



Lung Cancer Europe

8th LUCE REPORT ON LUNG CANCER

November 2023



Financial impact of lung cancer:
A European perspective

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8th
**LuCE REPORT
ON LUNG CANCER**

Financial impact of lung cancer:
A European perspective

November 2023

All the Report materials are accessible here:





Lung Cancer Europe

WELCOME TO THE 8th EDITION OF THE LuCE REPORT

This is an annual initiative led by lung cancer patient organisations across Europe with the purpose of raising awareness relating to the main challenges faced by people impacted by this disease.

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LuCE Individual members involved in this project:
Anne-Marie Baird (Ireland) and Ewelina Szmytko (Poland)

Lung cancer is a diagnosis that no one wants to receive and its impact reaches far beyond the realm of physical health. It is a diagnosis that can bring about profound changes in the lives of those affected and their loved ones, extending to the financial well-being of individuals and families. In this report, we explore the often-overlooked aspect of the financial burden that accompanies a lung cancer diagnosis.

The financial implications of lung cancer are far-reaching and multifaceted. From the immediate costs of medical treatment and medications to the long-term financial consequences of reduced income, increased expenses, a lung cancer diagnosis can place immense strain on individuals and families. It is a stark reminder that the burden of this disease extends beyond the medical arena and into the realm of financial stability and security.

The report delves into the various facets of the financial impact of lung cancer, seeking to shed light on the challenges faced by those on this difficult journey. We examine the costs associated with diagnosis, treatment, and follow-up care, as well as the toll it takes on employment, income, and the ability to access necessary resources. But the report is not just about highlighting the challenges; it also offers insights into potential solutions and avenues for support.

Our goal is to contribute to a comprehensive approach to lung cancer care.

It is our sincere hope that this report serves as a valuable resource for healthcare professionals, policy makers, advocates, and most importantly, those individuals and families who are facing the challenges of lung cancer. Ultimately, our goal is to contribute to a comprehensive approach to lung cancer care, one that not only focuses on medical treatment but also takes into account the holistic well-being of patients and their families.



Debra Montague

Board member of Lung Cancer Europe (LuCE)

As we work collectively to raise awareness, advance research, and improve access to care, let us not forget the importance of addressing the financial impact of lung cancer.



We dedicate this report to our board member,

Marjo Forsblom,

who passed away on the 22nd October 2023



*Marjo was a beautiful shining
light in our community.
May she rest in peace.*



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1. ABOUT THIS REPORT

1.1. DESCRIPTION AND OBJECTIVES

Lung Cancer Europe (LuCE) is an independent non-profit organisation, committed to making lung cancer a European health priority. LuCE, as the voice of Europeans impacted by lung cancer, works to ensure that people living with this disease get the care they need to achieve the best possible outcomes.

LuCE advocates for a person-centred multidisciplinary care approach, one that requires an understanding of how the disease impacts people's lives. This is why LuCE is committed to providing evidence-based documents that share **real-world data** and insights from people with lung cancer and their loved ones.

Previous LuCE Reports highlighted the great physical, emotional, and social repercussions of lung cancer. These reports implied that **lung cancer negatively impacts personal finances**. Less income and more medical and non-medical expenses were reported by a substantial number of participants. These findings emphasise the need to understand the scope and repercussions of the financial difficulties associated with lung cancer.

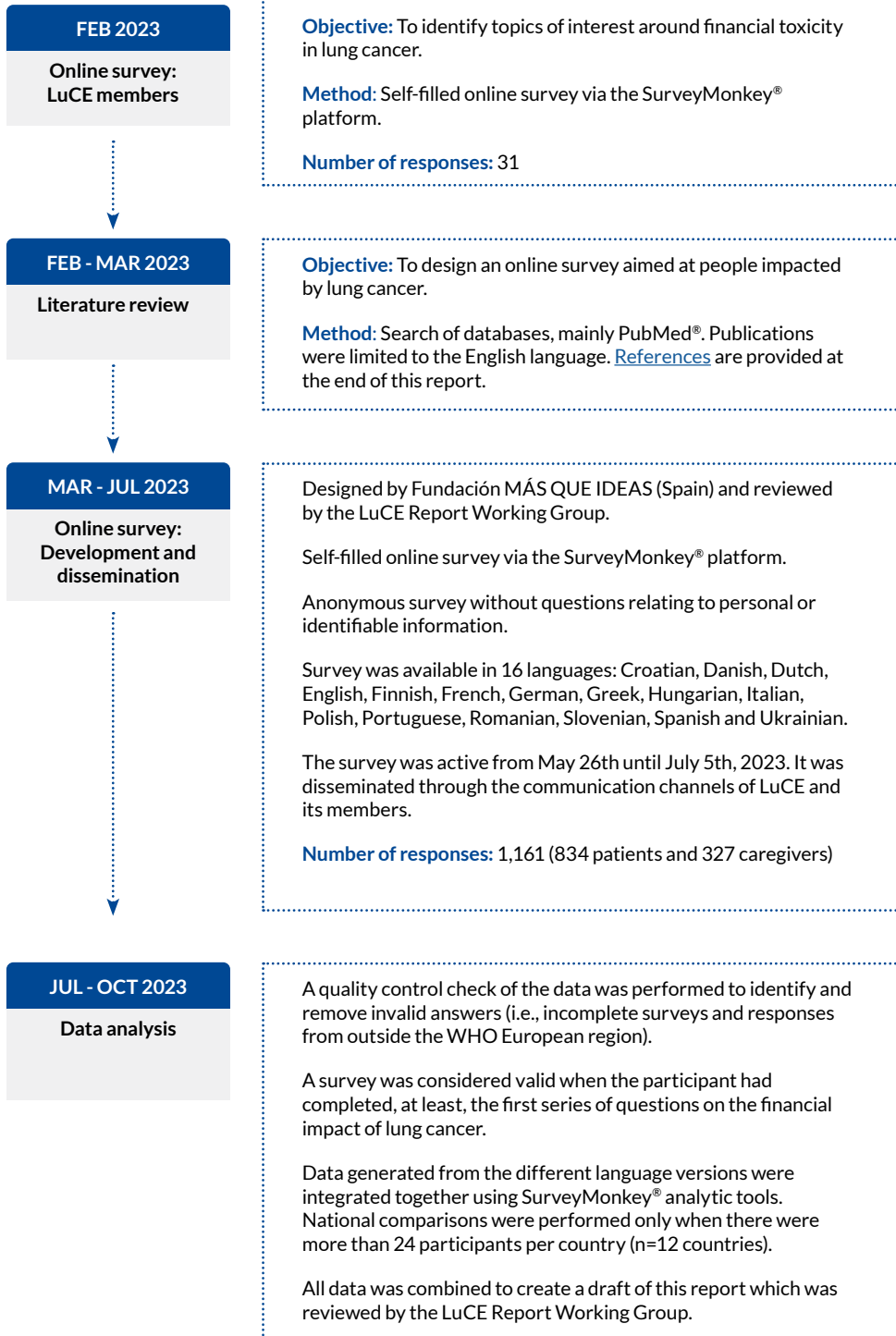
This report titled **Financial impact of lung cancer: A European perspective** is a descriptive research analysis that explores the economic burden of lung cancer and its treatments, as reported by people diagnosed with lung cancer and caregivers. For the purpose of this report, the term 'caregiver' refers to informal caregivers: people who assist individuals diagnosed with lung cancer, as family, friends or partners (not healthcare professionals).

The findings of this report suggest that a negative financial burden is common after diagnosis. Data presented helps us to understand the real economic impact of this disease on people's lives. It stresses the need for multidimensional interventions to effectively mitigate these difficulties.

RESEARCH OBJECTIVES:

- To explore the extent of financial toxicity among people impacted by lung cancer.
- To understand the causes of the economic impact of lung cancer on the household financial situation.
- To explore the factors associated with high financial distress among people impacted by lung cancer.
- To identify how people cope with life when facing financial difficulties.
- To identify relevant interventions to help people to reduce and/or deal with financial repercussions.

1.2. METHODOLOGY

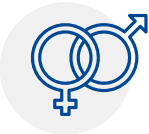





1.3. PARTICIPANT CHARACTERISTICS: Overview

The total number of survey participants was 1,161: 834 people diagnosed with lung cancer (71.8%) and 327 people caring for someone with lung cancer (28.2%). The number of responses per question varies because most questions were not mandatory.

The most relevant research limitations were female over-representation (76.5%), and the underrepresentation of those older than 64 (22.2%).

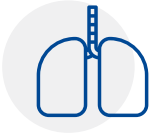
A brief snapshot of the participant characteristics is provided below. Complete survey participants characteristics can be found in [Annex I](#).

	People with lung cancer (n=834)		People caring for someone with lung cancer (n=327)	
	Women Men	75.8% 23.4%	Women Men	78.3% 21.1%
	35-44 45-54 55-64	8.9% 25.9% 39.0%	35-44 45-54 55-64	26.0% 24.2% 21.4%
	Top 4 countries: The United Kingdom The Netherlands Germany Spain	12.7% 10.3% 10.0% 9.2%	Top 4 countries: Greece Ukraine Spain The United Kingdom	22.6% 22.0% 9.8% 8.6%
	Work situation at diagnosis Employee: full time Retired	44.1% 20.8%	Work situation at diagnosis Employee: full time Retired	48.3% 18.4%

People with lung cancer (n=834)		People caring for someone with lung cancer (n=327)	
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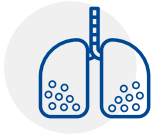
Financial situation before diagnosis		Financial situation before diagnosis	
In control of financial situation	74.4%	In control of financial situation	67.6%
Able to meet monthly expenses	78.8%	Able to meet monthly expenses	71.4%



Type of lung cancer			
Non-small cell lung cancer (adenocarcinoma)	74.1%	Non-small cell lung cancer (adenocarcinoma)	64.2%



Tumour biomarker			
ALK	26.0%	ALK	14.4%
Unknown	18.5%	Unknown	23.9%
EGFR	18.3%	EGFR	13.2%
No mutations	14.2%	No mutations	20.3%



Stage at diagnosis			
Stage IV	50.8%	Stage IV	56.6%
Stage I-II	28.6%	Stage I-II	20.2%
Stage III	17.3%	Stage III	21.7%



Time from diagnosis			
Diagnosis < 1 year	23.4%	Diagnosis < 1 year	41.0%
Diagnosis: 1-3 years	39.3%	Diagnosis: 1-3 years	36.4%

2. KEY FINDINGS

THE COST OF LUNG CANCER

- Most participants experienced both medical (73.5%) and non-medical expenses (87.2%) because of lung cancer.
- The costs reported most often were travel for medical reasons (83.7%), household utility bills like telephone or heating (77.3%), and personal items such as dressings, bandages, and creams (72.3%).
- 62.9% reported reduced household income since diagnosis. Half (49.5%) experienced a decrease of more than 30% in their income compared to the situation prior to the diagnosis.



- The repercussions on financial income were mainly related to employment, with 1 out of 4 participants citing an inability to work as one of the reasons for a decrease in income, followed by work absence (27.9%), and retirement due to illness (26.8%).

FINANCIAL DISTRESS

- 66.7% reported financial difficulties because of the disease. The financial burden was more frequently reported by caregivers (77.9%) than people with lung cancer (62.3%).
- 31.6% used more than 20% of their household income to pay expenses related to lung cancer.
- 36.8% found it difficult to live on their usual household income because of lung cancer. This was more common among people with a low-income prior to diagnosis (73.7%), caregivers

(46.3%), and those diagnosed less than 1 year (45.5%).



- Almost half of participants (45.7%) had difficulties paying expenses associated with lung cancer. Among these, house expenses - utility bills, home care, housekeeping, etc.- (49.4%) and hospital visit costs (39.8%) were the most difficult to pay.
- The level of perceived financial distress doubled after a lung cancer diagnosis: 46.8% felt financially stressed after diagnosis (vs. 27.7% before) and 28.6% were not able to meet their monthly expenses (vs. 14.5% before).
- 64.7% were forced to reduce their household expenditure to deal with lung cancer-related expenses. The most frequent adjustment was to cut down leisure activities (47.6%).
- 26.9% reported higher levels of debt following diagnosis, and 22.6% used savings in order to mitigate the financial burden.
- Factors associated with high financial toxicity include a lack of a public health system that covers lung cancer treatment and care, low income at baseline, caregiving, recent diagnosis, young patients and country of residence.

HEALTH REPERCUSSIONS OF PEOPLE EXPERIENCING FINANCIAL DIFFICULTIES

- 88.4% stated that at least one sphere of their life was negatively affected by economic repercussions.
- The most significant repercussions reported were related to mental health (67.5%), followed by lifestyle and social activities (59.0%).
- Participants with a high economic burden cited poorer health in all dimensions.
- 82.1% considered that financial difficulties were a barrier to treatment, recovery, and care.
- 26.5% of respondents (with or without financial difficulties) admitted having made decisions that affected their self-care or adherence to treatment based on economic considerations. Those who were experiencing economic stress were more likely to forgo or delay care (70.2% vs. 10.8%).
- A substantial number of people impacted by lung cancer (with or without financial difficulties) considered that their personal finances controlled their access to supportive services (40.5%), early or rapid diagnosis (38.6%), and access to innovative treatments or medicines (35.0%).
- Higher economic repercussions were experienced by caregivers and people from Eastern European countries across all domains.

SUPPORT AND RESOURCES

- 1 out of 5 participants sought financial support from public health services (21.6%) or social services (20.6%). However, 40.8% of the respondents who sought help from social services and 29.7% who sought support from healthcare systems did not receive the assistance that they needed.
- 39.2% stated that there were no public financial benefits for people with cancer in their country, and 21.3% did not know whether these existed.
- Although caregivers also experienced significant financial strain, 46.7% did not know whether public benefits for caregivers existed in their countries, while 26.8% directly said there was no financial support available for caregivers.
- 28.7% admitted to having discussed finances with their healthcare team, and only a few (5.7%) reported doing so frequently.
- Only a minority who reported economic difficulties (17.4%) had ever talked with social workers or discussed their situation with social services.
- Financial or material support provided by loved ones (not necessarily by their caregivers) was reported by 30.4%.
- Support for costs related to medication and healthcare was considered a priority, with half (53.0%) identifying that this was the financial support most needed.



3. RESULTS

3.1. MONETARY STRAIN: The cost of lung cancer

Financial toxicity is the negative impact of the cost of care on financial well-being. People impacted by lung cancer face high out-of-pocket expenses associated with medical care, which is not covered or reimbursed by government or insurers. Apart from medical costs, other factors contributing to this financial hardship include non-medical and indirect costs.

A. Direct medical costs

Buying personal items for lung cancer is the most frequent medical cost

Most participants live in countries where there is a public health system that covers treatment and care*. However, even in countries with universal healthcare, additional out-of-pocket (OOP) expenses are commonplace¹.

People diagnosed with lung cancer and caregivers can incur different cancer-related expenses which cause financial hardship. Three out of 4 (73.5%) had paid some medical related expenses because of lung cancer. Most participants had experienced costs for **personal items** such as dressings, bandages, and creams (72.3%), **pharmaceutical bills** (63.2%) and **hospital bills** (56.3%).

Medical expenses because of lung cancer (LC)

(n = 827 people with LC / n = 327 caregivers)

	ALL PARTICIPANTS	PEOPLE WITH LUNG CANCER	CAREGIVERS
Personal items	72.3%	69.9%	78.3%
Pharmaceutical bills / co-payment	63.2%	61.7%	67.2%
Hospital bills	56.3%	51.4%	68.7%
Healthcare professional services	49.9%	47.7%	55.2%
Private consultations with medical professionals	49.9%	42.0%	69.6%
Testing: scans, molecular diagnosis, biopsies, etc.	45.8%	38.0%	65.6%

TABLE 1. Medical expenses because of lung cancer.

* Mentioned by 69.3%. Another 20.4% also mentioned it but stated that some co-payments and fees existed.

“We paid for the entire cycle of chemotherapy and radiotherapy, which were not available to us in Croatia. (Caregiver from Croatia)

“Some new medicines are not approved in Finland. The cost is paid completely by the patient, which is unfair! (Patient from Finland)

“Walker, crutches, cane, incontinence products, painkillers, anti-bedsore mattress, dressing material. Many things that we buy with our own money. (Caregiver from Ukraine)

As Figure 1 shows, **private consultations, and healthcare services** (psychologists, nutritionists, etc.) **are the medical costs with the highest impact on finances.**

The differences in responses between people with lung cancer and caregivers were remarkable. Caregivers were much more likely to report the impact of medical costs, especially hospital bills (75.7% vs. 52.3% in people with lung cancer), personal items (67.2% vs. 45.8%), and pharmaceutical bills (66.2% vs. 46.3%).

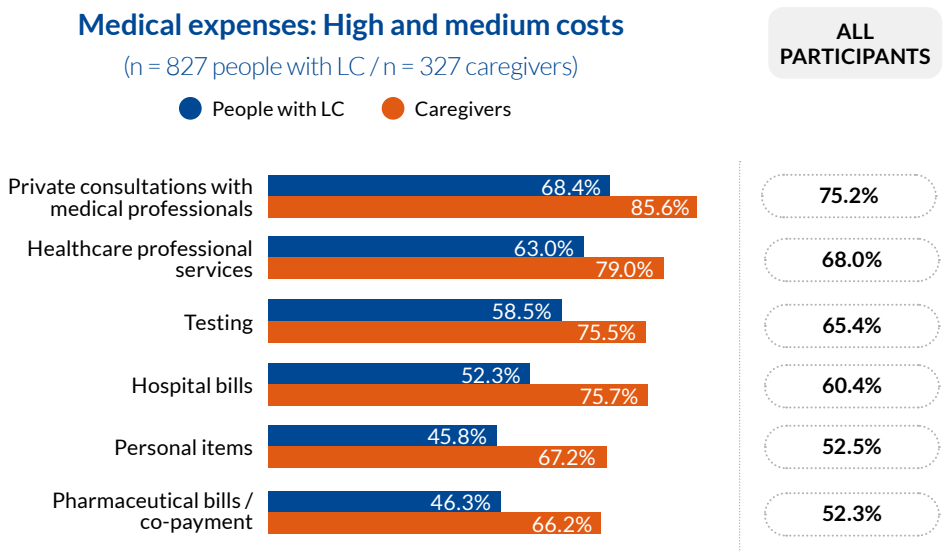


FIGURE 1. Medical expenses: High and medium costs.

“

I could not access physiotherapy and psychiatric treatments because they were too expensive. (Patient from France)

“

Part of the preparations for the side effects of the therapy were costly, and some tests were paid privately because the urgency of the situation. (Caregiver from Croatia)



“

I need lymphatic drainage due to edema and swelling, typical side-effects of the biological medicine I take. The costs of these treatments are high and they are only available privately. (Patient from Italy)

“

Small cell lung cancer is a poorly understood disease. We had to do additional tests at our own expense. We live in a small town where there are no good specialists so we had to travel to the capital and order paid services at private oncology clinics. (Caregiver from Ukraine)

B. Direct non-medical costs

Outside of medical and healthcare costs, people impacted by lung cancer also reported non-medical costs related to treatment and care, such as transportation or hospital parking. In addition, other expenses may arise from the disease, such as the care of family members or home adaptations. These costs increase financial distress and exacerbate disparities in care.

Transportation for medical reasons was the most frequent non-medical cost

Table 2 shows the highest non-medical cost reported was **travel and transport** for care, tests, and treatments (83.7%) followed by **household utility bills** such as telephone or heating (77.3%).

It is notable that **caregivers reported more costs** than people with lung cancer in all domains. The **greatest difference was found in expenses related to dependent care**, where 60.8% of caregivers reported concerns vs. 25.2% of patients. The second largest difference was observed in **home modifications** and adaptations (48.3% vs. 28.5%).

Non-medical expenses because of lung cancer (LC)

(n = 826 people with LC / n = 327 caregivers)

	ALL PARTICIPANTS	PEOPLE WITH LUNG CANCER	CAREGIVERS
Travel and transport	83.7%	81.3%	89.8%
Household utility bills	77.3%	74.5%	84.3%
Eating out	64.5%	59.1%	77.9%
Hospital parking	60.4%	60.1%	61.3%
Homecare / housekeeping	49.8%	45.4%	60.8%
Care of family members	35.6%	25.2%	60.8%
Overnight accommodation	34.8%	29.6%	47.7%
Home modifications / adaptations	34.2%	28.5%	48.3%

TABLE 2. Non-medical expenses because of lung cancer.

“ I was hospitalized for 25 days due to a complication. There were many expenses for the family who had to visit me. It was far from home and train tickets are expensive. (Patient from Denmark)

“ We live in a city where there is no oncologist or pulmonology department. So you must drive 2h 30min to get to the nearest hospital in the region which offers these specialties. (Caregiver from France)

“ It is also expensive to heat your home and with lung cancer one cannot afford to be cold as you feel it anyway and this can impact one’s health. (Patient from the United Kingdom)

Both people with lung cancer and caregivers selected household **utility bills as the highest non-medical expenditure** (Figure 2). However, there were significant differences between the two groups. Caregivers reported the cost of caring for other family members as significant much more frequently than patients (82.0% vs. 53.1%). This situation was also observed in expenses associated with the home setting. These included homecare (75.8% vs. 58.3%) and expenses associated with home modifications imposed by the disease (74.0% vs. 53.6%).

Non-medical expenses: High and medium cost

(n = 826 people with LC / n = 327 caregivers)

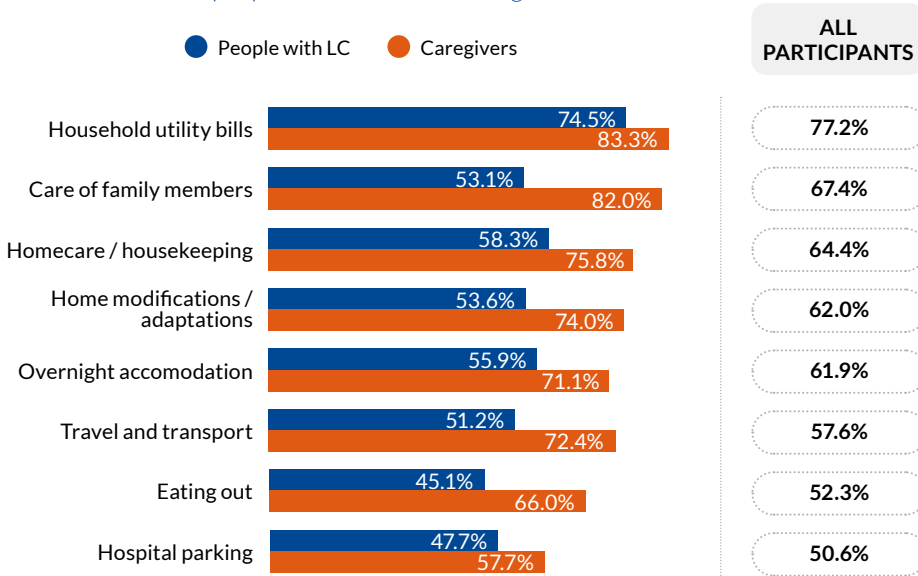


FIGURE 2. Non-medical expenses: High and medium costs.

C. Indirect costs: income reduction

Literature shows that financial distress is not only associated with higher expenses². Indirect costs result from the **loss of resources and opportunities** due to lung cancer. After diagnosis, people may experience varied levels of income reduction, mainly because of salary loss³.

According to our survey, **62.9% reported reduced household income** since diagnosis (Figure 3). This impact was reported slightly more often among caregivers (66.4%) than patients (61.5%).

Has your household income been reduced after the lung cancer diagnosis?

(n = 834 people with LC / n = 237 caregivers)

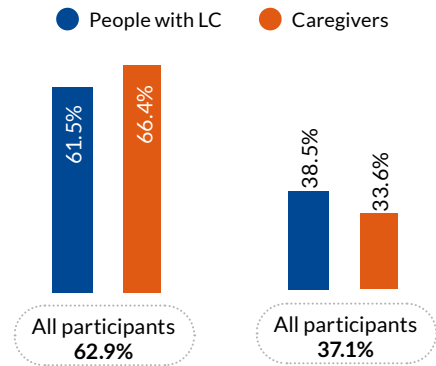


FIGURE 3. Income reduction.

62.9%
experienced
income
reduction

We observed differences in the loss of income by country. The **highest prevalence of income loss** was reported by participants from **Ukraine (78.7%), The Netherlands (76.7%) and Greece (73.9%)**. On the contrary, the lowest prevalence was reported by people from Denmark (36.5%), Italy (49.3%), and Spain (49.3%).

Of the 710 respondents who experienced a reduction in income, it is remarkable that 75.0% of them experienced a decrease higher than 20% and **half (49.5%) experienced a decrease higher than 30%** compared to life before lung cancer (Figure 4).

Once again, results show differences between countries. The highest income loss (over 30%) was reported by people from Ukraine (82.2%) and Italy (66.7%). In contrast, people from Spain (31.6%) and France (39.1%) were the least likely to report losses above 30% compared to the financial situation before the diagnosis. The reasons for these differences could be due to better income replacement programmes funded through social welfare systems by individual governments⁴.

“Income has declined so everything is more difficult to finance.
(Patient from The Netherlands)

“We only receive now 450 euros from the pension of my husband who is ill, and our rent is 300 euros. (Caregiver from Greece)

“I was put on category 2 invalidity by my employer and I receive a pension that makes me live below the poverty line. (Patient from France)

How much would you say the household income has decreased compared to your life before lung cancer?

(n = 501 people with LC / n=209 caregivers)

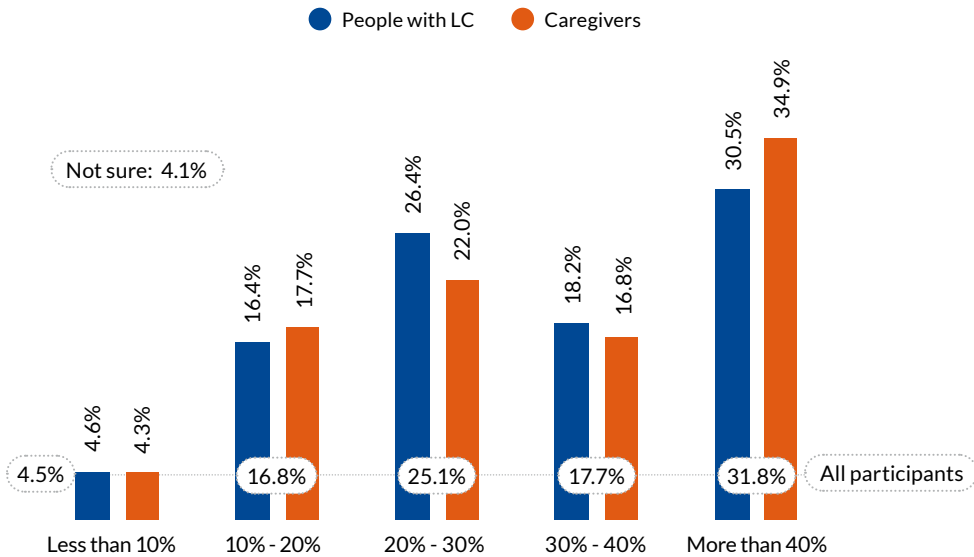


FIGURE 4. Level of income reduction.

Repercussions on financial income are mainly related to **employment**. Patients and family members are often unable to maintain full employment, often deciding to reduce working hours or quitting their jobs as a consequence of the disease, either directly or through caregiving⁴. Even if most countries in Europe provide **paid sick leave**, these compensation benefits are frequently provided only for a limited time⁵, or are insufficient to cope with daily expenses. Literature suggests that some contributors to financial toxicity are reduced ability to work, limitations in working hours or the type of jobs accessible, and reduced wages because of cancer⁶.

As illustrated in Table 3, **1 out of 4 identified the inability to work as one of the reasons for the decrease in income**. The next most cited reasons were work absences (27.9%) and retirement due to illness (26.8%). The impact of cancer on employment increases financial hardships and reduces the quality of life of people with lung cancer and their families⁷. Previous evidence has shown that employed individuals are at greater risk of suffering financial stress after diagnosis, since they are more likely to experience a significant drop in income⁸.

What have been the reasons for the household income reduction?

(n = 495 people with LC / n = 200 caregivers)

	ALL PARTICIPANTS	PEOPLE WITH LUNG CANCER	CAREGIVERS
Unable to work	39.7%	42.6%	32.5%
Work absence	27.9%	25.3%	34.5%
Retirement due to illness	26.8%	29.5%	20.0%
Reduction in work time	18.3%	16.8%	22.0%
Decline of productivity	16.0%	15.0%	18.5%
Job loss	15.4%	13.9%	19.0%
Not getting bonuses or benefits from work	10.6%	11.9%	7.5%
Less income because of changing employment	4.3%	3.6%	6.0%

TABLE 3. Reasons for income reduction.

“As a self-employed person, there is no social safety net and not all costs can be absorbed by my partner. (Patient from The Netherlands)

“My husband is sick. I can't stay in any job because I have to take care of him and run to the hospitals. (Caregiver from Ukraine)

“I started by receiving a full salary during sick leave. Now I get only 70%, which is a big difference. (Patient from The Netherlands)

“I work as an entrepreneur but I can't attend my business. I have to close the store and help my father financially, morally, and physically for treatment. There is no time for work. (Caregiver from Ukraine)

“My wife had to reduce her workload. (Patient from France)

“Working part-time means less money. (Patient from The United Kingdom)

“My husband stopped working to take care of me. (Patient from The Netherlands)

“I had to stop working to take care of my father. (Caregiver from Spain)

“I am on leave and receiving medical leave. And it's very little compared to what I earned. (Patient from Spain)

3.2. FINANCIAL DISTRESS: The impact on personal finances

Increased household expenses and reduced income are negative impacts of lung cancer. However, some people did not find that the financial burden resulted in hardship. Personal situations, context, perception, and capacity to cope influence how much distress each person feels from these changes³.

Financial hardship relates not only to the quantifiable impact, but also to the perceived distress that people experience because of the costs associated with care and treatment.

66.7% experienced financial difficulties

Figure 5 shows the magnitude of economic impact: 66.7% of people affected by lung cancer reported financial challenges as a result of the disease. These **difficulties were more frequently reported by caregivers** (77.9%) than patients (62.3%). The impact was very significant (quite a bit / very much) for 1 out of 4 participants (22.6% of people with lung cancer and 36.6% of caregivers).

To what extent have you experienced financial difficulties as a result of lung cancer care and treatments?

(n = 802 people with LC / n = 312 caregivers)

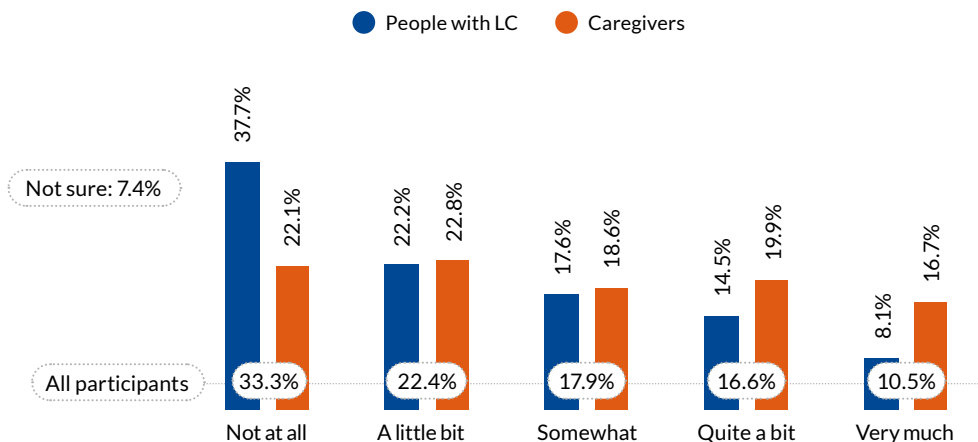


FIGURE 5. Extent of financial difficulties.

One of the main factors associated with financial strain is the amount of income required to pay for expenses related to lung cancer. Lung cancer treatment and care may lead to catastrophic expenses, even in countries with universal public healthcare systems⁴.

Our findings show that **21.2% of people impacted by lung cancer needed more than 30% of their household income to pay for expenses related to lung cancer** (Figure 6). This level of spending is defined as ‘catastrophic’ by literature, and even some studies suggest that it must be considered catastrophic if higher than 20%⁹ (which represents 31.6% of the people surveyed in our research).

1 out of 5 reported catastrophic spending due to lung cancer

What percentage of your household monthly income are used to pay for expenses related to lung cancer?

(n = 830 people with LC / n = 325 caregivers)

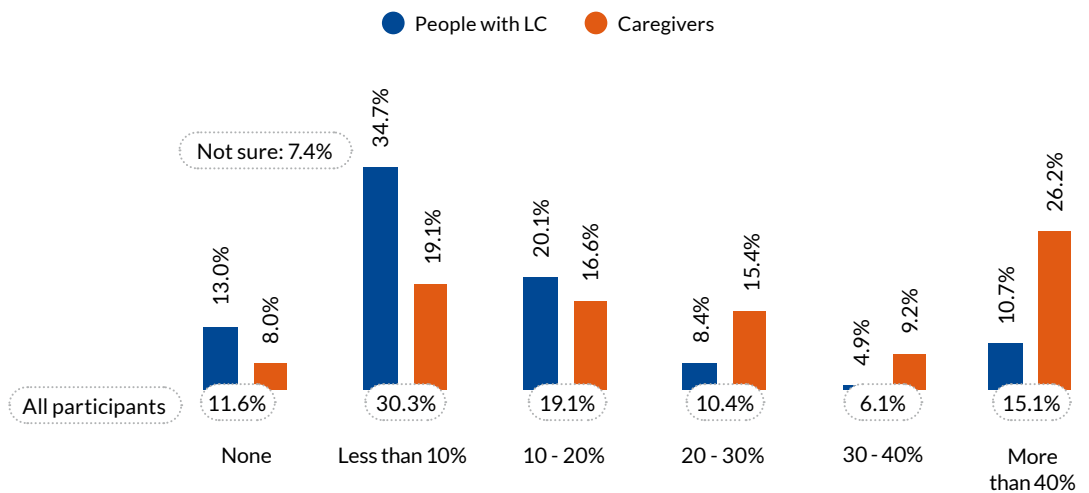


FIGURE 6. Income used to pay lung cancer expenses.

1 out of 3 found it difficult to live on their household income

Expenses related to lung cancer affected the capacity for managing finances in such a way that, according to our research, **36.8% of people found it difficult to live on their household income** (Figure 7). This is a significant percentage, and it is **more severe among caregivers** than people with lung cancer (46.3% vs. 33.3%).

How difficult is it for you to live on your total household income right now because of the lung cancer diagnosis?

(n = 711 people with LC / n = 277 caregivers)

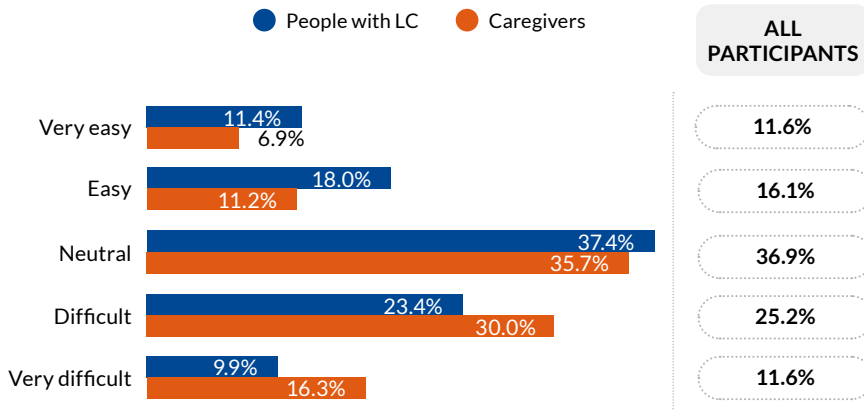


FIGURE 7. How difficult is to financially live after diagnosis.

Difficulties living on the current household income was more frequently reported by people with lower income levels prior to diagnosis. A total of 73.7% of survey respondents who were not able to meet their monthly expenses before diagnosis confirmed that they were experiencing difficulties at the time of completing this survey. This percentage fell to 30.3% in the group with higher income status at baseline*.

Time from diagnosis is also a predictor of higher risk to experience economic difficulties. **The more recent the diagnosis was, the more difficult it was for patients to live on their income.** A total of 45.5% of patients diagnosed less than 1 year ago admitted having difficulties, compared with 25.4% of those diagnosed more than 5 years ago. In people who finish cancer treatment, evidence suggests that the financial burden decreases in the months to years after cancer treatment is completed¹⁰. However, increased costs may persist even years after diagnosis¹¹. They reach a maximum during the last year of life¹².

“ I need to go back to work as soon as possible. If I don't start working, my income will drop by 40%. (Patient from Spain)

“ With the help I receive, I can pay everything, but I have little capacity to save, and I have a big mortgage to pay for the house. (Patient from Italy)

“ The price of treatment is several times higher than the average monthly income of my family. (Patient from Ukraine)

* Participants who responded 'I was able to meet my monthly expenses' before lung cancer diagnosis (see Table 4)

As Figure 8 shows, the severity of lung cancer financial toxicity is so high that 45.7% of participants (42.0% of patients and 54.9% of caregivers) have had **difficulties paying expenses associated with lung cancer**.

According to people who reported these problems (n=522), **house expenses** (49.4%) and **travel costs to hospitals** (39.8%) were the most difficult expenses to pay. The greatest difference between people with lung cancer and caregivers was related to hospital and medical bills: caregivers found them much more difficult to pay than patients (46.6% vs. 27.9%).

Have you had difficulties paying for expenses related to lung cancer?

(n = 818 people with LC / n = 324 caregivers)

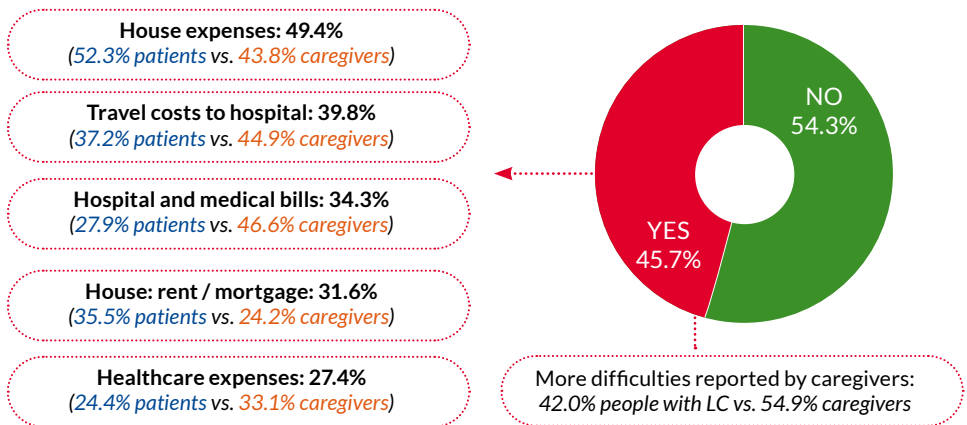


FIGURE 8. Difficulties paying for lung cancer expenses.

Lung cancer is a risk factor of financial distress

As shown in Table 4, **the level of perceived financial distress doubled after the lung cancer diagnosis**. The percentage of people that did not **feel in control** of their finances increased from 15.8% (before diagnosis) to 36.9% (at the time of completing this survey).

Similarly, almost half of respondents (46.8%) reported being **financially stressed**, almost 20 points higher than before diagnosis. It is startling to find that around 3 out of 10 participants (28.6%) reported **not being able to meet their monthly expenses** (compared to 14.5% before diagnosis).

Household financial situation: vulnerability

(n = 992 participants: both people with LC and caregivers)

	Before diagnosis	After diagnosis	
Not in control of my financial situation	15.8%	36.9%	↑
Financially stressed	27.7%	46.8%	↑
Not able to meet monthly expenses	14.5%	28.6%	↑

TABLE 4. Household financial situation before and after diagnosis.

64.7% reported sacrifices such as reducing expenses to pay for expenses of lung cancer care

Cancer costs and economic burdens impact patients and families and force them to make sacrifices. The direct and indirect costs of lung cancer cause financial instability for many people, leading to difficulties in affording necessities and daily expenses such as clothes, travel, and home utilities¹³.

Most respondents (64.7%) had been forced to reduce their household expenses to deal with expenses after their lung cancer diagnosis. People surveyed reported life changes to adapt to the situation such as **cutting down leisure activity** (47.6%). This was more often reported by caregivers than patients (54.0% vs. 45.1%). Additionally, around 1 out of 3 participants also mentioned that they needed to **change plans** (37.0%) and **reduce basic spending**, like clothes, education, or food (36.8%).

Have you made any of the following financial adjustments to reduce your household expenses after the lung cancer diagnosis?

(n = 823 people with LC / n = 324 caregivers)

	ALL PARTICIPANTS	PEOPLE WITH LUNG CANCER	CAREGIVERS
Forgo or reduce spending for leisure activities (travels, hobbies, etc.)	47.6%	45.1%	54.0%
Change in plans (business opportunities, retirement, property purchase, car change, etc.)	37.0%	35.7%	40.1%
Forgo or reduce basic spending (clothes, food, education, etc.)	36.8%	34.4%	42.9%
Skip bill payments	12.4%	11.3%	15.1%

TABLE 5. Financial adjustments to reduce expenses.

“ I had to reduce my expenses. I only do a few things to maintain and improve my psyche and physique. I have given up e.g., magazines, singing in a choir, going to the hairdresser, visiting friends, buying Christmas and birthday presents, opera, concerts, theatre, etc. (Patient from Finland)

“ I moved to a smaller and cheaper apartment. Because of the limited financial resources, all social life has been left out. I can't afford anything or going anywhere on vacation. I can't participate in any social activities with friends due to lack of money. (Patient from Finland)

“ I went back to live with my mother. This allowed me to be in balance with my monthly expenses. My income is very low with sick leave. (Patient from France)

Financial adjustment also included strategies to cashing in and having additional resources to deal with difficulties. Over half (52.8%) of participants proactively took steps to increase their household liquidity to cover expenses related to lung cancer.

52.8% had made financial adjustments after the lung cancer diagnosis

In order to mitigate the financial burden, **22.6% utilised savings, 17.9% borrowed money and 14.7% sold possessions.** These coping behaviours to finance expenses or manage daily living costs potentially leave people in a precarious financial position, thus contributing to their socioeconomic instability and increase financial vulnerability.

Have you made any of the following financial adjustments after the lung cancer diagnosis? (n = 796 people with LC / n = 312 caregivers)

	ALL PARTICIPANTS	PEOPLE WITH LUNG CANCER	CAREGIVERS
Withdraw money from retirement or saving funds	22.6%	22.7%	22.1%
Borrow money	17.9%	16.5%	21.5%
Sell assets or possessions	14.7%	14.2%	16.0%
Early return to work	8.8%	10.9%	3.2%
Other	7.2%	6.4%	9.3%
Find a second job	4.3%	2.9%	8.0%

TABLE 6. Financial adjustments to increase household liquidity.

“ I have the pressure to have to go back to work soon, otherwise there may be no further entitlement to sick pay or follow-up benefits. (Patient from Germany)

“ I don't want her to worry but she is aware we are using savings. (Caregiver from The United Kingdom)

“ After the diagnosis, cancer treatment may be the only destination of my savings. For the rest of my life. (Patient from Finland)

“ We have already sold all our property, we are left without a home, there is no way out. (Caregiver from Ukraine)

“ I had to sell my apartment. (Patient from Finland)

“ I pay substantially from savings. (Patient from Germany)

Costs associated with lung cancer and some financial adjustments may bring an increase in the level of debt.

Our data shows that **1 out of 4 people surveyed stated that their debt level increased** after the lung cancer diagnosis.

According to literature, people with cancer are 2.65 times more likely to go bankrupt than people without cancer¹⁴, and this is a risk factor for early mortality⁷.

Has your debt level increased after lung cancer diagnosis?
(n = 974 participants: both people with LC and caregivers)

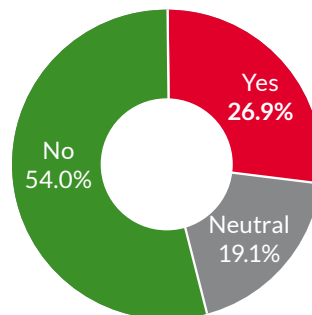


FIGURE 9. Debt level after diagnosis.

Financial situation is a barrier to clinical trial participation

Participating in a clinical trial offers an opportunity to access new therapeutic options, frequently associated with better outcomes¹⁵. However, trials often involve regular travel, relocation, or interruption of employment. Consequently, income is frequently associated with trial participation¹⁶.

A total of 19.9% of people surveyed had participated (or their loved one had) in a clinical trial. From a total of 198 people, **16.2% experienced higher financial distress because of their participation in the trial** (Figure 10). Once again, our data suggests that caregivers experience higher economic impact.

Even if this impact affects only a minority of people, trial participation should never result in a financial burden for patients and families. **Costs related to trial participation are a barrier** and influence patient decisions¹⁷. As a result, **patients with lower income are less likely to participate in clinical trials**¹⁸. This is so relevant that the American Society of Clinical Oncology (ASCO) made a policy statement addressing financial barriers to patient participation in clinical trials. ASCO encouraged targeted financial support, and transparency regarding the costs of trial involvement¹⁹.

During the clinical trial, have you experienced higher household financial distress?

(n = 198 participants: both people with LC and caregivers)

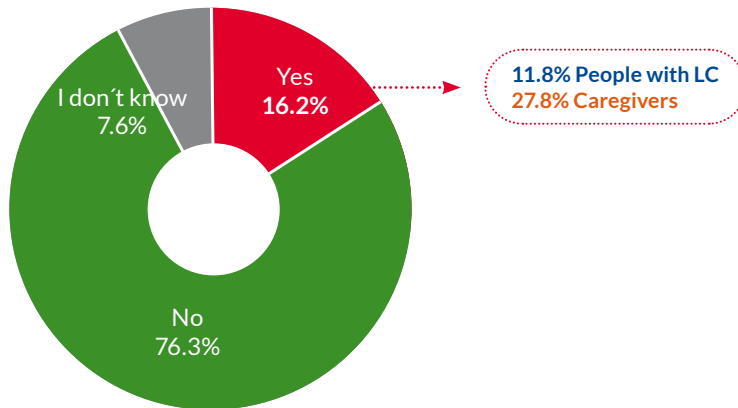


FIGURE 10. Financial distress during the clinical trial.



“ I had to move to another city and not everything was covered. (Patient from Spain)

“ Extra costs for services not covered by the national health service accentuated after the trial. (Caregiver from Italy)

“ The trial requires me to travel to the clinic for one day every three weeks. (Patient from The United Kingdom)

“ We had to pay for CT, MRI ourselves. Health insurance didn't pay for it either. (Caregiver from Germany)

According to our research, **predictors of higher financial hardship** are lack of full public healthcare coverage, low income at baseline, caregiving, being diagnosed less than one year ago, being a young patient and country of residence.

Factors associated with high financial toxicity

	> 20% income to pay lung cancer expenses	High impact of financial difficulties reported
Lack of full public healthcare coverage	<p>87.1% of respondents who lacked a public health system that covered LC treatment and care, use over 20% of income to pay for care; and 45.4% of those required to make co-payments reported the same.</p> <p><i>(This falls to 18.1% among participants who reported having a full public health system.)</i></p>	<p>71.7% of respondents who lacked a public health system that covered LC treatment and care, reported high financial difficulties; and 44% of respondents required to make co-payments reported the same.</p> <p><i>(This falls to 15.7% among participants who reported having a full public health system.)</i></p>
Low income at baseline	<p>54.1% <i>(This falls to 26.0% among people who were able to meet their monthly expenses before diagnosis.)</i></p>	<p>53.0% <i>(This falls to 20.0% among people who were able to meet their monthly expenses before diagnosis.)</i></p>
Caregiving	<p>50.8% <i>(This falls to 24.1% among people diagnosed with lung cancer.)</i></p>	<p>36.5% <i>(This falls to 18.8% among people diagnosed with lung cancer.)</i></p>
Recent diagnosis (less than 1 year ago)	<p>45.1% <i>(This falls to 26.2% among people diagnosed more than one year ago.)</i></p>	<p>34.4% <i>(This falls to 23.4% among people diagnosed more than one year ago.)</i></p>
Young patients (less than 55)	<p>31.1% <i>(This falls to 19.8% among those older than 54.)</i></p>	<p>30.3% <i>(This falls to 17.8% among those older than 54.)</i></p>
Country of residence	See Table 8	See Table 8

TABLE 7. Factors associated with high financial toxicity.

Healthcare coverage and social welfare provisions vary significantly across countries surveyed, influencing the level of financial impact of lung cancer⁴. In addition, the country’s socioeconomic status contributes to economic vulnerability of patients, and most middle-income and low-income countries demand out-of-pocket payments during treatment²⁰.

Data from our research suggests associations between financial hardship and country of residence, being much higher in Eastern European countries (Table 8).

Differences of financial distress across Europe

	> 20% income to pay lung cancer expenses	High impact of financial difficulties reported
Ukraine	86.7%	69.7%
Greece	56.5%	48.9%
Croatia	41.9%	31.0%
Poland	30.8%	33.3%
Finland	18.2%	24.2%
Spain	18.2%	12.2%
Italy	14.6%	6.7%
Germany	13.2%	11.0%
France	10.8%	19.5%
The Netherlands	10.6%	24.7%
United Kingdom	10.4%	15.2%
Denmark	5.9%	0.0%

TABLE 8. Financial distress: Differences across Europe.

3.3. WELL-BEING: Repercussions of financial stress on health

Financial difficulties are common for those diagnosed with lung cancer. Repercussions are complex and multidimensional, and ripple out from the person with lung cancer throughout the family. The economic consequences are over and above the direct impacts on health and well-being from the disease itself.

Previous research has shown that there is association between higher financial stress and worse quality of life in people impacted by cancer²¹. In order to explore the health repercussions of financial stress, the following questions were only asked to those people who reported, at least, a little bit of financial difficulties*.

Mental health and lifestyle were reported as the most negatively affected areas from financial distress

88.4% pointed out that, at least, one sphere of their lives was negatively affected by economic repercussions. The impact on daily lives is an additional burden to individual wellbeing. In the literature, the impact on daily lives of financial toxicity is defined in terms of psychosocial costs²².

The main repercussions reported by people surveyed were in **mental health** (67.5%) and **lifestyle and social activities** (59.0%). Literature suggests that financial toxicity in cancer is associated with increased psychosocial distress¹² and psychological symptoms like depression²³. Emotional repercussions and financial difficulties affect the lifestyle of people impacted by lung cancer. As Table 9 shows, almost half of participants (47.6%) stated that they had forgone or reduced spending on leisure activities.

Have the financial difficulties negatively affected you in any of the following areas? (n = 477 people with LC / n = 238 caregivers)

	ALL PARTICIPANTS	PEOPLE WITH LUNG CANCER	CAREGIVERS
Mental health	67.5%	61.6%	79.2%
Lifestyle and social activities	59.0%	58.7%	59.8%
Social relationships	37.2%	35.2%	41.1%
Physical well-being	36.5%	34.2%	41.1%
Family	35.8%	33.1%	41.1%
Working life	29.0%	27.9%	31.4%
Spiritually	21.7%	16.6%	32.2%

TABLE 9. Impact of financial difficulties.

* People who responded "A little bit", "Somewhat", "Quite a bit" or "Very much" to the question "To what extent have you experienced difficulties as a result of lung cancer and treatments?" (Figure 5).

Caregivers reported higher negative impact across all domains, compared with people with lung cancer. The greatest differences were observed in mental health (79.2% vs. 61.6%) and spirituality (32.2% vs. 16.6%).

Participants with high impact of economic repercussions rated poorer health across all dimensions, compared with those with low financial hardship, especially on spirituality (65.8% vs. 12.3%), physical well-being (58.8% vs. 16.9%), and family (57.6% vs. 17.6%)*.

Our research suggests that a substantial number of people impacted by lung cancer are at high risk of financial vulnerability. This has a great impact on their well-being, fiscal security, and overall health²⁴. Therefore, there is a need to identify these people as early as possible and offer multidisciplinary care and longitudinal follow-up.

Family and future earning potential are the main financial concerns

Worries about financial repercussions are common in people impacted by lung cancer with some type of economic difficulty: **91.4% experienced psychosocial repercussions** (Figure 11).

The most frequent worry was related to their families (61.8%) followed by the impact on future earning potential (51.0%). Once again, social life was identified as an important psychosocial impact of economic difficulties and half of respondents had fewer social relationships and activities (48.1%).

Have the financial difficulties negatively affected you in any of the following areas?

(n = 481 people with LC / n = 236 caregivers)

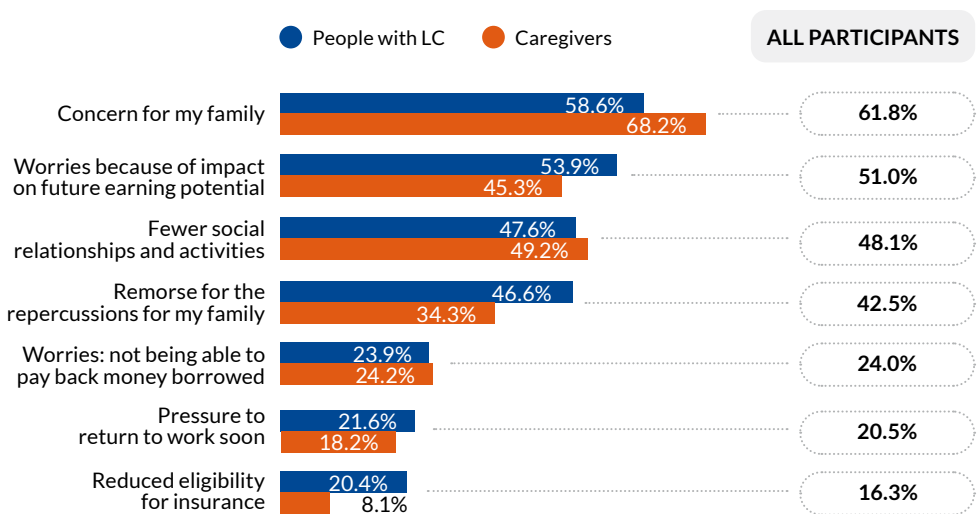


FIGURE 11. Psychosocial impact of financial difficulties.

* Comparison between high impact (quite a bit / very much) and low impact (a little bit) of financial difficulties (Figure 5).



“ Becoming financially dependent is a psychological concern difficult to assume.
(Patient from France)

“ You have to socialize so you don't feel alone but at the same time you don't have money for it.
(Caregiver from Spain)

“ I had to earn a living to pay the bills. This makes it difficult to rest physically and mentally.
(Patient from France)

“ I have less money for social activities and I'm less active. This is bringing on depression.
(Patient from the United Kingdom)

“ Due to the less financial security, I do fewer things with family than before. *(Patient from The Netherlands)*

“ Insecurity about the future, poor psychological state, changes in family plans.
(Caregiver from Greece)

“ It causes increased worry and panic about an already uncertain future.
(Patient from the United Kingdom)

“ It's stressful for the entire family, there's instability on every level of our life.
(Caregiver from the United Kingdom)



The financial strain of lung cancer affects the quality of life of people impacted by lung cancer. In addition, it is worth noting that a **substantial number of participants with financial difficulties (82.1%) perceived these difficulties as a barrier to treatment, recovery, and care.** It is worrying that 54.3% of caregivers stated that the financial situation highly impacted on these areas (by 'quite a bit' / 'very much'). This data shows that several respondents were unable to afford all the basic expenses associated with lung cancer.

Participants pointed out different reasons to explain why their personal finances may interfere with their care journey. Most frequent issues were: costs of treatments, logistics, diagnosis, healthcare, supportive services, and quality of life.

To what extent do you perceive your financial situation to impact your response to treatment, recovery or care?

(n = 485 people with LC / n = 236 caregivers)

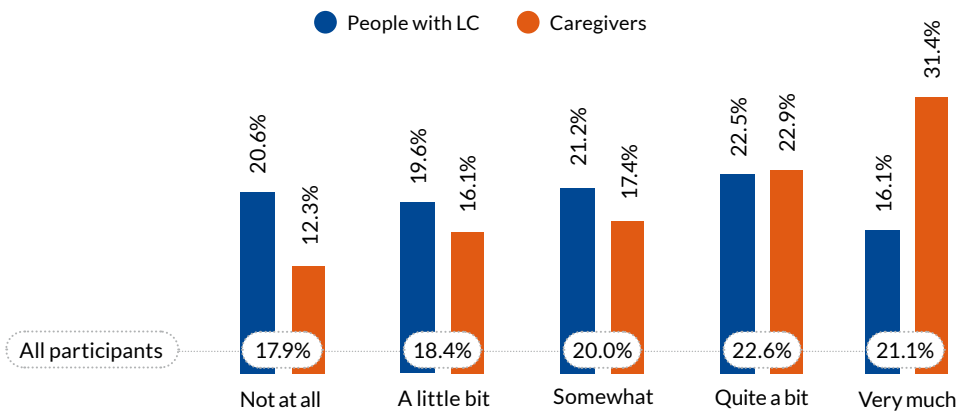


FIGURE 12. Impact on recovery and care.

Treatment and medicines

“ The cost of targeted drugs for the EGFR mutation is so high that I cannot afford it. *(Patient from Ukraine)*

“ My husband makes decisions for treatment based on not impacting his family financially after he is gone. *(Caregiver from the United Kingdom)*

“ With good finances, I would have gone to a private oncologist, and he would not have delayed the 3rd surgery. *(Patient from Greece)*

“ If we didn't pay for a private consultation, we would never have known that we could access compassionate use of a medication. *(Caregiver from Spain)*

“ The treatment has been covered by my private insurance, but it does not cover all options. *(Patient from Spain)*

“ I couldn't do my treatment in the pulmonary clinic because the health insurance didn't want to cover the journeys. *(Patient from Germany)*

Logistics

“ I cannot afford to go to the clinic where the treatment is more effective. *(Patient from Ukraine)*

“ Inability to afford transportation to the rehabilitation centre. *(Caregiver from Greece)*

“ I decided to treat myself in a city different from mine, which required me to spend the night and travel, assuming a greater expense. *(Patient from Spain)*

Diagnosis

“ Free examination of CT, MRI cannot always be done in a hurry (long queues up to 1-2 months). *(Patient from Ukraine)*

“ I would have liked to do more specialised tests like molecular testing, but unfortunately the cost is not covered by the state. *(Patient from Greece)*

Healthcare

“ The main obstacle is that I need to pay for oxygen, plus the cost of transporting the oxygen from my home to the hospital. (Patient from Greece)

“ I am unable to buy the support medicines required for my treatment, for which there is no reimbursement. I can't even afford asthma medication. (Patient from Finland)

“ To fight against side effects, it was necessary to spend a lot of money on support drugs (Patient from Ukraine)

Supportive services

“ Not all the needs of a cancer patient are covered by public healthcare. You have to look yourself for nutritionists, psychologists, additional doctors. (Patient from Spain)

“ The reduced financial capacity did not allow for good psychology and care in private settings. (Caregiver from Greece)

“ Lack of money for supportive treatments for recovery and processing (physical therapy, nutritional counselling, psychotherapy). (Caregiver from Germany)

Quality of life

“ Increased gas and electricity prices meant I was unable to heat my house adequately during the winter months leaving me cold and at risk of infection. (Patient from the United Kingdom)

“ I can no longer afford to move from my tiny studio flat which would impact the accessibility of receiving care at home. (Patient from the United Kingdom)

“ You can't buy enough good food, hygiene products and you don't have money for physical therapy, etc. (Patient from Finland)



People with cancer who experience considerable financial distress may alter their care to cover expenses associated with the disease²⁵. Physical health may even be sacrificed in an effort to save money by making some decisions that affect **adherence to treatment**²⁵. Some studies suggest that patients with greater economic difficulties have nearly double the likelihood of nonadherence to cancer medication¹⁰. This is one of the reasons why financial hardship is associated with worsened symptom burden, quality of life²⁶, and even hastens patient mortality²⁷.

1 out of 4 had made decisions that negatively affected self-care because of financial difficulties

A total of 26.5% of all participants (with or without financial difficulties) reported having made a decision that affected their self-care or adherence to treatment due to economic reasons. **Those under economic pressure were also more likely to forego or delay care (70.2% vs. 10.8%)*.**

Delaying or forgoing supportive services was the most frequently selected treatment sacrifice reported (14.1%) but financial difficulties go even further, significantly impacting other areas of people’s treatment and medical appointments (Figure 13).

People experiencing high financial difficulties reported greater difficulties across all domains: delaying/forgoing supportive services (19.9% vs. 5.6%), treatment or medication (14.9% vs. 0.5%) and medical appointments (12.8% vs. 1.1%), declining seeing a specialist (15.8% vs. 2.7%), and skipping or discontinuing medication (7.6% vs. 0.8%).

Have you ever made any of the following decisions because of financial difficulties? (n = 817 people with LC / n = 320 caregivers)

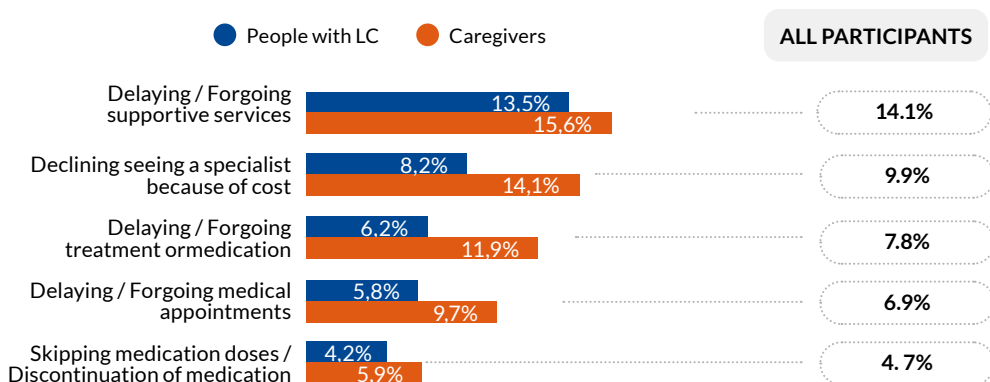


FIGURE 13. Decisions made due to financial difficulties and its repercussions on health.

* Comparison between high impact (quite a bit / very much) and no or low impact (not at all / a little bit) of financial difficulties (Figure 5).

Due to its influence on treatment adherence and efficacy, **financial toxicity should be discussed in medical and nurse consultations** at diagnosis and regularly thereafter. The potential impact of finances may negatively affect the prognosis and quality of life.

Many survey respondents (with or without financial difficulties) stated that their personal finances impacted their access to healthcare (Figure 14). A substantial number of people impacted by lung cancer considered that their **personal finances influenced their access to supportive services (40.5%), early or rapid diagnosis (38.6%) and innovative treatments or medicines (35.0%).**

These barriers were reported more commonly by people experiencing high economic repercussions than those with low or no financial difficulties, especially in relation to access to innovative treatments (60.3% vs. 24.1%) and clinical trials (45.3% vs. 14.1%). Healthcare and social services as well the Netherlands pharmaceutical industry should provide more assistance with this.

Access barriers due to personal finances

(n=990 participants: both people with LC and caregivers)

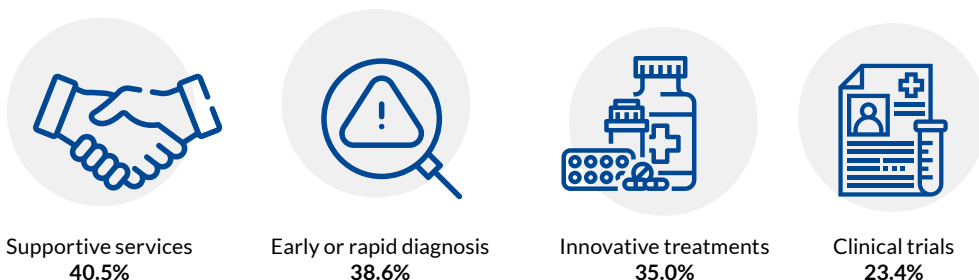


FIGURE 14. Access barriers due to personal finances.

Our research has found some differences in how people perceive their financial situation as a barrier to accessing diagnosis, care, and treatment. Table 10 shows that caregivers reported higher access barriers than people diagnosed with lung cancer. In addition, the information provided in table 11 indicates that there are differences by country. Participants from Eastern Europe reported higher barriers in the disease journey because of economic reasons.

We need the implementation of policies designed to offset the burden of direct medical costs, especially among people with low socio-economic status or those living in countries with very limited access to innovative diagnostic tests and treatments.

Do personal finances impact patients' access to any of the following?

(n = 711 people with LC / n = 279 caregivers)

	Yes		No		I don't know	
	Patients	Caregivers	Patients	Caregivers	Patients	Caregivers
Access to supportive services	36.7%	50.0%	41.8%	30.6%	21.5%	19.4%
Access to early or rapid diagnosis	31.8%	56.0%	43.1%	28.7%	25.1%	15.3%
Access to innovative treatments / medicines	28.7%	50.9%	47.2%	31.8%	24.1%	17.3%
Access to clinical trials	19.2%	34.1%	50.4%	39.1%	30.4%	26.8%

TABLE 10. Impact of personal finances on access: Differences between patients and caregivers.

Country breakdown of impacted services due to personal finances

(n = 711 people with LC / n = 279 caregivers)

	UKRAINE	POLAND	GREECE	SPAIN	FINLAND	CROATIA	DENMARK	GERMANY	UNITED KINGDOM	THE NETHERLANDS	FRANCE	ITALY
Access to supportive services	58.8%	70.0%	59.0%	50.0%	28.6%	31.8%	37.5%	38.5%	20.2%	34.8%	37.3%	15.8%
Access to early or rapid diagnosis	63.5%	70.0%	47.4%	38.1%	44.4%	39.1%	29.3%	15.8%	29.6%	14.5%	16.4%	23.7%
Access to innovative treatments	94.3%	40.0%	53.7%	23.4%	31.8%	20.8%	19.1%	25.6%	21.4%	13.0%	13.4%	5.3%
Access to clinical trials	65.4%	50.0%	43.6%	21.9%	27.0%	9.1%	14.6%	14.3%	6.1%	11.6%	6.0%	2.6%

TABLE 11. Country breakdown of impacted services due to personal finances.*

* National comparisons were performed only when there were more than 24 participants per country.

3.4. SUPPORT: Dealing with financial toxicity

Even when financial distress negatively affects the quality of life of people impacted by lung cancer, there is still a lack of resources and services available to address these needs. There are very few options, even in countries where there is economic help or extensive social coverage, these resources are limited, often insufficient, and frequently unknown²⁸.

Our research suggests that financial toxicity is common among people impacted by lung cancer, and it impacts the individual and household socioeconomic stability. In fact, only 39.5% of participants stated that there were benefits for people with cancer in their country. It is remarkable that **4 out of 10 (39.2%) stated that financial grants or assistance for patients were not available in their country** and another 21.3% did not know if these existed (Figure 15).

The data on benefits for caregivers is even more worrisome (Figure 16). While caregivers also experience significant financial strain, they report a lack of access to and knowledge about specific caregiver support, in our survey we found that only 1 out of 4 participants (26.6%) knew about specific caregiver benefits. It is surprising to find that **46.7% of caregivers were not aware of caregiver benefits in their countries**, and a further 26.7% reported that there was no financial support available for caregivers.

One of the issues may be that some caregivers do not see themselves as someone who should receive help and therefore may not have considered applying for benefits²⁹.

Are there public financial benefits for people diagnosed with cancer in your country?

(n = 711 people with LC / n = 279 caregivers)

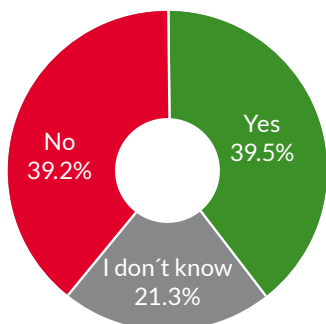


FIGURE 15. Public benefits for people with cancer.

Are there public financial benefits for caregivers in your country?

(n = 708 people with LC / n = 278 caregivers)

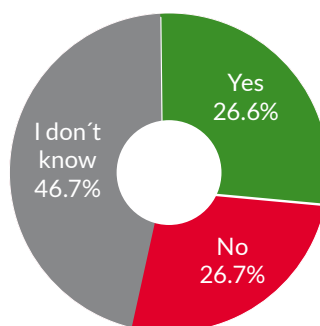


FIGURE 16. Public benefits for caregivers.

Only a minority received assistance from public services. Main support reported was through loved ones.

A lack of public knowledge, availability or accessibility of financial benefits led to only a minority of people impacted by lung cancer receiving monetary or material assistance from public services. Figure 17 shows that only **1 out of 5 survey respondents had sought financial support from public health (21.6%) or social services (20.6%)**. It is also worth noting that those that attempted to access financial support were not always successful: 40.8% of the people who sought help from social services and 29.7% in healthcare services did not get the assistance they needed.

Worryingly, **only 15.2% and 12.2% of participants received financial or material support from healthcare and social services respectively**. These numbers are very low considering that 45.7% of respondents had difficulties paying for expenses related to lung cancer, and 36.8% found it difficult to live on their household income due to the disease.

This data suggests that even when financial supports exist, accessing them is not always feasible or they may be insufficient. Strict eligibility criteria or difficulties to pursue the application are barriers to accessing these benefits³⁰. **Improving access to financial support is an urgent need**, as patients and families may also feel overwhelmed, intimidated, or embarrassed about seeking benefits for illness purposes³¹.

Financial challenges are pushing people impacted by lung cancer to seek support in personal and private circles. Almost **1 out of 3 participants (30.4%) had asked for financial or other material assistance from loved ones** and 13.0% had contacted private organisations to help address their economic needs.

“More help means more health and less spending in the medium and long term. (Patient from Spain)

“If you apply for something, for example a PGB or mobility scooter, you have to wait months for an interview. In the end I bought it myself. (Caregiver from The Netherlands)

“There is not enough money even for basic expenses. I also have an elderly mother, 85 years old, who also needs medicines and to be taken care of. My daughter and son-in-law, who work, help a lot, but they give almost 60% of their wages. (Patient from Ukraine)

“After spending 35 years a London taxi driver, I wound up with brain metastases so was unemployed overnight. I had no support financially for 6 months, only survived because my wife didn't retire. No real support for the self-employed. (Patient from the United Kingdom)

Have you sought financial assistance or donations in kind (like creams, bandages, support with transportation) from any of the following?

(n = 796 people with LC / n = 310 caregivers)

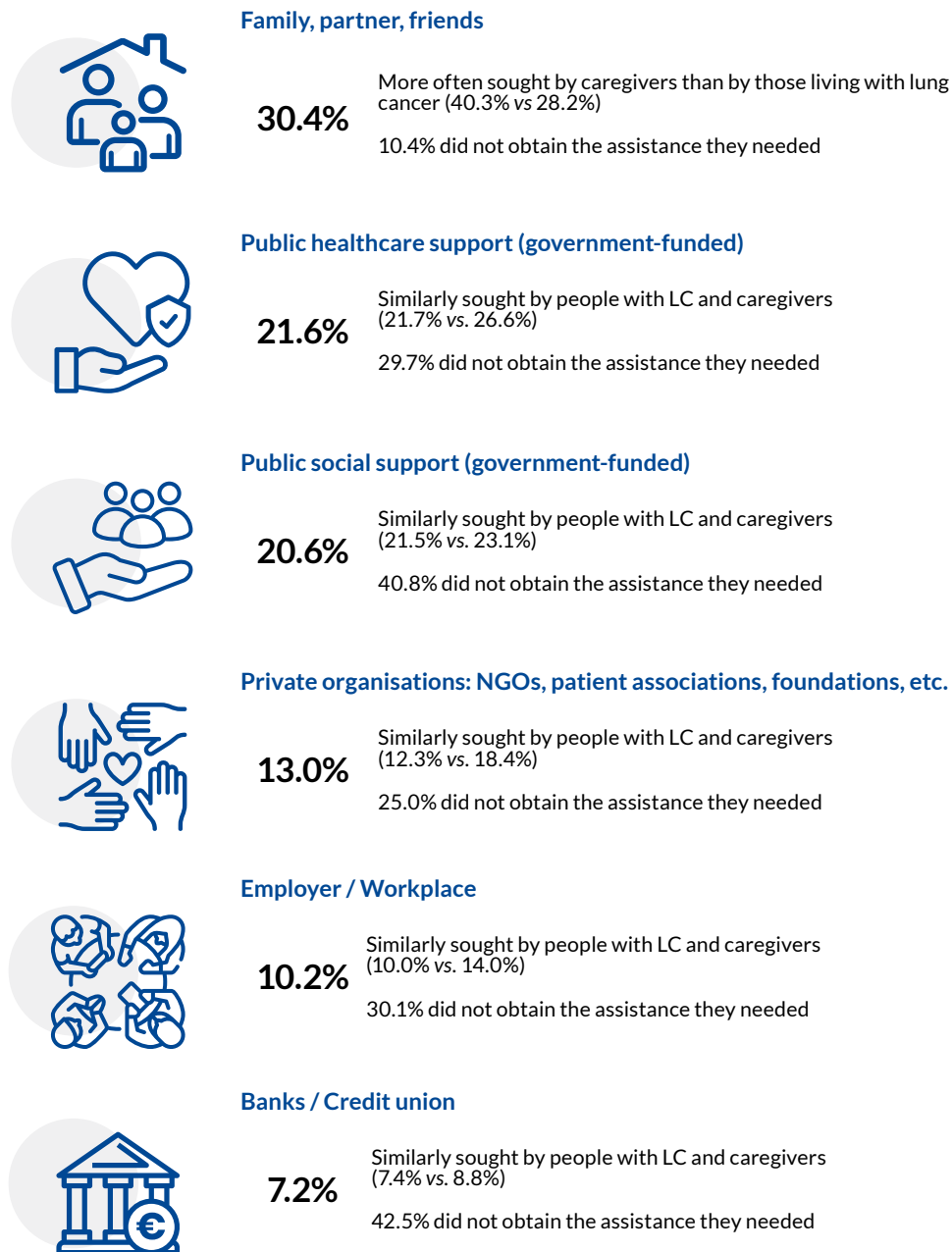


FIGURE 17. Financial assistance.

“My husband takes care of us; we have a small child who was a baby when I was diagnosed. My husband works all day at several jobs, I took care of the baby all by myself, through the chemo and surgeries. There was no one with us. Anyway, I solved it. So far! (Patient from Hungary)

“Medical science is advancing so quickly, government financial support cannot keep up. I am incurable but not receiving chemotherapy, so all forms I fill in assume I'm not that ill. (Patient from the United Kingdom)

One of the best strategies to improve access to financial support is channelling information through healthcare teams. Discussions between these teams and people impacted by lung cancer can help manage potential economic effects. These discussions may also serve to offer support services to people at high risk⁹.

However, a great majority of participants had never, or barely, talked about financial concerns with their healthcare teams (Figure 18). In fact, **28.7% had ever discussed finances, and only a small percentage (5.7%) did it frequently**. According to literature, some of the reasons for this stems from the stigma around discussing money, and the perception that alleviating financial burden is not the duty of healthcare teams³².

Have you talked with your healthcare team about financial issues associated with lung cancer?

(n = 799 people with LC / n = 312 caregivers)

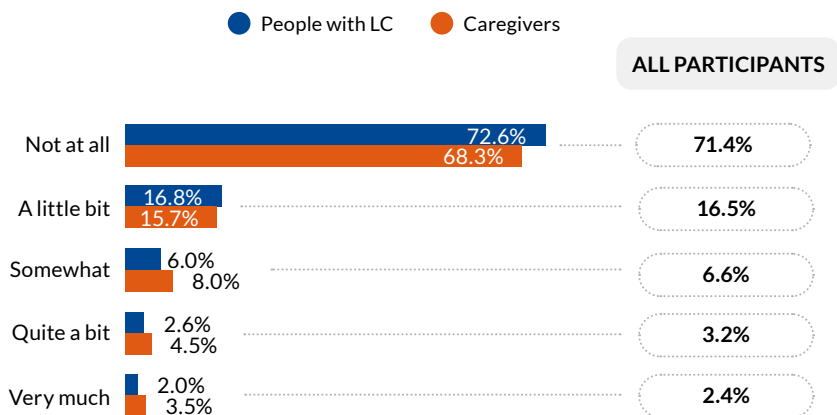


FIGURE 18. Talking with the healthcare team about financial issues.

Social workers are considered to be the most appropriate individuals equipped to handle these conversations and offer financial education³³. However, only a **minority of people (17.4%) who reported economic difficulties had ever talked with these professionals or attended social services** (Figure 19). These services were used slightly more frequently by people with lung cancer than caregivers (19.0% vs. 14.0%)

Among those experiencing high financial impact, we observe a higher proportion of access to these services (52.1%).

Worryingly, our findings show that nearly half (47.9%) of those reporting high economic impact of lung cancer were not supported by social services or social workers.

Half of people with high financial difficulties had not been supported by social workers or social services

Have you ever talked with a social worker or someone from social services about your financial situation?

(n = 485 people with LC / n = 235 caregivers)

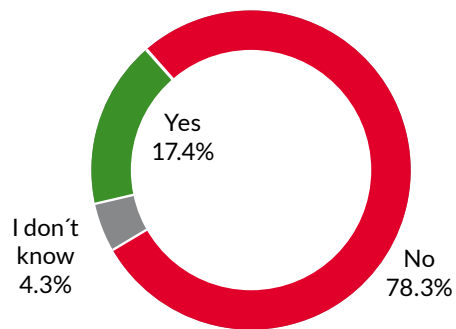


FIGURE 19. Support from social worker or social services.

Support for healthcare costs is a priority for people surveyed. Half of respondents reported healthcare costs as the most needed area for financial support. Even in countries with public health care systems that cover lung cancer treatment and care, the nature and extension of public support varies widely. Of note, the countries where participants reported a greater need for assistance were Ukraine (96.4%), Finland (81.3%), and Poland (72.2%).

It is worth noting that caregivers prioritised access to benefits for caregivers as their second priority. This is consistent with data obtained by the Eurobarometer survey that explored preferences on public contributions to helping caregivers. According to the Eurobarometer (2012), **financial remuneration for caregiving** is the most important support for family caregivers³⁴. This measure was also highly reported by participants from Spain (44.6%) and Italy (42.9%).

What types of financial support do you think are needed most for people impacted by lung cancer? (n = 714 people with LC / n = 279 caregivers)

	ALL PARTICIPANTS	PEOPLE WITH LUNG CANCER	CAREGIVERS
Costs of medication and healthcare	53.0%	51.0%	58.1%
Benefits for people with disability	27.0%	29.7%	20.1%
Energy costs and utilities	26.0%	27.0%	23.3%
Transportation	25.0%	25.6%	23.3%
Concessions for caregivers	24.6%	22.0%	31.2%
Family care	16.4%	13.7%	23.3%
Home adaptation - equipment	15.7%	15.6%	16.1%
Parking	14.3%	15.6%	11.1%
Support for work reintegration	14.5%	17.0%	8.2%
Accommodation and food	10.0%	10.4%	9.0%

TABLE 12. Financial supports most needed.

“ If working is no longer possible, a higher disability benefit. (Patient from The Netherlands)

“ Care for terminally ill patients. The only solution is a private clinic that costs huge amounts and there is no organised palliative care (Caregiver from Greece)

“ Cancer patients who are self-employed should have an annuity such that they can live and still be able to keep the business open for a future retirement. (Patient from Italy)



4. CALL TO ACTION

Screen for financial toxicity and provide programmes to assist with costs, if financial vulnerability is detected.

Healthcare teams should encourage discussions with people impacted by lung cancer to help explore their financial needs. Those affected should be directed to resources and information which can help to reduce expenses associated with treatment and care and to mitigate increased costs because of the disease situation.

Increase income replacement programme coverage for people unable to work because of lung cancer or caregiving.

Reduction of income due to changes in employment is one of the biggest repercussions of a lung cancer diagnosis. Employed individuals are more likely to experience a drop in income due to the disease. Appropriate compensation benefits should be funded through social welfare systems by governments and provided for those unable to work because of lung cancer.

5. ACKNOWLEDGEMENT

'Alone we can do so little, together we can do so much'.

We truly appreciate this quote from Helen Keller. She was a prolific novelist, teacher and advocate for people with disabilities, and she believed that we all must come together, putting our differences aside, to change the world.

We are passionate about working together to drive the change needed to improve lung cancer outcomes, and this is only possible through the support of many individuals committed to amplifying our voices, for people impacted by lung cancer.

We want to start by giving a special thank you to the **1,161 people who completed our survey**. This is the highest number we have ever obtained. Thank you for sharing your experiences and concerns on such a sensitive topic.

Our thanks to the **LuCE members involved in this report**, who reviewed the survey and translations, and disseminated it in their countries. We are very grateful that our members recognise the value of working together at the European level to face the challenges that we all share.

Thank you very much to the **people involved in the LuCE Report Working Group**: Anne-Marie Baird (Working Group chair), Yvonne Diaz, Sabine Hatzfeld, Merel Hennink, Erika Pataki and Diego Villalón. Our sincere gratitude for sharing your time and experience throughout this project.

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Lastly, we would like to thank all of the **organisations that provide support to LuCE**. 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, NovoCure, Pfizer, Regeneron, Roche, Sanofi, Takeda and Thermo Fisher.

6. LUNG CANCER EUROPE (LuCE)

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

Our vision

All Europeans (patients, families and caregivers) impacted by lung cancer will have equity in 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 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.



Lung Cancer Europe



Meet our team:

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Maeve O'Sullivan
(Ireland)
Executive Officer



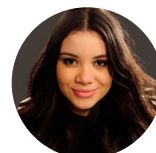
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(Spain)
Policy Officer



Tammy Cruickshank
(Spain)
Senior Project Manager



Catriona Grant
(Italy)
Senior Project Manager



Tihany Carrillo
(Spain)
Administrative Assistant

About our members

LuCE provides a platform for organisations and individuals working for people impacted by lung cancer. As of October 2023, there are 39 members (34 organisations and 5 individuals), representing 22 countries. We encourage you to learn more and support LuCE and our member organisations.

www.lungcancereurope.eu/our-members



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Individual members:



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Anne-Marie Baird



Regine Deniel Ihlen



Ewelina Szmytke



Tommy Björk

7. ANNEX I. Detailed breakdown of participant characteristics

PARTICIPANT DISTRIBUTION

(n = 834 patients / n = 327 caregivers)

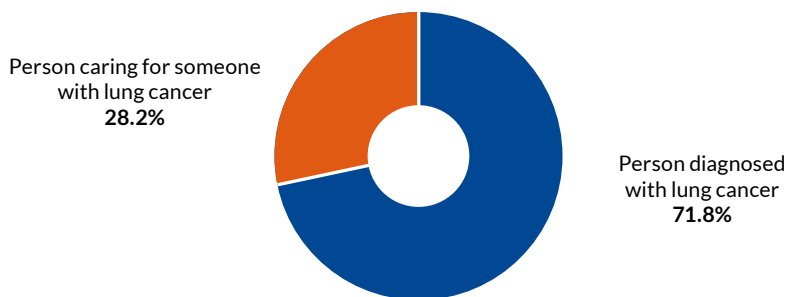


FIGURE 20. Participant distribution.

GENDER

(n = 834 patients / 327 caregivers).

	ALL PARTICIPANTS	PEOPLE WITH LUNG CANCER	CAREGIVERS
Women	76.5%	75.8%	78.3%
Men	22.7%	23.4%	21.1%
Non-binary	0.1%	0.1%	0.0%
Prefer not to say	0.7%	0.7%	0.6%

TABLE 13. Gender.

AGE

(n = 833 patients / n = 327 caregivers)

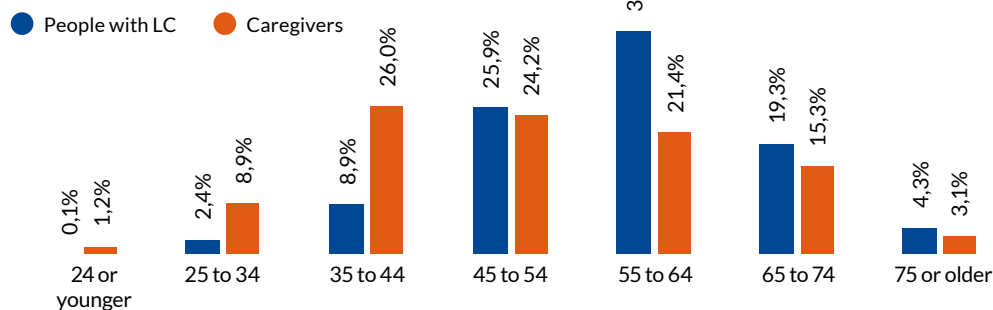


FIGURE 21. Age.

WORK SITUATION AT THE TIME OF DIAGNOSIS

(n = 832 patients / n = 327 caregivers)

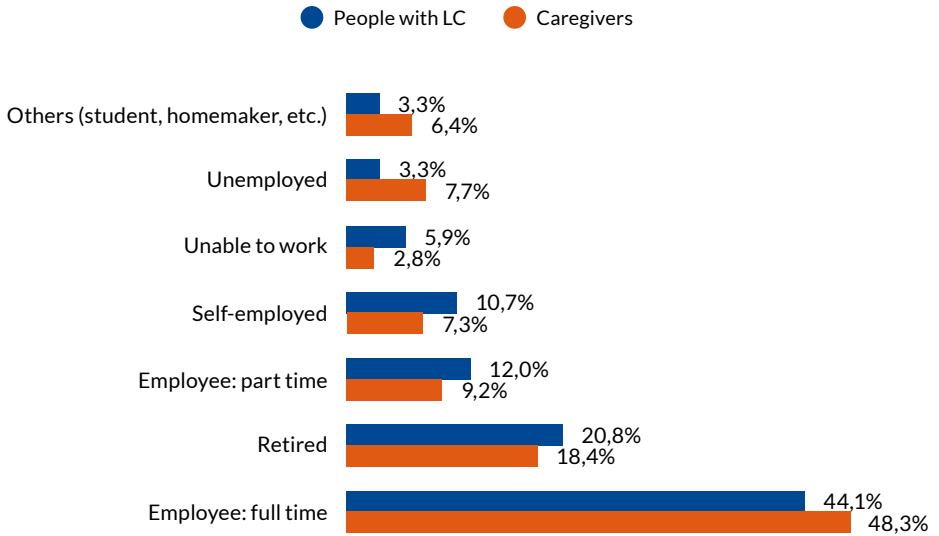


FIGURE 22. Work situation at diagnosis.

FINANCIAL SITUATION BEFORE DIAGNOSIS

(n = 832 patients / n = 326 caregivers)

	PEOPLE WITH LC				
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I felt in control of my financial situation	5.0%	9.1%	11.6%	37.2%	37.1%
I felt financially stressed	26.6%	30.7%	17.7%	18.9%	6.1%
I was able to meet my monthly expenses	5.8%	7.7%	7.7%	41.6%	37.3%

	CAREGIVERS				
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I felt in control of my financial situation	5.9%	14.4%	12.1%	42.3%	25.3%
I felt financially stressed	15.1%	30.3%	19.9%	26.3%	8.4%
I was able to meet my monthly expenses	5.2%	12.0%	11.3%	44.2%	27.3%

TABLE 14. Financial situation before diagnosis.

ACCESS TO A PUBLIC HEALTH SYSTEM THAT COVERS LUNG CANCER TREATMENT AND CARE

(n = 832 patients / n = 327 caregivers)

	ALL PARTICIPANTS	PEOPLE WITH LUNG CANCER	CAREGIVERS
Yes	69.3%	75.2%	54.1%
Partially, there are some co-payments / fees, which I can afford	13.1%	10.8%	19.0%
Partially, there are some co-payments / fees, which I can't afford	7.3%	5.4%	12.2%
No	8.7%	7.0%	13.2%
Other	1.6%	1.6%	1.5%

TABLE 15. Access to a public health system.

HAVE PRIVATE HEALTH INSURANCE

(n = 832 patients / n = 327 caregivers)

	ALL PARTICIPANTS	PEOPLE WITH LUNG CANCER	CAREGIVERS
Yes	31.8%	35.0%	23.6%
No	67.7%	64.5%	75.8%
I don't know	0.5%	0.5%	0.6%

TABLE 16. Have private health insurance.

COUNTRY OF RESIDENCE (n = 834 patients / n = 327 caregivers)

Country		ALL PARTICIPANTS	PEOPLE WITH LUNG CANCER		CAREGIVERS	
1	Ukraine	147	9.0%	75	22.0%	72
2	United Kingdom	134	12.7%	106	8.6%	28
3	Greece	120	5.5%	46	22.6%	74
4	Spain	109	9.2%	77	9.8%	32
5	The Netherlands	99	10.3%	86	4.0%	13
6	Germany	97	10.0%	83	4.3%	14
7	France	82	8.9%	74	2.4%	8
8	Finland	78	7.9%	66	3.7%	12
9	Italy	69	5.8%	48	6.4%	21
10	Denmark	60	6.2%	52	2.4%	8
11	Croatia	48	3.7%	31	5.2%	17
12	Poland	24	1.6%	13	3.4%	11
13	Hungary	18	1.8%	15	0.9%	3
14	Portugal	17	1.7%	14	0.9%	3
15	Belgium	14	1.6%	13	0.3%	1
16	Slovenia	11	1.0%	8	0.9%	3
17	Switzerland	8	0.8%	7	0.3%	1
18	Sweden	6	0.7%	6	0.0%	0
19	Ireland	5	0.4%	3	0.6%	2
20	Norway	5	0.6%	5	0.0%	0
21	Austria	2	0.2%	2	0.0%	0
22	Kosovo	2	0.2%	2	0.0%	0
23	Bosnia and Herzegovina	1	0.0%	0	0.3%	1
24	Cyprus	1	0.0%	0	0.3%	1
25	Estonia	1	0.1%	1	0.0%	0
26	Israel	1	0.0%	0	0.3%	1
27	Romania	1	0.0%	0	0.3%	1
28	Serbia	1	0.1%	1	0.0%	0
TOTAL		1.161		834		327

TABLE 17. Country of residence.

TYPE OF LUNG CANCER

(n = 831 patients / n = 327 caregivers)

	ALL PARTICIPANTS	PEOPLE WITH LUNG CANCER	CAREGIVERS
Non small cell lung cancer (adenocarcinoma)	71.3%	74.1%	64.2%
Small cell lung cancer	7.9%	6.7%	11.0%
Non small cell lung cancer (squamous)	5.9%	4.8%	8.6%
Non small cell lung cancer (other subtype)	4.0%	4.0%	4.0%
Another type of lung cancer	5.3%	5.1%	5.8%
I don't know	5.6%	5.3%	6.4%

TABLE 18. Type of lung cancer.

TUMOUR BIOMARKER

(n = 827 patients / n = 326 caregivers)

	ALL PARTICIPANTS	PEOPLE WITH LUNG CANCER	CAREGIVERS
ALK	22.7%	26.0%	14.4%
EGFR	16.8%	18.3%	13.2%
PD-L1	7.2%	5.9%	10.4%
ROS1	5.1%	5.8%	3.4%
KRAS	4.9%	5.4%	3.7%
BRAF	1.5%	1.5%	1.5%
MET	1.0%	0.7%	1.5%
HER2	0.6%	0.6%	0.6%
FGFR1	0.5%	0.7%	0.0%
NRG1	0.4%	0.4%	0.6%
RET	0.3%	0.4%	0.3%
NTRK	0.2%	0.0%	0.6%
CTLA-4	0.1%	0.1%	0.0%
NRAS	0.1%	0.1%	0.0%
I don't know	20.0%	18.5%	23.9%
No mutations	15.9%	14.2%	20.3%
The tumour has not been tested	7.2%	6.4%	9.2%
Still in the process of biomarker testing	2.9%	2.1%	5.2%

TABLE 19. Biomarker status.

STAGE AT DIAGNOSIS

(n = 833 patients / n= 327 caregivers)

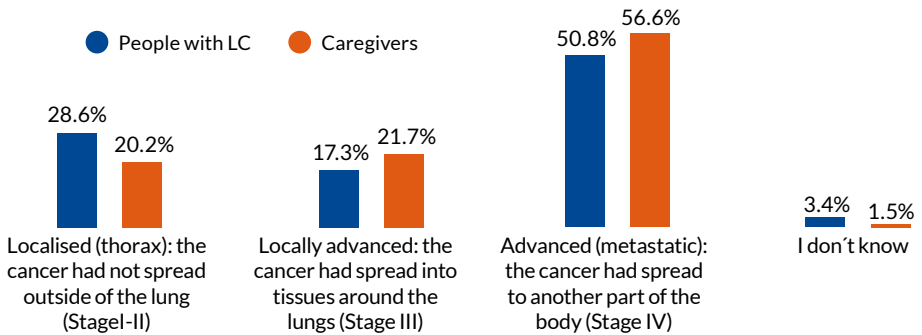


FIGURE 23. Stage of lung cancer at diagnosis.

TIME FROM DIAGNOSIS

(n = 834 patients / n= 327 caregivers)

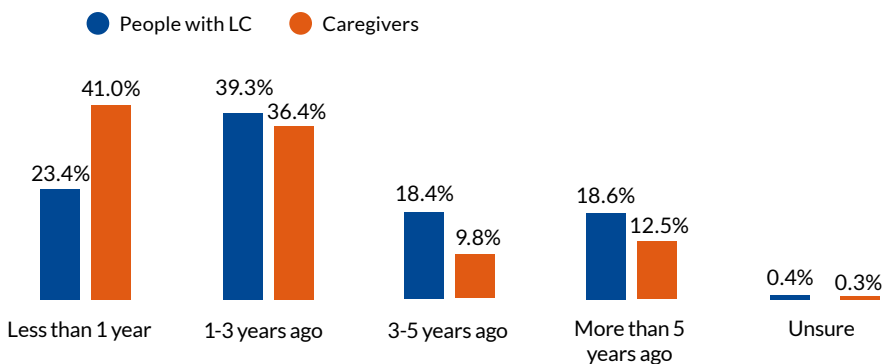


FIGURE 24. Time from diagnosis.

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