

8th LUCE REPORT ON LUNG CANCER



Financial impact of lung cancer in the United Kingdom

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Table of contents:

Page 04 • Introduction

Page 05 • Project description and methodology

Page 06 • Results

Page 15 • Call to action

Page 16 • About us



INTRODUCTION

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 also 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.

This report is focused on the United Kingdom (UK) responses of a wider pan-European online survey. It 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. The report is not just about highlighting the challenges; it also offers insights into potential solutions and avenues for support.

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.

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.



DESCRIPTION AND METHODOLOGY

DESCRIPTION:

This report is a descriptive research analysis that explores the economic burden of lung cancer, as reported by people diagnosed with the disease and those in a caregiving capacity, specifically within the UK. This project is part of a wider pan-European 8th LuCE Report 'Financial impact of lung cancer: A European perspective'.

Access the full report here: www.lungcancereurope.eu.

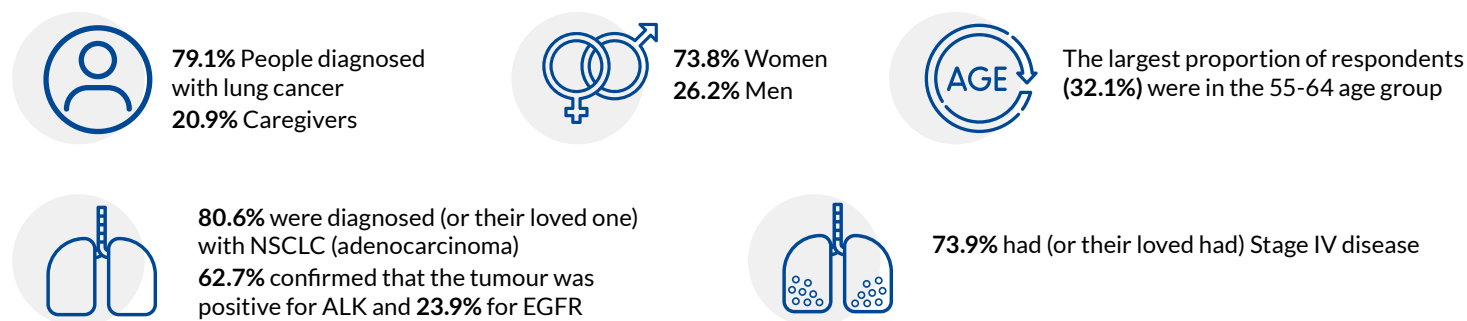


METHODOLOGY:

An online survey was self-filled by people impacted by lung cancer in the WHO European Region. The survey, which was confidential and did not include questions related to personal information, was active from May 6th until July 5th, 2023.

This Country Report includes results obtained from 134 participants from the UK. This represented 11.5% of the total number of participants of the 8th LuCE Report (134 / 1,161). The figures in this report compare data collected from people living in the United Kingdom with the average collected from participants across Europe.

Overview of participants based in the UK:

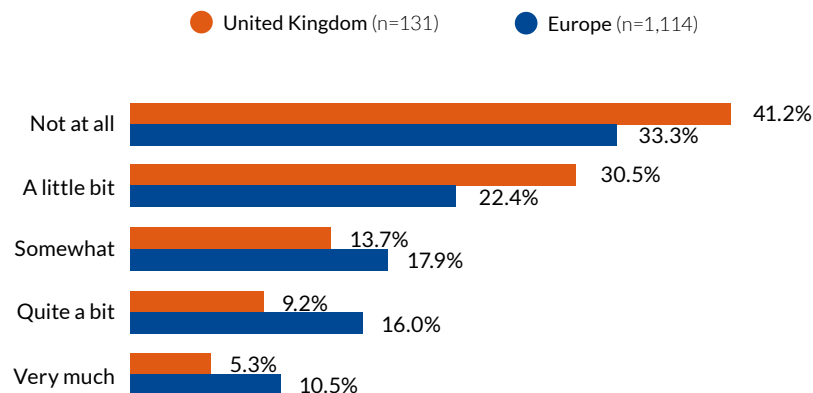


RESULTS

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 completely reimbursed by government or insurers. Apart from medical costs, other factors contributing to this financial burden include non-medical and indirect costs.

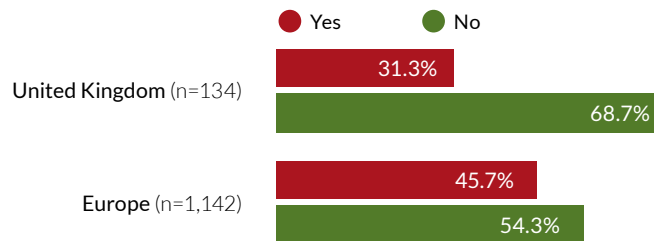
The following shows the magnitude of the economic impact: 58.8% of people affected by lung cancer in the UK reported financial challenges as a result of the disease. The impact was very significant (quite a bit / very much) for 14.5% of participants.

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

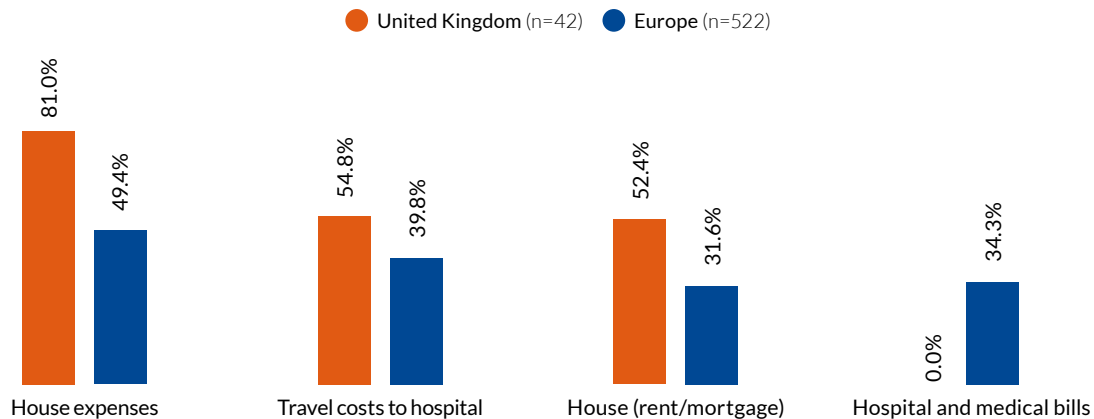


31.3% of UK participants had trouble paying for certain expenses. According to those who reported these problems (n=42), house expenses (81.0%) and travel costs to hospitals (54.8%) were the most difficult expenses to pay.

Have you had difficulties paying for certain expenses?



Difficulties paying expenses



One of the main factors associated with financial strain is the amount of income required to pay for expenses related to lung cancer.

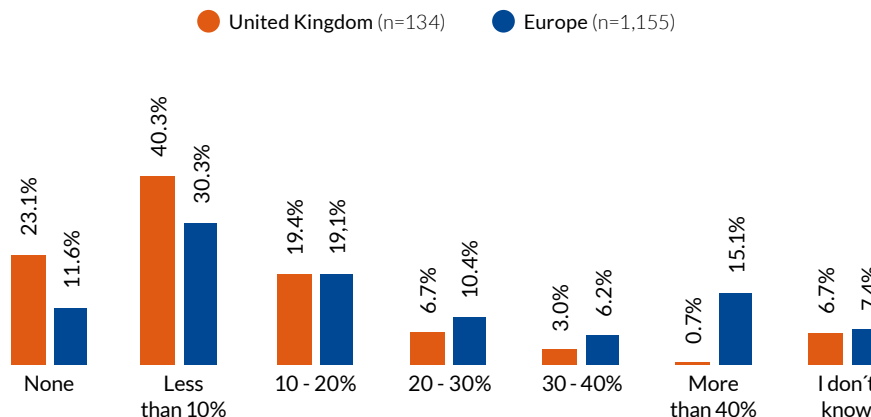
Our findings show that 29.8% of participants from the United Kingdom needed more than 10% of their household income to pay for expenses related to lung cancer.

“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.

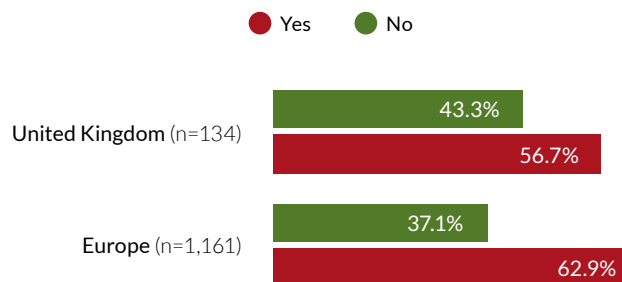
Indirect costs are caused by the loss of resources and opportunities due to lung cancer. After diagnosis, people may experience varied levels of income reduction.

According to our survey, 56.7% reported reduced household income since diagnosis. 1 out of 3 identified the inability to work as one of the reasons for the decrease in income, followed by reduction in work time (32.8%).

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



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



Main reasons for the household income reduction (n=74)



Unable to work
36.1%
(Europe: 39.7%)



Reduction in work time
32.8%
(Europe: 18.3%)



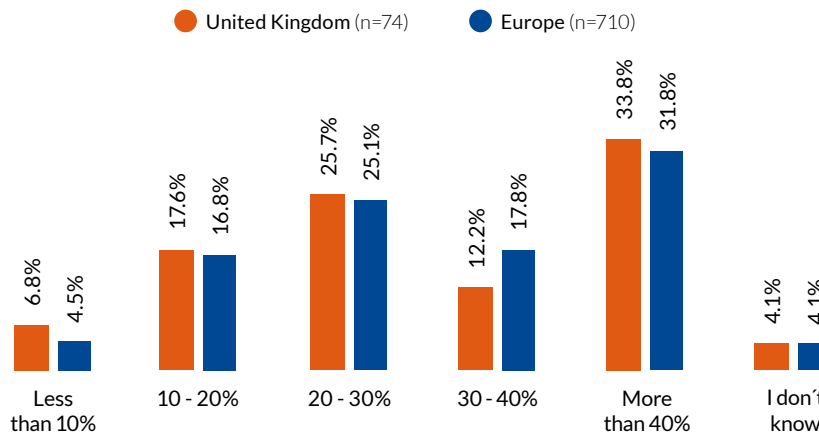
Retirement due to illness
22.9%
(Europe: 26.8%)



Work absence
18.0%
(Europe: 27.9%)

Of the 74 respondents who experienced a reduction in income, 71.7% of them experienced a decrease higher than 20% and almost half (46%) experienced a decrease higher than 30% compared to life before lung cancer.

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



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.

Cancer costs and economic burdens impact patients and families forcing them to make sacrifices.

Most respondents (56%) had 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 changing plans (47%) or cutting down leisure activity (36.6%).

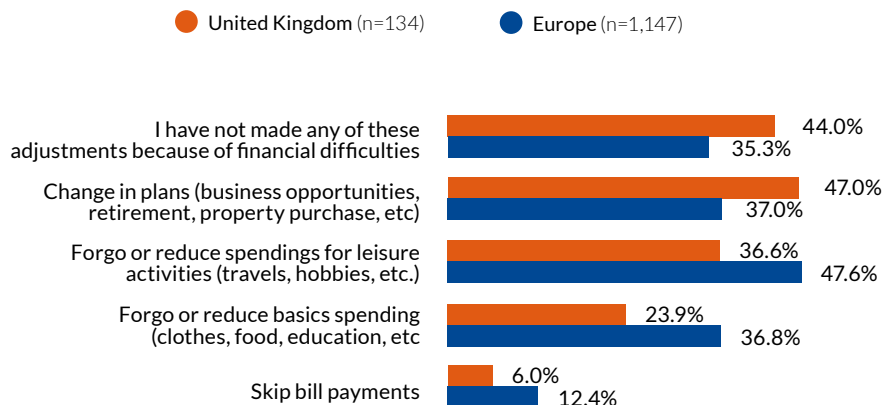
I have to work full time to be able to pay living expenses.

My husband makes decisions for treatment based on not impacting his family financially after he is gone.

Financial adjustment also included strategies to cashing in and having additional resources to deal with difficulties. In order to mitigate the financial burden, 30.8% utilised savings, 11.5% sold possessions and 11.5% borrowed money.

I don't want her to worry but she is aware we are using savings.

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



Other financial adjustments United Kingdom (n=130); Europe (1,108)



Withdraw money from retirement or saving funds
30.8%
(Europe: 22.6%)

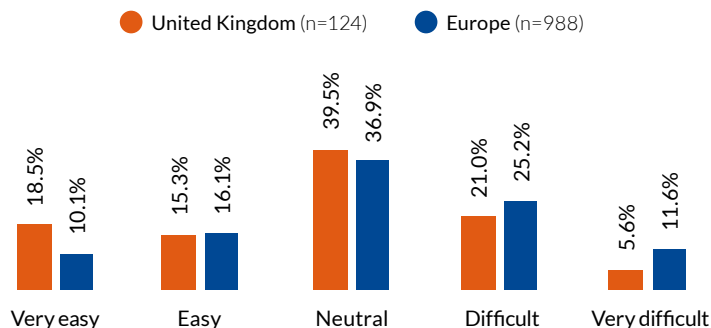


Sell assets or possessions
11.5%
(Europe: 14.7%)



Borrow money
11.5%
(Europe: 17.9%)

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



Expenses related to lung cancer affected the capacity for managing finances in such a way that, according to our research, 26.6% of people impacted by lung cancer in the UK found it difficult to live on their household income.

“It causes increased worry and panic about an already uncertain future.

“It's stressful for the entire family, there's instability on every level of our life.

Our research suggests that lung cancer is a risk factor of financial distress. The percentage of people that felt financially stressed increased from 18.1% (before diagnosis) to 31.0% (at the time of completing the survey). Similarly, 1 out of 4 participants (26.8%) reported not feeling in control of their financial situation, 8 points higher than before the diagnosis.

Household financial situation: vulnerability after diagnosis

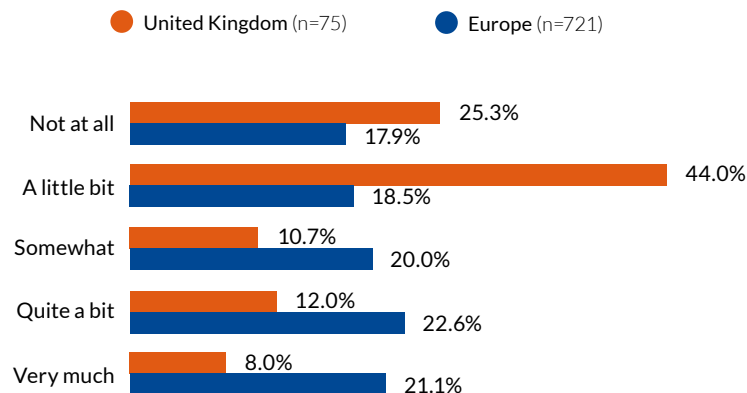
	United Kingdom (n=131)		Europe (n=992)	
	Before diagnosis	After diagnosis	Before diagnosis	After diagnosis
Not in control of my financial situation	18.7%	26.8%	15.8%	36.9%
Financially stressed	18.1%	31.0%	27.7%	46.8%
Not able to meet monthly expenses	13.6%	19.7%	14.5%	28.6%
Debt level increased	-	18.9%	-	26.9%

The financial strain of lung cancer affects the quality of life of people impacted by lung cancer. It is also very important to note that 74.7% of people facing financial difficulties agreed that their financial situation had an impact on their response to treatment and care.

Many survey respondents (with or without financial difficulties) stated that their personal finances impacted their access to healthcare.

People impacted by lung cancer from the UK considered that their personal finances influenced their access to early or rapid diagnosis (27.4%) and innovative treatments or medicines (21.0%).

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



IMPACT OF FINANCIAL REPERCUSSIONS ON ACCESS



Early or rapid diagnosis
27.4%
(Europe: 38.6%)



Innovative treatments
21.0%
(Europe: 35.0%)



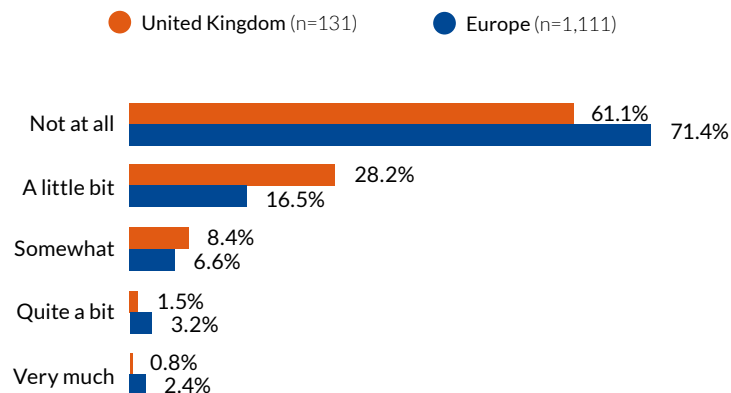
Supportive services
19.4%
(Europe: 40.5%)



Clinical trials
6.5%
(Europe: 23.4%)

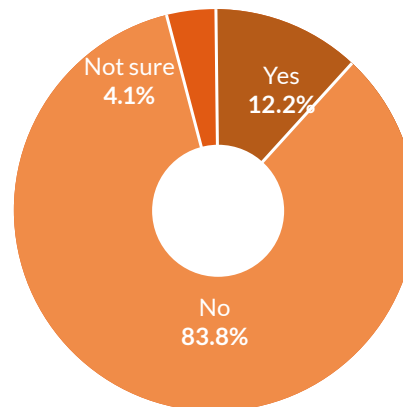
One of the best strategies to reduce the impact of financial consequences is channelling information through healthcare teams. Discussions between these teams and people impacted by lung cancer can help manage potential economic effects. However, a majority of participants had never, or barely ever, talked about financial concerns with their healthcare teams. In fact, 38.9% had ever discussed finances, and only a small percentage (2.3%) did it frequently.

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



Social workers are considered to be the most appropriate individuals equipped to handle these conversations and offer financial education. However, minority of people (12.2%) who reported economic difficulties had ever talked with these professionals or attended social services.

Have you ever talked with a social worker or someone from social services about your financial situation? (n = 74)



Europe (n=720)		
Yes	No	Not sure
17.4%	78.3%	4.3%



Indirect costs should not be underestimated.

Some 56% of participants from the United Kingdom reported reduced household income since diagnosis. A total of 71.7% of them experienced a decrease higher than 20% and almost half (46%) experienced a decrease higher than 30% compared to life before lung cancer.

This research shows the importance of addressing the financial impact of lung cancer in the United Kingdom. Despite the economic repercussions not being as severe as in other European countries, 58% of people affected by lung cancer in the United Kingdom still reported financial challenges as a result of the disease. It is also very important to note that 3 out of 4 people facing financial difficulties agreed that their financial situation had an impact on their access to treatment and care.





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.

ABOUT US



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.

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.

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www.lungcancereurope.eu

LuCE Members in the United Kingdom



ALK Positive UK

A registered charity established by patients, their families and friends. Our Vision: People with ALK-positive lung cancer in the UK will thrive and live a long and fulfilling life unhindered by their disease. ALK Positive UK exists to:

- Support the ALK+ lung cancer patient community.
- Empower people affected by ALK-positive lung cancer.
- Advocate for improvements in the diagnosis, treatment and care of ALK-positive lung cancer across the UK.
- Represent the voice of the ALK-positive lung cancer community

www.alkpositive.org.uk



Lung Cancer Nursing UK (LCNUK)

LCNUK was established in 1998 to improve the understanding of the expertise and professionalism of specialist nurses amongst healthcare professionals and policy makers. With approximately 300 members, in many different roles and locations, LCNUK provides nurses with essential networking, support and education in order to optimise the patient experience.

www.lcnuk.org



ALK+ International

ALK+ International is a patient and family-led charity, created with a single mission: to improve the life expectancy for ALK+ cancer patients.

We aim to achieve this by fundraising for ALK+ research, providing grants, advocacy and education. Our team is committed to making a difference and is passionate about our goal. We believe that #TogetherWeCan further ALK+ cancer research.

www.alkinternational.org



Lung Cancer Europe
Many Faces, One Voice

www.lungcancereurope.eu

Lung Cancer Europe (LuCE) is the voice of people living with
lung cancer and their families at European level

info@lungcancereurope.eu

