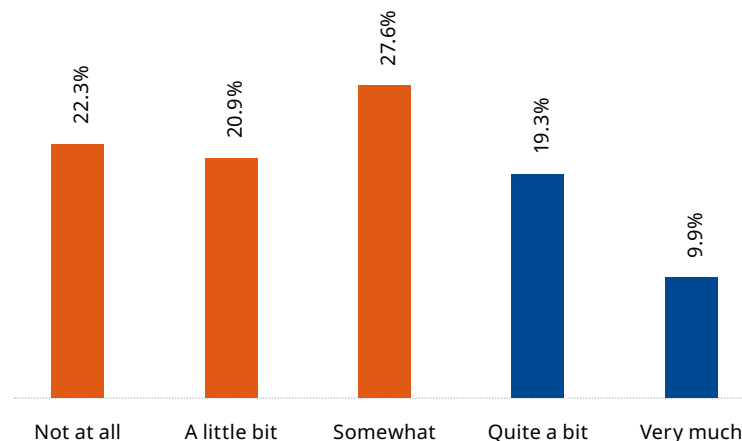


Figure 28. Extent of equipment for supporting to manage side effects.

Healthcare communication and information exchange

Good communication and person-centred conversations are fundamental to improve support and ensure that care is aligned with personal preferences³². However, our findings show that **33.5% did not positively value their communication with their healthcare team** (Table 15). This data is even more worrisome among **caregivers**, as **only half reported a positive experience** with their interaction with physicians and the healthcare team. These **results are worse than those obtained in 2020**, stressing the need to improve the communication skills of healthcare providers.

Once again, **women reported a lower satisfaction** regarding communication with the healthcare team, particularly among caregivers. Almost 1 out of 4 female caregivers negatively valued the interaction with healthcare professionals, compared to 8.1% of male caregivers.

How do you rate the communication with your physicians and healthcare team along the disease journey?

All participants (n=1,750)






	Comparison between data collected in 2020 and 2024		Comparison between people with lung cancer and caregivers in 2024	
	All participants in 2024 (n=1,750)	All participants in 2020 (n=455)	People with lung cancer in 2024 (n=1,259)	Caregivers in 2024 (n=491)
	3.0%	2.5%	1.7%	6.5%
	8.6%	5.6%	6.8%	13.0%
	21.9%	17.5%	18.7%	30.1%
	41.0%	34.4%	43.8%	33.8%
	25.5%	40.0%	29.1%	16.5%

Table 15. Communication satisfaction with healthcare team.

What factors have influenced the exchange of information with the healthcare team?

All participants (n=1,553)

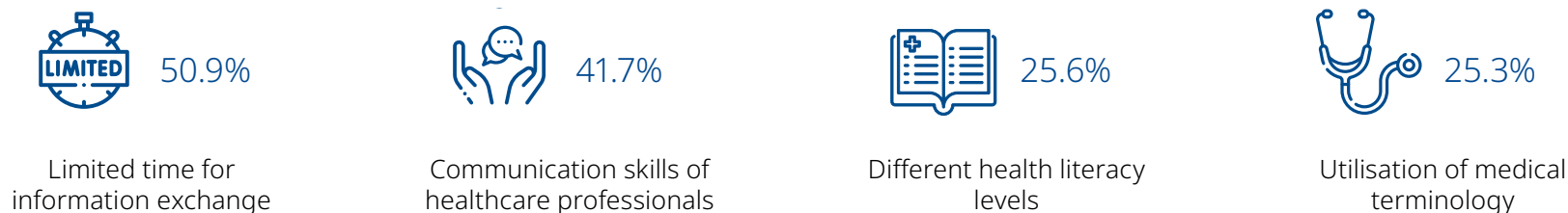


Figure 29. Top factors influencing the exchange of information.

	All participants (n=1,553)	People with LC (n=1,094)	Caregivers (n=459)
Limited time for information exchange	50.9%	49.7%	53.6%
Communication skills of healthcare professionals	41.7%	41.6%	41.8%
Different health literacy levels	25.6%	25.4%	25.9%
Utilisation of medical terminology	25.3%	25.1%	25.7%
Lack of confidence in exchanging information	13.5%	12.3%	16.6%
Personal beliefs or preferences	7.8%	7.3%	8.9%
Geographical limitations	5.3%	5.2%	5.5%
Technological barriers	2.7%	3.2%	1.5%
Age disparities	2.6%	2.2%	3.5%
Language barriers	2.4%	2.6%	2.2%
Cultural or ethnic differences	1.5%	1.6%	1.3%

Table 16. Factors influencing the exchange of information (patients vs. caregivers).

When asked about the influences on the exchange of information (Figure 29 / Table 16), we observed that the main factors relate to healthcare issues, such as the **limited consultation time** (50.9%), poor **communication skills** (41.7%), and the use of **complex information** (25.3%). These results stress the need for person-centred models that improve the partnership between individuals and their healthcare providers.

A longer time for information exchange is a priority when making important decisions, so physicians can have the opportunity to inform, educate, and discuss the different care and treatment options.

Health literacy was cited by survey participants as the third most important factor that influenced the exchange of information. **Health literacy is associated with the knowledge, skills, understanding and confidence to access, comprehend, and use information.** Therefore, this should be considered by health professionals when communicating and providing information to people affected by lung cancer.



Time, meaningful conversations, offering alternatives, avoiding pressure, providing better explanations, and being taken seriously are all essential.

(Person with lung cancer from Germany)

We have had positive experiences with our pulmonologist, including clear explanations, thoroughness, and compassionate care. This fosters trust and provides time and reason to reflect.

(Caregiver from the Netherlands)

Personal discussions with the doctor and healthcare staff should include the presentation of different treatment options. Patients should be given enough time to ensure that meetings do not feel rushed.

(Person with lung cancer from Finland)

We need calm and quiet conversations with the doctor/specialised nurse, where there is time to ask questions.

(Person with lung cancer from Denmark)

Provide more information that is easily understandable to the average person about treatment types and procedures specific to each patient.

(People with lung cancer from Croatia)

Certainly, the empathy and competence of the doctor towards the patient are crucial, as they translate into trust and, consequently, a calm acceptance of the proposed treatments.

(Caregiver from Italy)

I've missed the approach of listening to and recognising the patient as an individual with their own physiological particularities, rather than seeing them as merely a carrier of a disease treated solely by professionals without considering the patient as an active participant in the care process.

(Person with lung cancer from France)

I'd request clear communication, including with family and loved ones.

(Caregiver from The Netherlands)



Seeking information outside of healthcare system

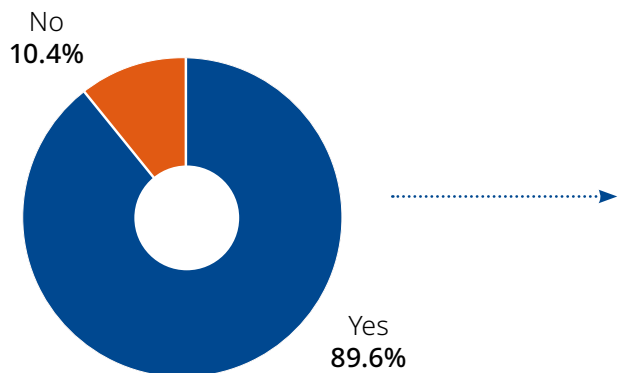
Searching for information about lung cancer can help individuals gain knowledge and make informed health decisions. This is especially important when barriers to accessing information from healthcare providers exist, as previous data in this report has shown.

Figure 30 shows that a majority of **participants** (89.6%) responded that they **had sought health information outside the healthcare system**. Although most participants usually found the information they were looking for, it is worth noting that almost **1 out of 4 either did not find the information or, if they did, the information was not accurate*** (Figure 31).



Have you ever sought additional health information outside the healthcare system?

All participants (n=1,747)



Experiences seeking additional health information outside the healthcare system.

All participants (n=1,565)

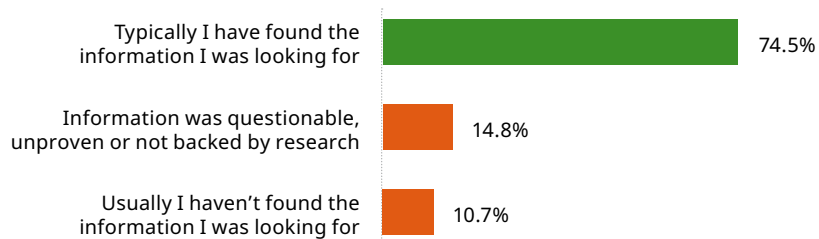


Figure 30. Information seeking outside the healthcare system.

Figure 31. Experience in seeking information outside the healthcare system.

* The response option was 'Yes, but information was questionable, unproven or not backed by research'.

Results from people with lung cancer and caregivers were similar (Tables 17 and 18). Caregivers reported slightly higher information-seeking behaviour (91.3% vs. 88.9% in patients), while patients more frequently reported finding the information they were looking for (75.7% vs. 71.5% in caregivers).

It is worth noting that, among patients, **those with higher levels of education sought information more frequently*** and usually **found the information more often****.

	People with LC (n=1,255)	Caregivers (n=492)
Yes	88.9%	91.3%
No	11.1%	8.7%

Among those who sought information

	People with LC (n=1,116)	Caregivers (n=449)
Usually, I haven't found the information I was looking for	10.1%	12.2%
Information was questionable, unproven or not backed by research	14.2%	16.3%
Typically, I have found the information I was looking for	75.7%	71.5%

Table 17. Information seeking outside the healthcare system (patients vs. caregivers).

Table 18. Experience in seeking information outside the healthcare system (patients vs. caregivers).

“No information is received from the treatment team at all. I obtained information from the internet and then by asking the treatment team.”
(Person with lung cancer from Finland)

“Clinicians should understand that patients who search for information on the internet need support in their search.”
(Person with lung cancer from France)

“There is no time to ask questions during medical check-ups or receive proper information in person. Online, there is no opportunity to consult with the doctor, and reaching them by phone is very difficult and time-consuming, sometimes only achievable after several days.”
(Person with lung cancer from Hungary)

*Tertiary education: 92.3%; Secondary education: 87.3%; Primary education: 77.1%.
**Tertiary education: 77.6%; Secondary education: 74.7%; Primary education: 69.0%.

What sources have you used to get information about lung cancer?

All participants (n=1,757)

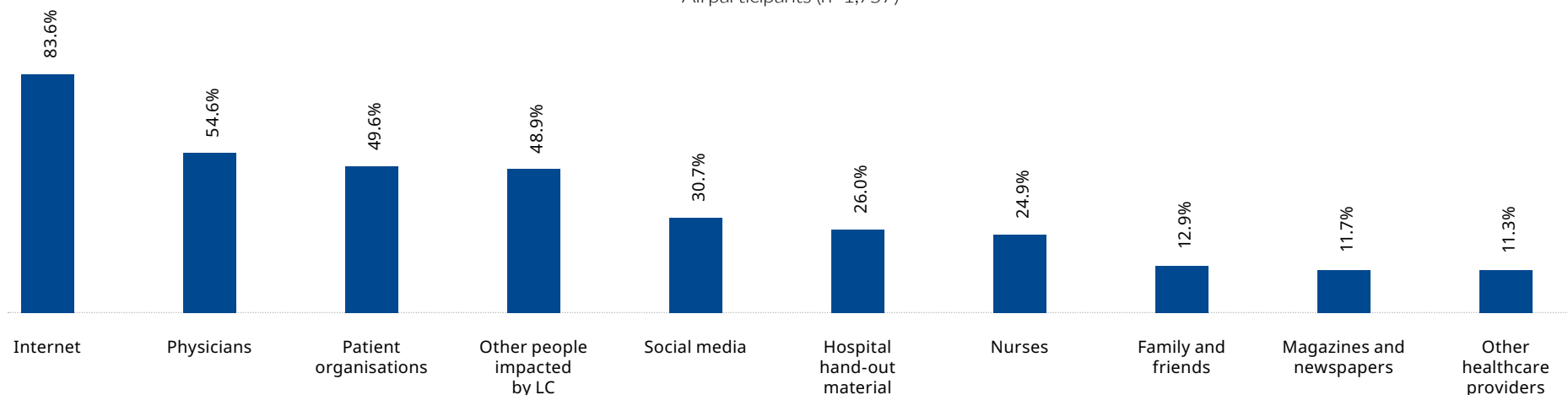


Figure 32. Sources of information.

Information seeking is common among people affected by lung cancer. In a technologically advanced era, we find that a majority of participants (83.6%) have used the internet to search for information about the disease (Figure 32).

The internet was the most frequently used source for lung cancer information, with physicians being the second most frequent source. It is notable that **only half of participants (54.6%) reported receiving information through their physicians**. A similar proportion reported receiving information through patient organisations (49.6%) and other people impacted by lung cancer (48.9%).

The last decades have witnessed technological progress in the way society communicates and receives information, leading some people to become more reliant on online information³³. However, as shown in Figure 31, information found on the internet is not always accurate, complete or tailored to individual needs and circumstances. Therefore, we urgently need to **improve the communication between the clinical team and people impacted by lung cancer**.

	People with LC (n=1,263)	Caregivers (n=494)
Internet	83.0%	85.0%
Physicians	54.4%	55.3%
Patient organisations	52.2%	42.9%
Other people impacted by LC	49.7%	46.8%
Social media	27.7%	38.5%
Hospital hand-out material	27.6%	21.7%
Nurses	26.2%	21.7%
Family and friends	12.4%	14.0%
Magazines and newspapers	11.5%	12.4%
Other healthcare providers	10.6%	13.0%

Table 19. Sources of information (patients vs. caregivers).

Our survey also indicates that **patient organisations were a significantly more utilised source of information for patients with stage IV and stage III disease** (59.0% and 58.2%, respectively) compared to those with stage I-II (38.5%). The same pattern was observed among caregivers: 47.0% of those caring for someone with stage IV and 44.4% with stage III sought information from patient organisations, whereas this percentage was only 30.5% for caregivers of individuals with stage I-II disease.

Table 19 highlights a number of **differences between people with lung cancer and caregivers regarding the sources of information used**. Patients cited using patient organisations (52.2% vs. 42.9%) and hospital hand-out material (27.6% vs. 21.7%) more commonly, while caregivers used social media more (38.5% vs. 27.7%).

I am part of a social network of 300 people with ALK ROS1, and I learn a great deal from others in the group.

(Person with lung cancer from the United Kingdom)

Oncologists often have many patients and need to see each one quickly to manage their workload. They are under significant time pressure.

(Person with lung cancer from Spain)



I explored the risks of brain radiation from an American publication that the oncologist had not yet seen.

(Person with lung cancer from Finland)

Sharing experiences with other patients can lead to better treatment outcomes. I believe that lectures and educational sessions would help patients better understand their illness and explore possible treatments.

(Person with lung cancer from Slovenia)

3.3. SHARED DECISION-MAKING: EXPERIENCE, CHALLENGES AND RECOMMENDATIONS

Attitudes and experiences in shared decision-making

Healthcare decisions are also influenced by personal values and preferences, and this requires clinicians and patients to work in partnership to determine treatment and care options most aligned with individual needs and priorities. Shared decision-making should be part of quality cancer care. Patient involvement in decisions is associated with positive outcomes, such as increased knowledge about the treatment and care options, and better quality of life³⁴.

Physicians have traditionally held the decision-making responsibility. However, there is a **growing emphasis on shared decision-making**, where people living with a disease, or their loved ones, are more actively involved in their healthcare decisions. This approach respects patient autonomy and encourages active discussion between patients, caregivers and healthcare providers.

Our research finds consensus on the importance of patient engagement in healthcare decisions. **Almost all people with lung cancer surveyed (98.0%) believed their opinion must be considered in the decision-making**

process (Figure 33). Seven out of 10 patients surveyed thought that their opinions and preferences should be taken into account in the decision-making process (by quite a bit / very much). This percentage was similar in our survey conducted in 2021 (at 72.2%). On the other hand, a small number of patients felt that their opinion did not have to be considered or considered just a little bit (8.9% in 2024 vs. 10.7% in 2021).

In Figure 34, we observe that **91.5% of caregivers surveyed also responded that their opinions should be taken into account in discussions** regarding treatment and care. Notably, 35.1% considered that their voice should be highly considered (by quite a bit / very much). This is almost 8 points higher than in 2021.



Often, patients leave decisions to family members because they are unsure how to manage the emotions caused by their condition.
(Caregiver from Spain)

Do you think that your opinion and preferences should be taken into account when deciding about treatments and care?

People with LC (n=1,278)

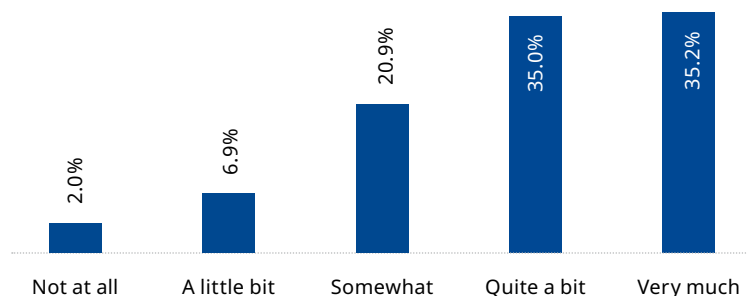


Figure 33. Patients' attitudes toward shared decision-making.

As a caregiver, do you think that your opinion and preferences should be taken into account when deciding about treatments and care?

Caregivers (n=505)

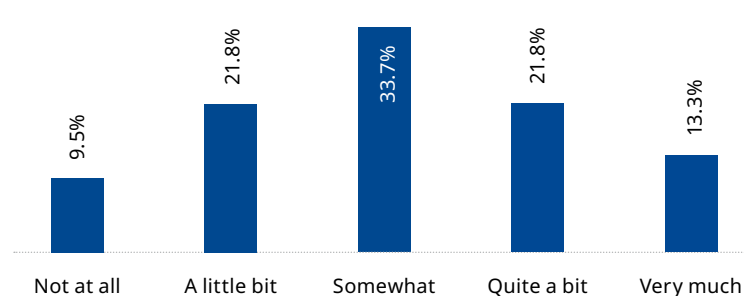


Figure 34. Caregivers' attitudes toward shared decision-making.

According to the literature, there is discordance between the role that patients want to play in treatment decision-making and their perceived involvement³⁵. As shown in Figure 35, the actual participation of patients in decision-making was not as frequent as they would have liked. Although 70.2% of people with lung cancer surveyed believed that their opinion was very important in deciding treatment, **only 49.3% reported being highly involved** in this process, and **55.9% felt that their opinion was being considered**.

The data obtained was similar to that collected in 2021³¹. The main difference is that the percentage of patients who actively participated in decision-making was 56.7% in 2021, compared to 49.3% in 2024.

This data is even more worrying among women with lung cancer. For example, while 31.5% of male patients stated their opinion was always considered in decision-making, this percentage fell to 25.4% among women.

As illustrated in Figure 36, caregivers play an important role in decision-making. The majority of caregivers (62.7%) stated that they were involved in this process in some way. However, it is important to highlight that **37.6% reported some doubts whether their loved one was offered the best possible treatment and care**.

“*The primary decisions about one’s life must be made by the patient themselves.*
(Caregiver from Ukraine)

“*I am fortunate with my treating doctor and team; they always discuss things with me and provide information.*
(Person with lung cancer from Hungary)

“*In our case, the patient’s and relatives’ opinions were rarely solicited; instead, they were simply informed about what would be done.*
(Caregiver from Finland)

Select the option that best describes your experience regarding treatment decisions.

People with LC (n=1,285)

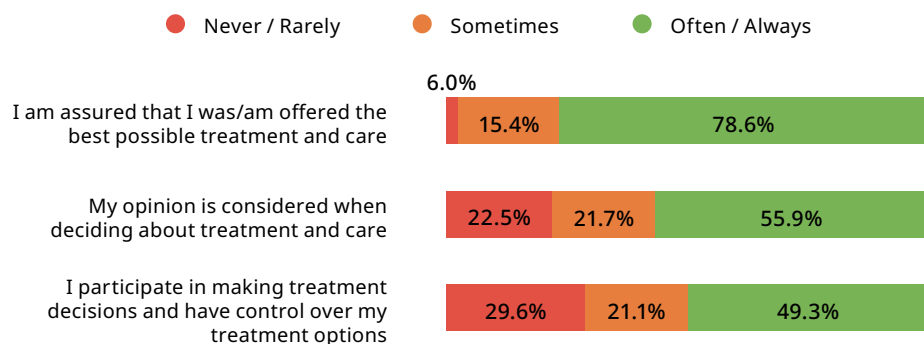


Figure 35. Patients’ experience with treatment decisions.

Select the option that best describes your experience regarding treatment decisions.

Caregivers (n=506)

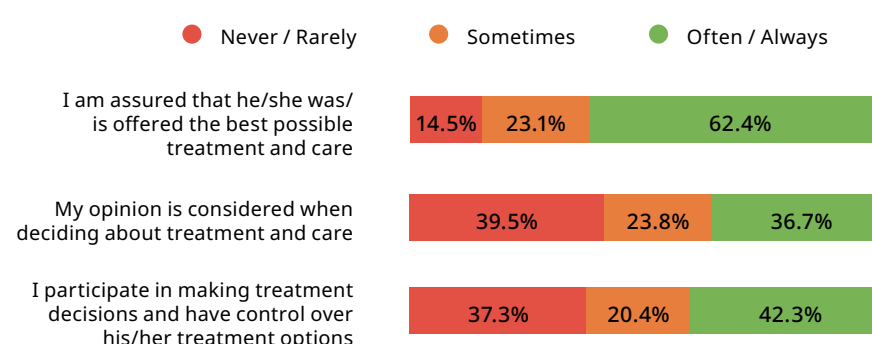


Figure 36. Caregivers’ experience with treatment decisions.

As illustrated in this report, many caregivers are directly involved throughout the disease. They contribute by attending medical appointments, helping with care and treatment decisions, and coordinating medical care, among many other things. Many share the disease journey with their loved one and, therefore, are involved in the decision-making process. In this regard, the 6th LuCE Report (2021) found that 49.0% were directly involved in treatment decisions and 32.2% were the primary decision-maker³¹.

Figure 37 illustrates the significant role of caregivers in treatment and care decisions. **Six out of 10 people with lung cancer reported needing the support of their loved ones** to make decisions. Therefore, communication between people with lung cancer, caregivers and healthcare team is crucial.

However, **48.9% of caregivers reported having guarded medical information** to protect their loved ones, up from 44.3% in the 6th LuCE Report (2021). It is worth noting that the proportion of caregivers who frequently hid information has increased 10 percentage points over the past 3 years.

“*The care team should engage in conversations with partners and close family members, as they know the patient best. Since patients often may not fully recognise their own illness, involving relatives routinely is important.*
(Person with lung cancer from the Netherlands)”

I need the support of my relatives to make decisions about treatment and care.

People with LC (n=1,285)

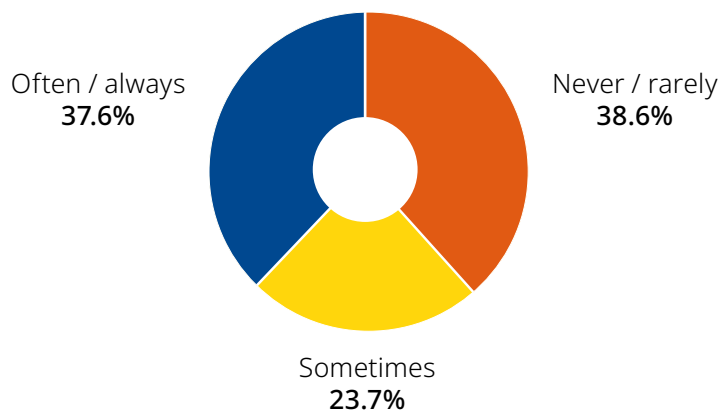


Figure 37. Support of relatives in decision-making.

I have guarded medical information to protect the patient.

Caregivers (n=506)

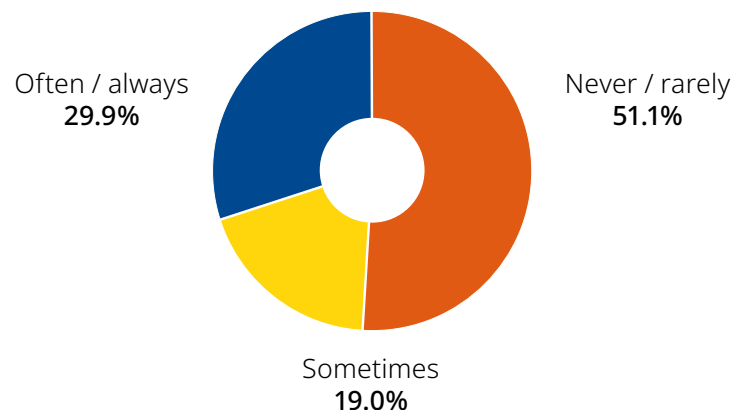


Figure 38. Caregivers guarding medical information.

Do you feel that your treatment and care has aligned with your personal preferences (or your loved one's)?

All participants (n=1,777)

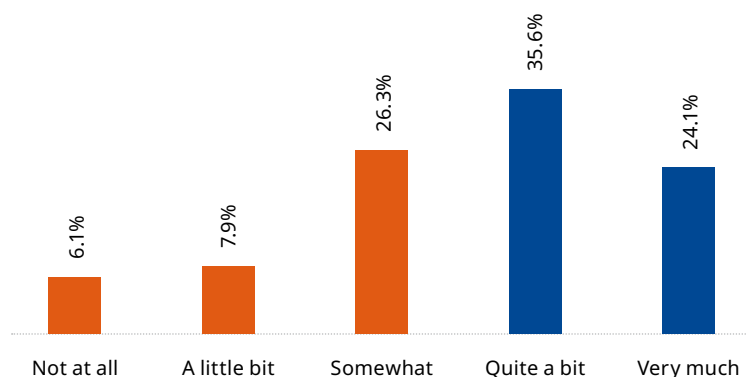


Figure 39. Treatment aligned with patient preferences.

	People with LC (n=1,271)	Caregivers (n=506)
Not at all	4.6%	9.7%
A little bit	7.0%	10.1%
Somewhat	24.9%	29.8%
Quite a bit	37.8%	30.0%
Very much	25.7%	20.4%

Table 20. Treatment aligned with patient preferences (patients vs. caregivers).

As research continues to uncover the diverse nature of tumours, the range of potential treatment options expand. This may improve the possibility for personalised cancer treatment and makes selecting the optimal treatment increasingly dependent on individual preferences³⁶.

The data presented in this report highlights the insufficient involvement of patients and caregivers in decision-making. Consequently, **only 6 out of 10 participants felt that the treatment and care plan aligned with patient preferences** (Figure 39).

Among caregivers, the data is even more concerning (Table 20). Only half felt the plan was aligned with their loved one's preferences, while 19.8% indicated that it was either not aligned at all or only barely.

Despite this worrying data, our findings show that only a minority of people impacted by lung cancer expressed their concerns about this discordance. As illustrated in Figure 40, **1 out of 4 respondents (26.7%) acknowledged having disagreed with their physician** about treatment or care decisions. However, **21.9% of them did not discuss their disagreement** with their clinician (Figure 41).

Although caregivers reported disagreeing more frequently than patients (30.5% vs. 25.2%), they discussed these disagreements during medical consultations less often than patients (66.2% vs. 83.8%).

Additionally, our findings show that **people with lung cancer with higher levels of education tended to disagree with their physician more often and discuss these disagreements more frequently** during medical consultations compared to those with lower levels of education.

A total of 28.1% of people diagnosed with lung cancer with tertiary education had ever disagreed with their physician about their proposed treatment and care plan (compared to 22.8% in secondary education and 16.4% in primary education). Furthermore, 49.3% of those with tertiary education had spoken with their physicians about the disagreement (compared to 43.6% in secondary education and 27.6% in primary education).

Have you ever disagreed with your physician's proposed treatment or care plan?

All participants (n=1,785)

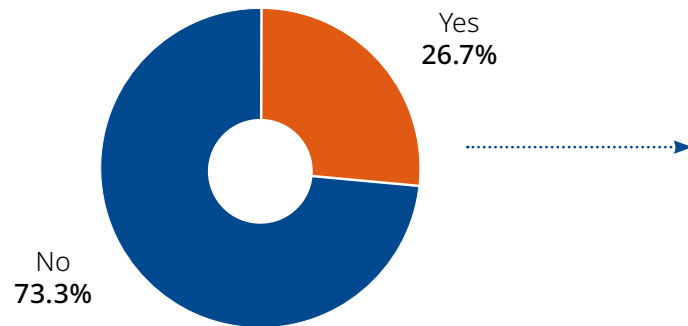


Figure 40. Disagreement with physician.

If so, did you discuss your disagreement with your physician?

All participants (n=474)

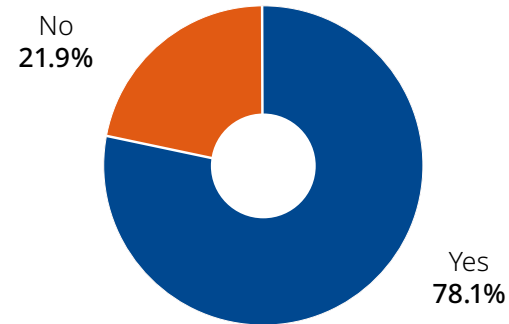


Figure 41. Discussion of disagreements.

	People with LC (n=1,280)	Caregivers (n=505)
Yes	25.2%	30.5%
No	74.8%	69.5%

Table 21. Disagreement with physicians (patients vs. caregivers).

	People with LC (n=370)	Caregivers (n=104)
Yes	83.8%	66.2%
No	16.3%	33.8%

Table 22. Discussion of disagreements (patients vs. caregivers).

“More psychological support is needed in general, particularly to build confidence in the patient's own wishes. Many patients are filled with fear and worry about appearing difficult or disagreeing with their oncologist or healthcare team.
(People with lung cancer from the United Kingdom)

Patient and caregiver satisfaction is an important factor in the healthcare journey. **Only 59.5% of respondents positively valued their involvement in the decision-making process** (Table 23). Caregivers expressed lower satisfaction compared with people diagnosed with lung cancer, with 14.4% reporting negative perceptions of their participation in the decision-making process.

Our study suggests that satisfaction is positively influenced by the level of involvement, with **greater patient involvement leading to higher decision satisfaction**. Good satisfaction was reported by 84.3% of patients who responded that they highly participated in making treatment decisions, compared to 30.1% of patients who never or barely participated in decisions.

Once again, our findings show some differences based on gender. **Men reported being more highly satisfied with their level of involvement more frequently than women**, both in the group of people diagnosed with lung cancer (30.9% of men vs. 20.7% of women) and among caregivers (24.7% of men vs. 13.4% of women).

In addition, **older individuals with lung cancer were more likely to report satisfaction** with their level of involvement than younger participants. Specifically, 27.5% of patients over 64 reported being very satisfied, compared to 21.6% of those aged 55 to 65 and 17.25% of those aged 45 to 54.

How satisfied are you with your level of involvement in the treatment and care decision process?

All participants (n=1,783)






	All participants (n=1,750)	People with LC (n=1,277)	Caregivers (n=506)
	3.6%	3.1%	4.9%
	7.5%	6.7%	9.5%
	29.4%	27.3%	34.8%
	38.7%	40.0%	35.4%
	20.8%	22.9%	15.4%

Table 23. Satisfaction with the level of involvement in decision-making.



I have great trust in my doctor(s), and over the years, I have never seriously questioned the chosen path. However, I do feel there is room for further discussion.

(Person with lung cancer from the Netherlands)

We have insufficient time during consultations to explain thoroughly and ask questions, which is necessary for making informed decisions.

(Person with lung cancer from Spain)

I have a medical team that hid nothing and explained things progressively at each stage, offering treatment options with each new discovery.

(Person with lung cancer from Belgium)

I faithfully followed the team's recommendations, believing I had no right to choose differently since I initially trusted the team I had selected.

(Person with lung cancer from Greece)

I trust my doctor. I don't want to get involved in the decision-making process.

(Person with lung cancer from France)

We need to be recognised as true partners in care and decision-making.

(People with lung cancer from the United Kingdom)



Factors influencing decision-making

When deciding on treatment, our research shows that **3 out of 4 participants followed their physician's recommendations** (Figure 42). Far fewer participants chose the option 'had no choice' (27.8%) and the 'expectations of positive clinical outcomes' (26.1%).

What influenced the decision to undergo the treatments you (or your loved one) have received?

All participants (n=1,785)

76.9%

Physician recommendation

28.8%

Had no choice

27.1%

Expectations of positive clinical outcomes

Figure 42. Top influential factors in decision-making.

	People with LC (n=1,280)	Caregivers (n=505)
Physician recommendation	76.2%	78.6%
Had no choice	27.8%	31.3%
Expectations of positive clinical outcomes	26.1%	29.7%
Lack of alternative therapeutic options	17.3%	21.4%
Treatment protocols and procedures	16.6%	20.4%
Second opinion	15.9%	17.8%
Family and/or friends	12.7%	20.6%
Other people impacted by lung cancer	11.2%	9.5%
Fewer side effects and risks	9.2%	11.1%
I searched and came across a potential treatment option*	8.8%	8.3%
Experience with previous treatments	3.3%	4.2%

Table 24. Top influential factors in decision making (patients vs. caregivers).

“

I decided on the trial after the oncologist's explanation.

(Person with lung cancer from Italy)

“

Few options so little decision-making offered.

(Person with lung cancer from Ireland)

“

I decided on my treatment after obtaining a second opinion from doctors in the USA.

(Person with lung cancer from Norway)

* In the survey completed by caregivers, this response option was 'My loved one searched and came across a potential treatment option'

Select the option that best reflects your preferences when making treatment decisions*

All participants (n=1,786)

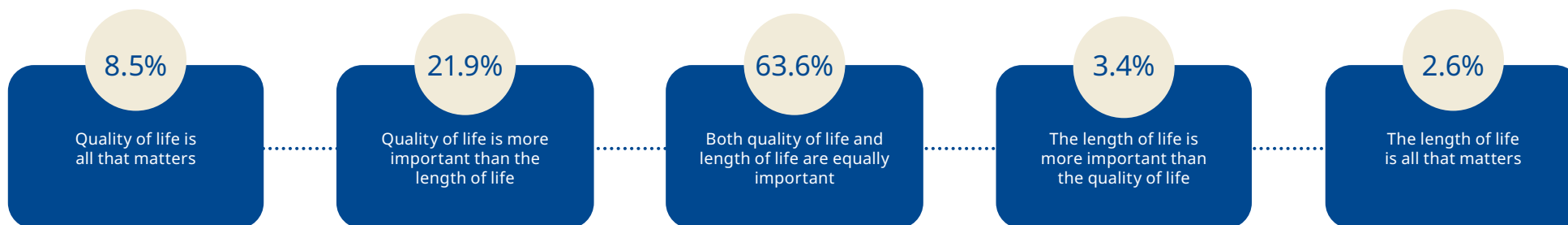


Figure 43. Quantity vs. Quality of life in treatment decisions.

During the treatment decision-making process, it is important that medical teams discuss preferences and risks those with lung cancer are willing to take, balancing quality and length of life³⁷. While most participants highlighted that both quality and length of life were equally important, it is notable that around **1 in 3 participants prioritised quality over length of life**. Only a minority of participants (6.0%) prioritised length over quality of life.

As shown in Table 25, there were no large differences between people with lung cancer and caregivers. However, we find an important age factor among people with lung cancer. **Elderly patients were more likely to prioritise quality over length of life**. Among those over 64, 38.3% preferred quality of life, compared to 25.1% of those between 45 to 64. The younger age group more frequently prioritised length of life (7.6% vs. 4.1% in those over 64).

	People with LC (n=1,279)	Caregivers (n=507)
Quality of life is all that matters	7.2%	11.8%
Quality of life is more important than the length of life	22.4%	20.7%
Both quality of life and length of life are equally important	63.8%	63.3%
The length of life is more important than the quality of life	3.8%	2.4%
The length of life is all that matters	2.9%	1.8%

Table 25. Quantity vs. Quality of life in treatment decisions (patients vs. caregivers).

* Caregivers were requested to respond to this question based on their preferences, rather than the patient's preferences.

As shown in the previous figure, quality of life matters to people affected by lung cancer. Therefore, possible side effects are an important factor when deciding treatment³⁸. A total of **65.6% of respondents identified pain as the main consideration** when making decisions about treatment (Figure 44). The next was **breathing difficulties** (60.2%), followed by **fatigue** (53.5%) and **neurological repercussions** (48.3%).

Which of the following side effects do you consider to be significant factors when making decisions about treatment?

All participants (n=1,739)

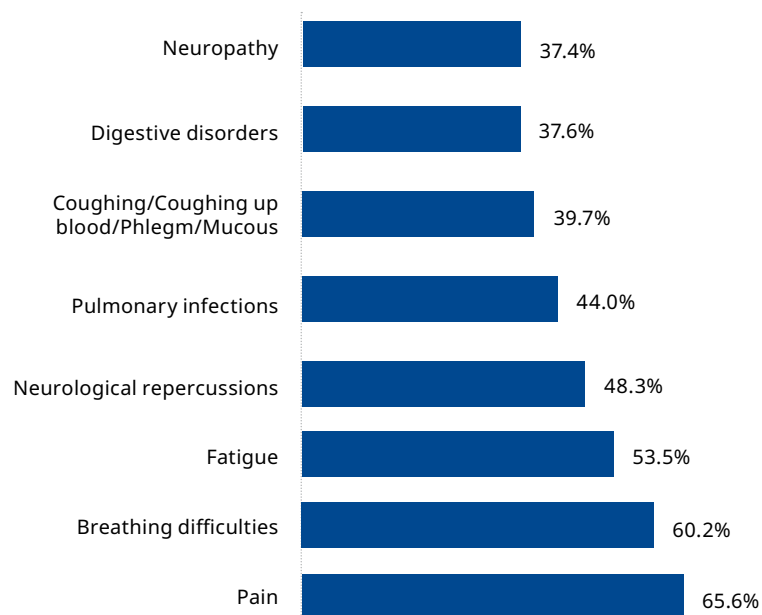


Figure 44. Most relevant side effects in treatment decisions

According to literature, the **relevance of side effects could differ between subgroups of people**³⁷. Among people with lung cancer, men were more likely to report the importance of fatigue (63.8% vs. 52.4% in women) and sexuality issues (19.5% vs. 7.9%). Conversely, female participants highlighted pain (65.3% vs. 53.9%), neurological repercussions (49.0% vs. 39.0%) and hair changes (25.7% vs. 10.6% in men).

	People with LC (n=1,239)	Caregivers (n=500)
Pain	62.7%	72.6%
Breathing difficulties	57.6%	66.8%
Fatigue	55.0%	49.8%
Neurological repercussions	46.7%	52.4%
Pulmonary infections	42.0%	49.2%
Coughing/Coughing up blood/Phlegm/Mucous	36.3%	48.2%
Digestive disorders	37.2%	38.6%
Neuropathy	37.1%	38.0%
Eating difficulties	25.3%	43.6%
Sleep disturbances	28.8%	26.0%
Weight changes	23.9%	25.2%
Oedema	22.5%	23.8%
Sore mouth	21.2%	24.2%
Hair changes	22.3%	17.4%
Skin and nail alterations	20.0%	14.8%
Malnutrition	11.4%	30.8%
Eye itching	12.7%	9.2%
Sexuality issues	10.5%	5.8%
Fertility issues	2.2%	3.0%

Table 26. Relevant side effects in treatment decisions (patients vs. caregivers).

Barriers and recommendations for effective shared decision-making

Education is a key element for patient involvement. It is crucial to have a good understanding of the disease and the various treatment and care options to effectively participate in decision-making. However, **just under half of the participants (49.2%) recognised that the information was too difficult to understand** (Figure 45). Complex information was identified as the main obstacle to meaningful participation in decision-making.

Table 15 illustrated that 33.5% did not positively value their communication with their healthcare team. In this regard, **poor communication with healthcare**

professionals was selected as the second most common obstacle for meaningful participation in decision-making. Optimal communication is a central tenet of the increasing emphasis on shared decision-making³⁹. Poor communication and lack of information can have a detrimental effect on the management of symptoms, treatment decisions, psychosocial health, and overall quality of life⁴⁰. Thus, there is an urgent need to improve the communication skills of physicians and facilitate open and honest dialogue with patients and caregivers.

What are the key obstacles to achieving meaningful participation in the decision-making processes?

All participants (n=1,701)

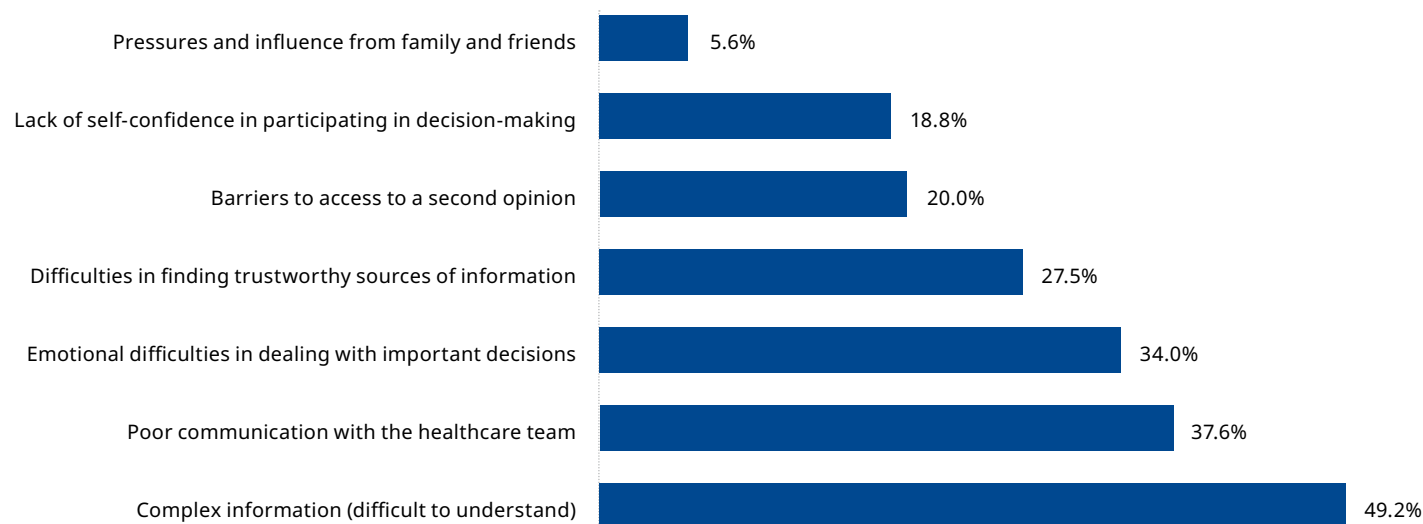


Figure 45. Obstacles to effective involvement in decision-making.

Caregivers more frequently reported barriers to achieving involvement in decisions (Table 27). People diagnosed with lung cancer identified complex information as the main obstacle, while caregivers selected poor communication with the healthcare team. It is also worth noting that 4 in 10 caregivers cited emotional difficulties when making important decisions.

	People with LC (n=1,209)	Caregivers (n=492)
Complex information (difficult to understand)	51.4%	43.9%
Poor communication with the healthcare team	34.8%	44.5%
Emotional difficulties in dealing with important decisions	30.9%	41.9%
Difficulties in finding trustworthy sources of information	26.6%	29.9%
Barriers to access to a second opinion	18.4%	24.2%
Lack of self-confidence in participating in decision-making	19.6%	16.7%
Pressures and influence from family and friends	5.1%	6.9%

Table 27. Obstacles to effective involvement in decision-making (patients vs. caregivers).

There was disagreement among doctors, which made it very stressful to determine the best course of action when I suddenly learned about my illness.

(Person with lung cancer from Greece)

Conflicting medical opinions often leave us, as laypeople, with the responsibility of deciding the direction.

(Caregiver from Hungary)

It is difficult to assess the risks and possible medium-term consequences of the alternatives.

(Person with lung cancer from Spain)

Ensuring that the caregiver and patient can communicate on the same level is crucial. I had long-standing complaints, but due to a lack of information, I couldn't ask the right follow-up questions. As a result, I lived with a growing metastasis for 1.5 years before I was taken seriously.

(Person with lung cancer from the Netherlands)

Which of the following do you believe could aid in making the best treatment and care decisions, taking into account your (or your loved one) personal preferences and values?

All participants (n=1,783)

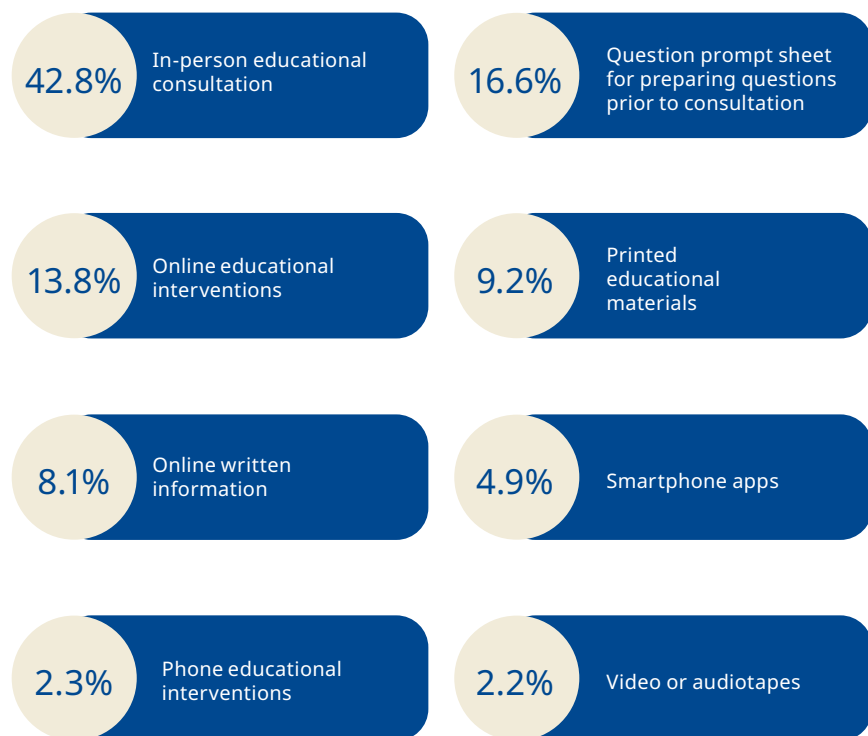


Figure 46. Decision aids.

Education for people with lung cancer and caregivers is fundamental to high-quality care. While health information refers to the delivery of health-related facts, health education involves systematic instruction that promotes an understanding of how to manage one’s health or disease⁴¹. Therefore, identifying the most effective aids to support and educate people affected by lung cancer is crucial to meeting their needs. Physician training is fundamental to knowing how to deliver information and provide education with sensitivity and empathy, according to personal preferences.

Decision aids (DAs) refer to resources which are used to help people make informed decisions, and are available in various forms, such as leaflets, guides and videos. Previous research has shown that DAs can have positive effects on people with lung cancer³⁴, for example, in prognostic understanding⁴² and satisfaction with communication and decision-making⁴³.

Face-to-face educational consultations (42.8%) were cited as the main aid, followed by a **question prompt sheet** (16.6%), which can help to facilitate involvement during consultations by questions being prepared in advance.

	People with LC (n=1,246)	Caregivers (n=499)
In-person educational consultation	42.6%	43.3%
Question prompt sheet	16.5%	17.0%
Online educational interventions	13.7%	14.0%
Printed educational materials	9.8%	7.8%
Online written information	8.5%	7.0%
Smartphone apps	5.1%	4.6%
Telephone educational interventions	2.2%	2.6%
Video or audiotapes	1.7%	3.6%

Table 28. Decision aids (patients vs. caregivers).

I miss greater dedication to each patient, including more information through brochures and educational materials, as well as the option for telephone conversations with the doctor if needed.

(Person with lung cancer from Serbia)

I've found the system to be quite outdated. They do not typically respond to or engage via email, rely on a delayed letter system, and often discourage exploring or discussing alternative options.

(Person with lung cancer from the United Kingdom)



What measures would encourage individuals affected by lung cancer to become more engaged in healthcare treatment and care decisions?

Healthcare staff should have more time to engage in conversations with patients.

(Person with lung cancer from Slovenia)

More accurate, comprehensive, and helpful attitudes and information are needed.

(Caregiver from Hungary)

Providing written information in addition to oral and giving time to understand.

(Person with lung cancer from Italy)

Provide them with choices, explain the details, including the pros and cons. Ensure explanations are clear, allow time for reflection, and suggest considering a second opinion.

(Person with lung cancer from France)

Being better informed by the medical team with more consultation time to clear doubts and make the right decisions, being better informed about clinical trials.

(Person with lung cancer from Spain)

Feeling empowered, confident, and allowed to have a two-way conversation/discourse with their clinical team.

(Caregiver from the Ireland)

Engage in open discussions with the treating physician about all available options, including their side effects and benefits.

(Person with lung cancer from Belgium)

It is necessary to build greater trust between doctors and patients.

(Person with lung cancer from Bulgaria)

We need proper and complete information about the proposed treatment, including the schedule, expected results, and potential side effects.

(Person with lung cancer from Greece)

Provide information on possible treatment methods based on international protocols and explain the rights and responsibilities of both patients and medical staff.

(Caregiver from Ukraine)

We need to communicate better why it is important for patients to be actively involved.

(Person with lung cancer from Germany)

Reports are often written in technical language, and they should be explained in plain terms so that patients and their families can understand.

(Caregiver from Hungary)

Receive all personal information in written form so you can review it later, as it might not fully sink in during the appointment.

(Person with lung cancer from the Netherlands)

Being guided step by step through the struggle of undergoing treatments helps to experience them in a more active and participatory way. Feeling heard about the discomforts of side effects and perceiving understanding and support in making them more bearable greatly contributes to building trust and actively participating in care.

(Person with lung cancer from Italy)

The power balance between patient and clinicians has to change. We do not have full access to clinical discussions about our case. Test results are not always discussed properly. There is a need to know mindset on behalf of the clinicians. It's possible clinicians don't want to worry us. Some people want to know everything; others don't. If you see different clinicians at each appointment, they will not know you. Consistency of clinician is essential.

(Person with lung cancer from the United Kingdom)

We need closer and simpler explanations from doctors. Above all, a team of specialists should be formed to integrate all the patient's needs—such as nutrition, exercise, relaxation, and psychology. Access to these services should be made easier.

(Caregiver from Spain)

Personal discussions with the doctor and healthcare staff should include the presentation of different treatment options. Patients should be given enough time to ensure that meetings do not feel rushed.

(Person with lung cancer from Finland)

Feeling more valued during oncology check-ups is essential. There are often too many patients and too few oncologists, who can sometimes lack empathy.

(Caregiver from Italy)

Sincere listening and detailed information according to the patient's requests (such as documents and patient networks) are essential. Additionally, a compassionate evaluation of the patient's ability to participate in the care process is crucial.

(Person with lung cancer from France)

Taking the time to communicate well with the patient and improving collaboration between healthcare providers. Knowing the patient well and establishing a trusting relationship seem to me to be the foundation of any treatment.

(Person with lung cancer from Belgium)

We need more detailed and well-explained information, and there should be a greater emphasis on listening to the patient.

(Person with lung cancer from Italy)

I think it's important that medical professionals provide realistic opportunities for positive outcomes to their patients.

(Person with lung cancer from Switzerland)

To feel secure about participating in this process, we need clear and comprehensive information.

(Caregiver from Spain)

Receive basic information that you can understand and be treated by a consultant who specialises in your specific type of lung cancer. Trust in your care and maintain hope, as it's your life at stake.

(Person with lung cancer from the United Kingdom)

Explain everything clearly and don't hide anything. While certain things may seem self-evident to doctors, it's not common for them to face a layperson.

(Caregiver from the Netherlands)

We need more information and a specialised multidisciplinary team for lung cancer patients, particularly for managing the side effects of treatments.

(Caregiver from Spain)

Good communication with the same doctor is essential. As relational beings, it's important that this aspect is always planned for.

(Person with lung cancer from Sweden)

Having a clinical nurse specialist was a key part of why I felt more confident in my treatment and care to ask questions and become knowledgeable about my disease and treatment. Every patient should have a clinical nurse specialist who has the time to explain things clearly, provide practical and emotional support, and respond to calls and queries when oncologists would not be able to.

(Person with lung cancer from Ireland)





4. Call to action

Raise awareness of lung cancer and early detection, and support risk reduction efforts.

We urge public authorities and institutions to commit to educating the public and healthcare professionals about lung cancer risk factors and symptoms, ensuring that everyone understands that anyone with lungs can get lung cancer.

Enable shared decision-making to help improve quality of life.

Clinicians should develop and put in place a communication strategy to encourage and support discussions with people impacted by lung cancer to help explore their wishes and expectations concerning treatment and care decisions. For effective involvement, healthcare teams should offer complete, clear and comprehensive information about the disease and the treatments and supportive services available based on individual's preferences and needs.

5. Acknowledgments

LuCE is committed to working on the needs and challenges faced by people impacted by lung cancer in Europe. We are **deeply grateful to the 2,040 individuals who have shared their valuable experiences with us**. Year on year the number of survey participants has grown, allowing us to better understand the needs and interests of the community across Europe. Thank you very much for your time and generosity.

This report is the result of fantastic teamwork.

First and foremost, we want to express our deep gratitude to the individuals who participated in the **LuCE Working Group for this project**: Anne-Marie Baird, Yvonne Diaz, Nicoline Ehrhardt, Angeliki Souri, and Diego Villalón. Thank you for your dedication in designing the survey, as well as in preparing the report and additional materials. Thank you to the **LuCE Executive team** for providing support and assistance in the generation of this report.

This initiative would not be possible without all our **LuCE members involved in this report**, who disseminated the survey in their countries and reviewed the accuracy of the translations. We have a deep admiration for your work, and we cannot thank you enough for the tremendous effort in advocating for the interests of people impacted by lung cancer.

We also want to give a special thank you to **Fundación MÁS QUE IDEAS** for their continued support. This report would not have been possible without the key role they played in bringing this to fruition.

Lastly, we would like to thank our **industry partners** for their support of this project and LuCE, which is instrumental in driving our mission forward.

Thank you for your commitment to people impacted by lung cancer: Amgen, AstraZeneca, Bayer, BluePrint Medicines, Bristol Myers Squibb, Boehringer Ingelheim, Daiichi Sankyo, Gilead, Janssen, Lilly, Merck, MSD, Novartis, Pfizer, Pharmamar, Pierre Fabre, Regeneron, Roche, Takeda and ThermoFisher.



*“Coming together is a beginning, staying together is progress, and working together is success.”
(Henry Ford)*

6. About LuCE



Lung Cancer Europe

Lung Cancer Europe (LuCE) is a not-for-profit umbrella organisation established in 2013 to provide a platform for lung cancer patient advocacy associations and networks at a European level.

Our vision

All Europeans impacted by or at risk of lung cancer will have access to optimal care so that they have the best possible outcomes and quality of life.

Our mission

LuCE is the voice of Europeans impacted by or at risk of lung cancer. We collaborate with members and other stakeholders to destigmatise the disease and ensure that those impacted by lung cancer get the care they need to achieve the best possible outcomes. We empower members to ensure strong and effective lung cancer patient advocacy across Europe.



 lungcancereurope.eu  info@lungcancereurope.eu

About our members

LuCE provides a platform for organisations and individuals working for people impacted by lung cancer. As of November 2024, there are 45 members (40 organisations and 5 individuals), representing 26 countries. We encourage you to learn more and support LuCE and our member organisations.

www.lungcancereurope.eu/our-members

Asociations



Österreichische Lungenunion
www.lungenunion.at



Association of Patients with Respiratory
Failure and Lung Transplantation



ALK POSIT ^{DNA}VE
Belgium

ALK Positive Belgium
www.alkpositivebelgium.be



PROLONG VZW
Prolong VZW
www.prolong.be



Moje Plíce
www.mojeplice.cz



Jedra
www.jedra.toraks.hr



Patientforeningen Lungekræft
www.lungekraeft.com



Suomen Keuhkosyöpötilaat
www.syopapotilaat.fi



Suomen Syöpötilaat
www.syopapotilaat.fi



ALK FRANCE cancer poumon
www.alkros1francecancerpoumon.wordpress.com



Patients en Réseau/Mon Réseau Cancer du Poumon
www.monreseau-cancerdupoumon.com



ALK Positive Deutschland
www.alkpositiv-deutschland.org



Landesverband Baden- Württemberg für
 Lungenkrebskranke und deren Angehörige e.V
www.lungenkrebs-bw.de



Bundesverband Selbsthilfe Lungenkrebs e.V.
www.bundesverband-selbsthilfe-lungenkrebs.de



zielGENau
www.zielgenau.org



Fairlife Lung Cancer Care
www.fairlifelcc.com



K.E.F.I. of Athens – Association of
 Cancer Patients of Athens
www.anticancerath.gr



Lélek-zet Egyesület
www.lelekzetegyesulet.hu



Irish Lung Cancer Community
www.ilcc.ie



Israel Lung Cancer Foundation
www.ilcf.org.il



Associazione Insieme per i pazienti
 di Oncologia Polmonare IPOP ONLUS
www.associazione-ipop.org



European School of Oncology
www.eso.net



Women Against Lung Cancer in Europe
www.womenagainstlungcancer.eu



Dzīvības Koks
www.dzivibaskoks.lv



Longkanker Nederland
www.longkankernederland.nl



Lungekreftforeningen
www.lungekreftforeningen.no



Pulmonale
www.pulmonale.pt



Federatia Asociatiilor Bolnavilor de Cancer din Romania
www.fabc.ro



Punim plućima
www.punimplucima.rs



Društvo onkoloških bolnikov Slovenije
www.onkologija.org



Asociación Española de Afectados de Cáncer de Pulmón
www.afectadoscancerdepulmon.com



Fundación MÁS QUE IDEAS
www.fundacionmasqueideas.org



Leben mit Lungenkrebs
www.leben-mit-lungenkrebs.ch



ETOP IBCSG Partners Foundation
www.etop.ibcsg.org



Lungcancerförening
www.lungcancerforeningen.se



ALK Positive UK
www.alkpositive.org.uk



EGFR Positive UK
www.egfrpositive.org.uk



Lung Cancer Nursing UK (LCNUK)
www.lcnuk.org



Athena Women against Cancer
www.athena-wac.com



ALK Positive Europe
www.alkpositiveeurope.org



Oncogene Cancer Research
www.oncogeneresearch.org

Individual members



Nicoleta Mitrea



Filipe Paixão



Regine Deniel Ihlen



Tommy Björk



Ewelina Szmytko

7. ANNEX I. Detailed breakdown of participant characteristics

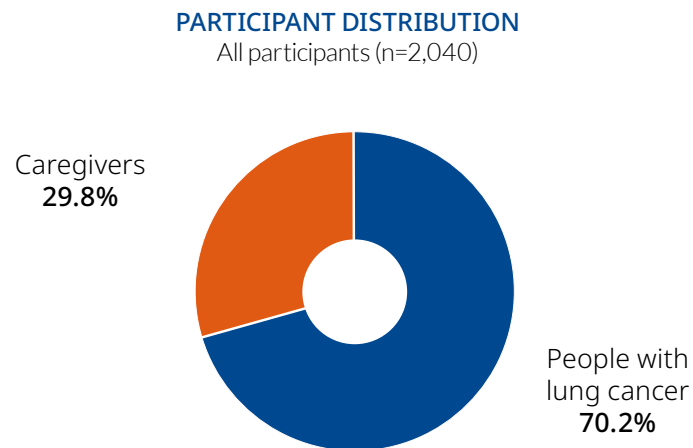


Figure 47. Participant distribution.

GENDER

	All participants (n=2,040)	People with LC (n=1,432)	Caregivers (n=608)
Female	78.6%	77.0%	82.2%
Male	21.2%	22.7%	17.6%
Non-binary	0.0%	0.0%	0.2%
Prefer not to say	0.2%	0.3%	0.0%

Table 29. Gender.

AGE

	All participants (n=2,038)	People with LC (n=1,431)	Caregivers (n=607)
24 or younger	0.5%	0.1%	1.5%
25 to 34	4.1%	1.3%	10.7%
35 to 44	12.1%	7.3%	23.4%
45 to 54	21.7%	19.5%	26.9%
55 to 64	33.0%	37.1%	23.2%
65 to 74	23.6%	28.7%	11.5%
75 or older	5.2%	6.2%	2.8%

Table 30. Age.

LEVEL OF EDUCATION

	All participants (n=2,037)	People with LC (n=1,431)	Caregivers (n=606)
Less than primary education	0.4%	0.6%	0.0%
Primary or lower secondary education	8.3%	9.4%	5.8%
Upper secondary / Post-secondary education	37.8%	39.5%	33.8%
Tertiary education	53.5%	50.5%	60.4%

Table 31. Level of education.

COUNTRY OF RESIDENCE	All participants (n=2,040)	People with LC (n=1,432)	Caregivers (n=608)
France	13.9%	17.3%	6.1%
United Kingdom	11.4%	13.1%	7.4%
Spain	9.9%	8.3%	13.7%
Greece	8.4%	4.4%	17.9%
Germany	8.0%	9.4%	4.9%
Netherlands	7.5%	7.8%	6.9%
Italy	6.9%	7.3%	5.9%
Hungary	5.5%	5.5%	5.8%
Ukraine	5.0%	2.9%	10.0%
Croatia	4.4%	4.3%	4.6%
Denmark	3.8%	4.1%	3.3%
Sweden	3.2%	4.0%	1.3%
Finland	2.5%	2.9%	1.3%
Norway	1.8%	2.0%	1.3%
Ireland	1.2%	1.1%	1.5%
Belgium	1.1%	1.1%	1.2%
Israel	1.0%	1.1%	0.8%
Slovenia	0.9%	1.0%	0.7%
Portugal	0.8%	0.8%	0.8%
Poland	0.6%	0.3%	1.3%
Serbia	0.5%	0.4%	0.8%
Switzerland	0.3%	0.4%	0.3%
Bulgaria	0.2%	0.1%	0.3%
Austria	0.1%	0.2%	0.0%
Bosnia and Herzegovina	0.1%	0.1%	0.3%
Romania	0.1%	0.1%	0.3%
Slovakia	0.1%	0.1%	0.3%
Latvia	0.1%	0.0%	0.3%
Luxembourg	0.1%	0.1%	0.2%
Cyprus	0.0%	0.1%	0.0%
Czechia	0.0%	0.0%	0.2%
Kosovo	0.0%	0.1%	0.0%
Malta	0.0%	0.1%	0.0%
Turkey	0.0%	0.0%	0.4%

Table 32. Country of residence.

TYPE OF LUNG CANCER

	All participants (n=2,033)	People with LC (n=1,426)	Caregivers (n=607)
Non small cell lung cancer (adenocarcinoma)	67.1%	73.8%	51.4%
I don't know	8.0%	6.4%	11.7%
Small cell lung cancer	6.6%	4.1%	12.4%
Non small cell lung cancer (squamous)	5.8%	4.2%	9.4%
Non small cell lung cancer (other subtype)	4.2%	3.8%	5.1%
Another type of lung cancer	3.9%	3.7%	4.6%
Non small cell lung cancer (large cell carcinoma)	2.4%	2.2%	2.8%
Non small cell lung cancer (adenosquamous carcinoma)	1.6%	1.6%	1.7%
Non small cell lung cancer (sarcomatoid carcinoma)	0.5%	0.3%	1.0%

Table 33. Type of lung cancer.

STAGE AT DIAGNOSIS

	All participants (n=2,035)	People with LC (n=1,428)	Caregivers (n=607)
Localised (thorax): Stage I-II	26.4%	28.3%	22.1%
Locally advanced: Stage III	17.7%	16.3%	21.1%
Advanced (metastasised): Stage IV	52.9%	52.2%	54.5%
I don't know	2.9%	3.2%	2.3%

Table 34. Stage at diagnosis.

TUMOUR BIOMARKER	All participants (n=2,035)	People with LC (n=1,428)	Caregivers (n=607)
I don't know	22.2%	18.6%	30.8%
EGFR	21.7%	24.7%	14.8%
ALK	20.9%	23.7%	14.1%
No, the tumour has no mutations	11.7%	11.3%	12.7%
The tumour has not been tested for biomarkers	9.7%	8.5%	12.8%
PD-L1	8.2%	8.7%	7.2%
KRAS	5.7%	6.1%	4.8%
ROS1	3.8%	4.7%	1.5%
Still in the process of biomarker testing	2.9%	2.1%	4.8%
BRAF	1.6%	1.7%	1.3%
MET	1.3%	1.4%	1.0%
HER2	0.8%	1.0%	0.5%
RET	0.6%	0.9%	0.2%
FGFR1	0.3%	0.1%	0.8%
CTLA-4	0.3%	0.2%	0.5%
NTRK	0.3%	0.2%	0.5%
NRAS	0.2%	0.2%	0.2%
NRG1	0.1%	0.1%	0.2%
Other	4.9%	4.7%	5.5%

Table 35. Tumour biomarker.

TYPE OF HOSPITAL

	All participants (n=2,034)	People with LC (n=1,427)	Caregivers (n=607)
First-level hospital (local)	18.5%	19.2%	17.0%
Second-level hospital (regional)	26.1%	25.9%	26.7%
Third-level hospital (university)	60.5%	59.3%	63.3%
I don't know	3.9%	4.8%	1.7%

Table 36. Type of hospital.

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