MARCH 2026

11th LuCE Report on Lung Cancer

LUNG CANCER AND MENTAL HEALTH:

A Focus on Lung Cancer Type, Biomarker Group, and Cross-Country Comparisons

Experiences reported by Europeans impacted by lung cancer

Lung Cancer Europe

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Lung Cancer Europe

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Debra Montague
President of Lung Cancer Europe (LuCE)

The impact of lung cancer extends far beyond the physical, exerting a considerable impact on the emotional and psychological well-being of those affected. While these crucial aspects are life-altering for many, they have long been neglected.

The 10th LuCE Report, published in October 2025, marked a pivotal moment. It represented the largest-ever global survey on the mental health of people living with lung cancer, providing insights into the lived experiences of 2,204 patients and caregivers. Following its publication, it became clear that the data warranted further analysis. This 11th report takes a deeper look at the emotional and psychological impacts across those affected by different lung cancers and biomarkers and offers insights into the differences between the countries surveyed. In turn, this report uncovers important differences and shared challenges among those living with lung cancer in Europe to guide equitable, multifaceted care pathways.

Many participants described the emotional impact of lung cancer as a lived, day-to-day burden, with most reporting emotional difficulties after diagnosis and substantial disruption in key areas of daily life, particularly social life and lifestyle. Yet support often failed to match this need: nearly one-third had received no mental health support and few felt fully confident in coping with the emotional impact of lung cancer, highlighting an urgent need for better information, stronger communication, and easier access to psychological care.

These results reinforce a clear mandate for change: mental health support must be recognised as a core element of lung cancer care, not a secondary concern. Addressing emotional well-being is fundamental to improving health outcomes, daily experiences, and quality of life for patients and caregivers alike. This report is a call to action for healthcare providers, policymakers, and healthcare systems worldwide to focus efforts on integrating comprehensive psychological care into every phase of the lung cancer journey, from initial diagnosis through survivorship.

We thank every patient and caregiver who shared their experiences. Your insights are the foundation of this research, and your voices will help shape a more compassionate, person-centred, and responsive future for lung cancer care.

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1. ABOUT THIS REPORT

Description

Lung Cancer Europe (LuCE) is an independent non-profit organisation, committed to making lung cancer a European healthcare priority. As the voice of Europeans impacted by or at risk of lung cancer, LuCE works to ensure these individuals receive the care they need to achieve the best possible outcomes.

Generating and disseminating evidence is essential to improving care and management across the entire lung cancer community. That is why LuCE's annual research reports explore and amplify the voices of people living with lung cancer and their caregivers, in turn, raising awareness of the ongoing and emerging challenges facing our community. For the purpose of this report, the term 'caregiver' refers to informal caregivers: people who are caring for, or have cared for, someone with lung cancer, such as family, friends, or partners (not healthcare professionals).

Given our significant role in supporting the overall well-being of people living with lung cancer and the people who care for them, LuCE remains deeply committed to addressing the psychological impact and mental health challenges highlighted by our members. As such, this 11th report presents the findings of a descriptive research analysis that closely examines the emotional and psychological impact of lung cancer. It aims to gain a deeper understanding of the unique experiences of communities impacted by different types of lung cancer and specific biomarkers across Europe, thereby offering valuable insights to guide healthcare initiatives, enhance support, and make a meaningful difference to patients' and caregivers' lives.

Scan to read the 11th Lung Cancer Europe Report.

Scan me

The key objectives of this research were to:

- Further investigate the unique emotional and mental health challenges faced by people living with lung cancer and those who care for them.
- Examine potential variation in mental health experiences across European countries.
- Identify the similarities and differences in mental health experiences among people with different lung cancer types and biomarkers.
- Establish opportunities to improve psychosocial support for the lung cancer community.

Methodology

An online survey served as the primary data collection method for this research. It investigated the mental health, psychological well-being, and care needs of people impacted by lung cancer, including patients living with the disease and those providing them with care.

By conducting an online survey, LuCE was able to reach a wide and diverse population across multiple European countries. This approach also protected participants' privacy and anonymity, helping ensure they felt comfortable sharing personal or sensitive information. However, online surveys do present some limitations; for example, people without internet access, those with low levels of digital literacy, or those in poor health may not have been able to participate in the survey.

The section below outlines the project's design, detailing the step-by-step methodology for data collection, analysis, and the subsequent reporting of results.

February - March 2025

LITERATURE REVIEW

- A structured literature review informed the survey design.
- The review used online scientific databases to identify existing, relevant English-language publications.
- The criteria for inclusion focused on studies, reports, and guides related to mental health, psychological impacts, supportive care, and quality of life for individuals impacted by lung cancer.
- A comprehensive list of references is available at the end of this report.

March - May 2025

ONLINE SURVEY DESIGN

- The survey was designed by the MÁS QUE IDEAS Foundation and reviewed by the LuCE Report Working Group to ensure ease of use and accessibility.

March - May 2025

ONLINE SURVEY DESIGN

- Key features of the survey included:
  - *Format:* The survey included 43 closed and three open questions to capture both quantitative and qualitative insights.
  - *Anonymity:* No personally identifiable information was collected, ensuring all participants remained anonymous.
  - *Flexibility:* Most questions were optional; only filter questions required a response. Therefore, the response counts vary from question to question.
  - *Accessibility:* To reach a broad European audience, the survey was translated into 19 languages: Bulgarian, Croatian, Danish, Dutch, English, Finnish, French, German, Greek, Hebrew, Hungarian, Italian, Latvian, Polish, Portuguese, Romanian, Slovenian, Spanish, and Ukrainian.
  - *Clarity:* LuCE members reviewed and verified the survey translations for accuracy and clarity.

May - July 2025

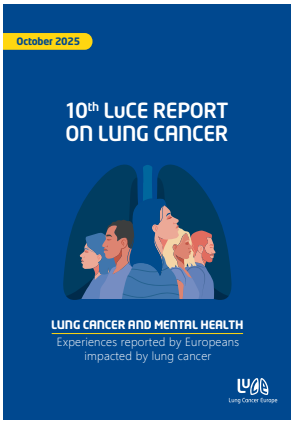
ONLINE SURVEY DISSEMINATION

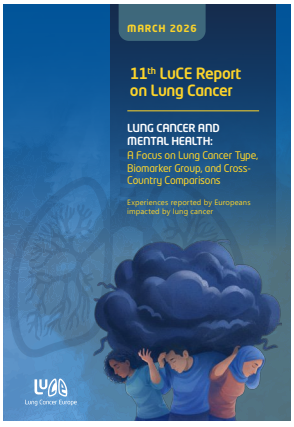
- The survey was active from 28 May to 6 July 2025.
- It was hosted on the SurveyMonkey® platform and promoted through LuCE's communication channels and its members.

July 2025 - February 2026

DATA ANALYSIS

- *Data validation:* A quality control check was performed to exclude incomplete survey submissions and those originating outside the WHO European region. Submissions were considered valid if participants completed the first two sections (a minimum of 25 questions).
- *Statistical analysis:* For the 10th report (published on 18 October 2025), analyses were conducted using SurveyMonkey® tools and Jamovi® software. Independent samples t-tests were conducted to identify statistically significant differences between groups. For the 11th report, participant responses were analysed using descriptive statistics. Furthermore, artificial intelligence (ChatGPT®) was used to assist with data analysis, interpretation of correlations and statistical outputs, and reporting in both reports.
- *Finalisation of two reports:* The analysed data were combined to produce drafts of both the 10th report and the follow-up 11th report. The 10th report was subsequently reviewed and finalised by the LuCE Report Working Group.





Participant sociodemographic and disease characteristics

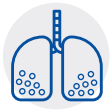
A total of 2,204 people participated in the survey, including 1,709 people living with lung cancer (77.5%) and 495 caregivers (22.5%) from 31 countries in the WHO European Region.

Most participants were women (78.3%), and the largest age group was 55–64 years (35.9%). Clinically, 70.4% of participants reported a diagnosis of non-small cell lung cancer (NSCLC) adenocarcinoma, either for themselves or the person they cared for. Stage 4 disease was reported by 56.2% of participants, and 60.7% reported a diagnosis within three years of participating in the survey. An overview of the main participant and disease characteristics are presented in Tables 1 and 2; the full characteristics are available in Annex I.

Table 1: Main sociodemographic characteristics of participants

	Sociodemographic factor	Participants (%)
GENDER	**Women** (n=1,708)	78.3
	Men (n=458)	21.0
AGE	**45-54** (n=473)	21.7
	55-64 (n=782)	35.9
	65-74 (n=528)	24.2
COUNTRY	**France** (n=379)	17.2
	UK (n=374)	17.0
	Netherlands (n=248)	11.3
EDUCATION	**Upper secondary** (n=776)	35.7
	Tertiary education (n=1,243)	57.1

Table 2: Disease characteristics of participants

	Disease characteristic	Participants (%)
 LUNG CANCER TYPE	**NSCLC adenocarcinoma** (n=1,531)	70.4
	NSCLC squamous carcinoma (n=99)	4.5
	NSCLC large cell carcinoma (n=44)	2.0
	NSCLC adenosquamous carcinoma (n=33)	1.5
	NSCLC sarcomatoid carcinoma (n=12)	0.6
	NSCLC other subtype (n=72)	3.3
	SCLC (n=140)	6.4
	Another type of lung cancer (n=87)	4.0
	Don´t know (n=158)	7.3
 BIOMARKER	**EGFR** (n=507)	23.5
	ALK (n=470)	21.8
	PD-L1 (n=152)	7.0
	KRAS (n=130)	6.0
	Other* (n=284)	13.2
	No biomarker (n=229)	10.6
	Don´t know or in process of testing (n=491)	22.7
	Has not been tested for biomarker (n=186)	8.6
 STAGE	**Stage 1–2** (n=556)	25.6
	Stage 3 (n=363)	16.7
	Stage 4 (n=1,223)	56.2
	Don´t know (n=34)	1.6
 TIME SINCE DIAGNOSIS	**Less than 1 year** (n=538)	24.5
	1 to 3 years (n=794)	36.2
	3 to 5 years (n=418)	19.1
	5 years or more (n=444)	20.2

**Includes ROS1, BRAF, MET, HER2, RET, FGFR1, CTLA-4, NRAS, NTRK, NRG1, or "other" biomarker (details provided by participants in free-text response)*

2. KEY FINDINGS

Mental health ratings were broadly positive, but lung cancer eroded mental well-being.

60.1% **rated their current mental health as 7–10 out of 10, on average (1 = very negative; 10 = very positive).**

- When asked specifically about **lung cancer's impact,** responses shifted towards **neutral or negative**, with "good" mental health falling from **60.1% (average current rating) to 30.0% (average impact rating)**. This impact was particularly evident in **small cell lung cancer (SCLC), NSCLC squamous carcinoma, and those without biomarker testing**.

Emotional difficulties were widespread, typically described as manageable, but some subgroups reported substantial disruption to their lives.

An average of 89.3% **reported emotional difficulties after diagnosis, most often occasional but manageable (average: 42.6%).**

- A higher burden was reported in **NSCLC sarcomatoid carcinoma** (although a small group, all participants reported some level of emotional difficulties that have greatly impacted daily life, with **25.0%** describing them as constant and disruptive) and among **KRAS** participants (**40.3%** reported difficulties very often with significant daily impact).

Social life and lifestyle were most consistently affected by mental health, with work and finances showing a more polarised impact.

- The mental health impact of lung cancer was felt most strongly in **social life/lifestyle** and **family life**; effects across **work/finances** were polarised, with many reporting either a **severe impact** or **no impact**.
- The most severe impact on social life/lifestyle ("very much") was most commonly reported in **NSCLC sarcomatoid carcinoma (36.4%), NSCLC squamous carcinoma (34.3%), and those without an identified biomarker** - including participants with no positive biomarker, unknown biomarker status, or no biomarker testing **(average: 22.4%)**.
- An average of **44.8%** reported their mental health affected **work/finances** "very much" or "quite a bit," again highest in **NSCLC sarcomatoid carcinoma** and those **who had not been tested for a biomarker**.

Most people felt they were coping, but few felt truly confident in managing the emotional impact of lung cancer, suggesting unmet psychosocial needs.

- Most felt **"somewhat" (average: 32.2%)** or **"quite" (average: 41.8%)** capable of managing emotional impacts.
- **"Very capable"** responses were uncommon, implying many are **getting by rather than feeling fully supported; NSCLC sarcomatoid carcinoma** again stood out, with **16.7%** reporting they felt **"not at all"** capable.

Support is uneven: many receive no support or must self-refer, and referrals to patient organisations are inconsistent.

On average,

31.0% **reported receiving no mental health support at any point in their care, and nearly 1 in 5 had to seek support independently.**

- Around **2 in 5** had **never** received a referral to a **patient/ non-profit organisation** from a healthcare professional (HCP) and a further **28.4%** with no referral sought it out themselves; only an average of **24.0%** felt emotional support from the healthcare team was **completely sufficient**.
- Groups most likely to report no referral to patient organisations (e.g., **NSCLC sarcomatoid carcinoma**, those who **did not know** their lung cancer type, and **SCLC**) were also **least likely** to seek these support services independently.

Priorities were consistent across groups: better information, symptom support, communication with HCPs, and access to mental health services.

- Across lung cancer types and biomarker groups, participants repeatedly prioritised:
  - **More information** on the disease, treatment, and care options
  - **More support** for symptoms and side effects
  - **Better communication** with healthcare professionals (HCPs)
  - **Improved access** to mental health services
- This points to shared, system-level opportunities to strengthen psychosocial care.

7 Overall mental well-being did not always align with perceived psychological impact across European countries.

- In some countries, participants reported **moderate-to-good overall mental health** while also describing lung cancer as having a **strongly negative psychological impact**; in others, **poorer overall mental health** more closely tracked with a **more negative perceived impact** of lung cancer.
- This pattern reinforces the need to assess **both overall mental well-being** and **cancer-specific psychological impact** to capture the full emotional burden experienced by people affected by lung cancer.

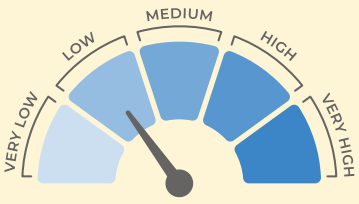
3. RESULTS

Factors to consider when reading this report

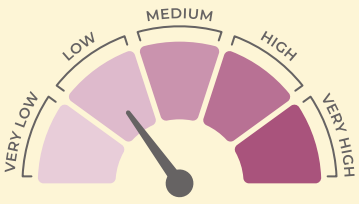
The results in sections 3.1 and 3.2 compare experiences across lung cancer types and biomarker groups. The findings should be interpreted as indicative patterns rather than definitive differences, given substantial variation in the number of participants across groups and small sample sizes. Further, participants could select more than one biomarker, meaning some individuals may be included in multiple biomarker groups. In this section, combinations of biomarkers were not analysed, and the analysis does not capture overlap between biomarker categories.

For all tables, percentages are based only on the total number of participants who answered each question. This means that participants who skipped a question are not included in the calculations. For tables that show results by lung cancer type, the percentages also exclude participants who did not report the type of lung cancer they or the person they care for has.

Please note the tones in the tables are not constant. Darker colours in the table heat maps represent responses selected by a relatively higher percentage of participants, while lighter colours represent responses selected by a relatively lower percentage.



Lung cancer type

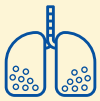


Lung cancer biomarkers

If you come across any words or phrases you don't understand, you may find it helpful to look at the list of key lung cancer terms on pages 68–70.

3.1 PARTICIPANT DEMOGRAPHICS AND DISEASE CHARACTERISTICS BY LUNG CANCER TYPE AND BIOMARKER GROUP

In this section, we explore the extent to which age, lung cancer stage, and time since diagnosis for survey participants differed by disease type and biomarker group.



Lung cancer type: You can find definitions of the different types of lung cancer mentioned in this report on pages 68–70.

Lung cancer biomarkers: A biomarker is a measurable feature (such as a protein or a gene change) that can be found in a sample of a person's blood or tissue. Doctors can test for biomarkers in the blood or tissue by sending it to a laboratory. Knowing which biomarkers a cancer is associated with can help doctors understand how the cancer behaves and which treatments may work best. You may find it helpful to look at the definitions of different biomarkers on pages 68–70.

3.1.1 PARTICIPANT AGE

Across lung cancer types, most participants were middle-aged or older adults. The majority were aged 45–74 years (81.9%; Table 3). More specifically, the most common age range was 55–64 years, with over one-third (35.8% across lung cancer types) of participants in this group.

Small differences in age profile were noted by lung cancer type. Younger adults (under 45) were the most common age group among participants impacted by SCLC (20.7%) and NSCLC squamous carcinoma (16.2%). In contrast, older adults (≥75 years) were more commonly represented among participants with NSCLC adenosquamous carcinoma (15.6%) and NSCLC large cell carcinoma (13.6%).

Table 3: Age of participants across lung cancer types

Lung cancer type	What is your age? (%)						
	18–24 (n=10)	25–34 (n=56)	35–44 (n=192)	45–54 (n=473)	55–64 (n=779)	65–74 (n=527)	75+ (n=136)
NSCLC adenocarcinoma (n=1531)	0.2	2.5	8.7	23.1	37.1	23.1	5.4
NSCLC squamous carcinoma (n=99)	0.0	3.0	13.1	24.2	26.3	26.3	7.1
NSCLC large cell carcinoma (n=44)	0.0	4.5	0.0	25.0	40.9	15.9	13.6
NSCLC adenosquamous carcinoma (n=32)	0.0	0.0	9.4	31.3	31.3	12.5	15.6
NSCLC sarcomatoid carcinoma (n=12)	0.0	0.0	0.0	8.3	58.3	25.0	8.3
NSCLC other subtype (n=72)	0.0	0.0	6.9	18.1	40.3	25.0	9.7
SCLC (n=140)	0.7	5.7	14.3	18.6	24.3	29.3	7.1
Another type of lung cancer (n=86)	2.3	2.3	9.3	14.0	41.9	26.7	3.5
I don't know (n=157)	2.5	1.9	6.4	14.6	32.5	32.5	9.6

Across biomarker groups, the age profile was concentrated in the 45–74 age range (81.8%), with the majority of participants in the 55–64 age group (36.2%; Table 4). In general, there was minimal representation among individuals aged under 45 (11.6%).

Participants in the KRAS group were slightly older, with the highest proportion in the 55–64 age category (46.2%) and relatively fewer in the younger age categories.

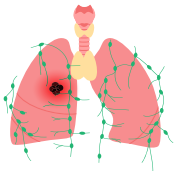
Table 4: Age of participants across biomarker groups

Biomarker group	What is your age? (%)						
	18–24 (n=15)	25–34 (n=59)	35–44 (n=207)	45–54 (n=517)	55–64 (n=875)	65–74 (n=584)	75+ (n=158)
EGFR (n=507)	0.6	0.8	7.9	19.7	38.7	25.2	7.1
ALK (n=470)	1.5	4.0	10.4	28.9	34.0	17.0	4.0
PD-L1 (n=152)	0.7	2.6	7.2	21.7	38.2	23.7	5.9
KRAS (n=130)	0.8	0.0	5.4	16.2	46.2	23.8	7.7
Other (n=255)	0.4	3.1	8.6	23.9	38.8	20.4	4.7
No biomarker (n=229)	0.0	1.7	7.0	22.3	34.1	27.5	7.4
I don't know (includes in the process of testing) (n=488)	0.4	3.3	8.0	15.4	33.4	31.1	8.4
Have not been tested for biomarker (n=184)	0.0	2.2	12.5	21.7	33.2	22.8	7.6

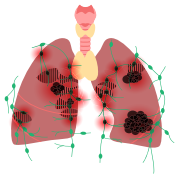
Across both lung cancer type and biomarker group, participants were predominantly middle-aged or older adults, with the majority between the ages of 45 and 74.

3.1.2 LUNG CANCER STAGE AT DIAGNOSIS

Lung Cancer Stages



Stage 1–2, or localised disease, has not spread outside the lung.



Stage 3, representing locally advanced disease, where the cancer has spread to the tissues surrounding the lungs.

Stage 4, or metastatic disease, has spread beyond the lungs to other parts of the body.

Across lung cancer types, the most frequently reported stage at diagnosis was Stage 4 (metastatic) (56.3%; Table 5), particularly among participants impacted by NSCLC adenocarcinoma (61.0%), a type of NSCLC other than those listed in the survey options (defined as 'other' NSCLC subtypes) (58.3%), and NSCLC adenosquamous carcinoma (54.5%).

Diagnosis at an earlier stage (Stage 1–2, localised disease) was reported by 25.5% of participants across cancer subtypes, highest among those reporting NSCLC sarcomatoid carcinoma (41.7%). Stage 3 (locally advanced disease) was generally the least common stage at diagnosis, reported by 16.6% of participants across lung cancer types.

Overall, the proportion of participants who did not know their stage at diagnosis was low (1.6%), but was higher (8.3%) among those who did not know their lung cancer type.

Table 5: Stage at diagnosis across lung cancer types

Lung cancer type	Of the following options, which defined the situation at diagnosis? (%)			
	Stage 1–2 (n=554)	Stage 3 (n=361)	Stage 4 (n=1221)	I don't know (n=34)
NSCLC adenocarcinoma (n=1527)	22.3	15.7	61.0	1.0
NSCLC squamous carcinoma (n=99)	33.3	26.3	40.4	0.0
NSCLC large cell carcinoma (n=44)	36.4	20.5	43.2	0.0
NSCLC adenosquamous carcinoma (n=33)	27.3	18.2	54.5	0.0
NSCLC sarcomatoid carcinoma (n=12)	41.7	16.7	41.7	0.0
NSCLC other subtype (n=72)	23.6	18.1	58.3	0.0
SCLC (n=140)	32.9	17.1	47.9	2.1
Another type of lung cancer (n=86)	37.2	19.8	40.7	2.3
I don't know (n=157)	35.7	15.3	40.8	8.3

Stage 4 (metastatic) disease was also most common across biomarker groups (56.6%; Table 6). This advanced stage was notably prevalent in participants reporting ALK (76.1%), EGFR (68.6%), and 'other' biomarkers (63.9%). For those participants reporting no identified biomarker, Stage 4 disease at diagnosis was less common (29.7%), and almost half (48.0%) stated the disease was localised (Stage 1–2).

For participants who did not know their biomarker status or who reported an absence of testing, the distribution was mixed, with a high proportion citing Stage 1–2 (37.9% and 38.7%, respectively) and Stage 4 (41.2% and 38.2%, respectively) at diagnosis.

These patterns may be explained by how often biomarker testing is performed across different care settings and at different disease stages. However, as patient and caregiver recall and awareness of biomarker status and testing could also influence responses, these results should be interpreted with caution.

Table 6: Stage at diagnosis across biomarker groups

Biomarker group	Of the following options, which defined the situation at diagnosis? (%)			
	Stage 1–2 (n=605)	Stage 3 (n=406)	Stage 4 (n=1366)	I don't know (n=38)
EGFR (n=507)	19.1	12.0	68.6	0.2
ALK (n=468)	8.8	14.1	76.1	1.1
PD-L1 (n=152)	14.5	27.6	57.9	0.0
KRAS (n=130)	24.6	20.8	54.6	0.0
Other (n=255)	18.0	15.7	63.9	2.4
No biomarker (n=229)	48.0	20.5	29.7	1.7
I don't know (includes in the process of testing) (n=488)	37.9	17.6	41.2	3.3
Have not been tested for biomarker (n=186)	38.7	19.9	38.2	3.2

Regardless of lung cancer type or biomarker group, Stage 4 (metastatic) disease was most commonly reported at diagnosis, highlighting that many patients entered the care pathway only after the cancer had progressed beyond the lungs.

3.1.3 TIME SINCE LUNG CANCER DIAGNOSIS

Overall, survey responses predominantly reflect the early-to-mid survivorship period, with over one-third of participants (35.9%) reporting 1–3 years since diagnosis across lung cancer types (Table 7).

Almost one-quarter of participants (24.4%) reported being within the first year of diagnosis. This was most common among those impacted by SCLC (32.9%), 'another type' of lung cancer (31.4%), and those who did not know their lung cancer type (36.7%). In contrast, fewer participants affected by NSCLC sarcomatoid carcinoma reported a diagnosis within the past year (8.3%).

Across lung cancer types, the number of participants reporting 3–5 years (19.1%) or ≥5 years since diagnosis (20.2%) was generally lower, apart from those affected by NSCLC sarcomatoid carcinoma, who were most likely to report being ≥5 years post-diagnosis (33.3%; over 10.0% higher than other cancer types). This suggests a greater representation of longer-term survivorship in this group.

Table 7: Time since diagnosis across lung cancer types

Lung cancer type	Approximately, how much time has passed since the lung cancer diagnosis? (%)			
	Less than one year (n=530)	1–3 years (n=787)	3–5 years (n=415)	5 years or more (n=439)
NSCLC adenocarcinoma (n=1527)	22.9	35.5	19.6	21.9
NSCLC squamous carcinoma (n=99)	23.2	41.4	20.2	15.2
NSCLC large cell carcinoma (n=44)	15.9	45.5	22.7	15.9
NSCLC adenosquamous carcinoma (n=33)	15.2	48.5	24.2	12.1
NSCLC sarcomatoid carcinoma (n=12)	8.3	33.3	25.0	33.3
NSCLC other subtype (n=72)	18.1	38.9	22.2	20.8
SCLC (n=140)	32.9	37.1	18.6	11.4
Another type of lung cancer (n=86)	31.4	36.0	12.8	19.8
I don't know (n=158)	36.7	33.5	13.3	16.5

As with lung cancer type, the most frequently reported diagnosis timeframe across all biomarker groups was 1–3 years (35.6%; Table 8). This timeframe was especially common among participants reporting EGFR (39.3%), KRAS (38.5%), and 'other' (38.0%) biomarkers.

Across biomarker groups, around one-quarter of participants (24.2%) were less than one year post-diagnosis. The higher prevalence among those who were unsure of the biomarker status (32.4%) or reported no biomarker testing (32.3%) suggests that patients with a more recent diagnosis may still be undergoing, or awaiting, biomarker testing.

The proportion of participants reporting 3–5 years since diagnosis was relatively consistent across biomarker groups (19.1%; range: 16.1–23.0%). In contrast, slightly greater variation was noted in those participants reporting five or more years since diagnosis (21.2%; range: 16.6%–26.7%). These differences may reflect variation in survivorship patterns and in levels of awareness of biomarker testing.

Table 8: Time since diagnosis across biomarker groups

Biomarker group	Approximately, how much time has passed since the lung cancer diagnosis? (%)			
	Less than one year (n=584)	1–3 years (n=859)	3–5 years (n=461)	5 years or more (n=512)
EGFR (n=507)	24.3	39.3	19.9	16.6
ALK (n=469)	16.6	34.1	23.0	26.2
PD-L1 (n=152)	21.7	36.2	19.7	22.4
KRAS (n=130)	20.0	38.5	19.2	22.3
Other (n=255)	16.1	38.0	19.2	26.7
No biomarker (n=229)	28.4	32.8	16.2	22.7
I don't know (includes in the process of testing) (n=488)	32.4	34.4	16.6	16.6
Have not been tested for biomarker (n=186)	32.3	29.6	16.1	22.0

Across lung cancer type and biomarker group, most participants reported 1–3 years having passed since the diagnosis, meaning the findings mainly reflect people in the early to middle stages of survivorship. Some groups, including NSCLC sarcomatoid carcinoma and ALK or 'other' biomarkers, had a higher proportion of participants who were five or more years after diagnosis.

While the 10th LuCE report offers more detail on the differences between participant demographics and disease characteristics, the findings showed that those with Stage 3–4 lung cancer, as well as younger participants (aged 18–64), reported a greater negative impact of the disease on their mental health than those with Stage 1–2 and older participants (aged 65 or older).[1] This was particularly evident in the impact on work and finances, and these individuals were also more likely to have been diagnosed with an anxiety disorder (either before or after diagnosis).[1]

Younger participants also reported more frequent and severe emotional disruptions to daily life following a lung cancer diagnosis, as well as greater impacts on social life and lifestyle, compared with older participants, and lower capability to manage the emotional impact of the disease.[1]

3.2 MENTAL HEALTH AMONG PEOPLE IMPACTED BY LUNG CANCER: DIFFERENCES BY LUNG CANCER TYPE AND BIOMARKER GROUP

Compared with other cancers, lung cancer is linked to greater physical hardship, symptom distress, and disease burden, and has been described as among the most physically and emotionally challenging cancer diagnoses.[2,3] This section explores differences in mental health among people impacted by lung cancer, depending on cancer type and biomarker group.

3.2.1 PARTICIPANTS' MENTAL HEALTH AT THE TIME OF THE SURVEY

Regardless of lung cancer type, most participants rated their mental health as good at the time of the survey, with scores ranging from 7 to 10 out of 10 (60.1%; Table 9). Participants impacted by NSCLC adenosquamous carcinoma (69.7%) and NSCLC adenocarcinoma (62.1%) were most likely to report these higher scores.

Overall, fewer participants (8.9%) scored their current mental health as poor (1–3 out of 10), ranging from 6.8% to 19.2% across lung cancer types. Poor mental health at the time of the survey was reported most often by participants impacted by NSCLC squamous carcinoma (19.2%), followed by those with NSCLC sarcomatoid carcinoma (16.7%) and SCLC (15.0%), suggesting increased psychological vulnerability in these individuals.

Table 9: Mental health today across lung cancer types

Lung cancer type	How would you rate your mental health today? Please rate it from 1 to 10, where 1 is 'very poor', and 10 is 'excellent' (%)		
	Poor (1–3) (n=193)	Moderate (4–6) (n=672)	Good (7–10) (n=1304)
NSCLC adenocarcinoma (n=1526)	7.2	30.7	62.1
NSCLC squamous carcinoma (n=99)	19.2	27.3	53.5
NSCLC large cell carcinoma (n=44)	6.8	36.4	56.8
NSCLC adenosquamous carcinoma (n=33)	9.1	21.2	69.7
NSCLC sarcomatoid carcinoma (n=12)	16.7	41.7	41.7
NSCLC other subtype (n=72)	12.5	27.8	59.7
SCLC (n=140)	15.0	40.0	45.0
Another type of lung cancer (n=87)	8.0	33.3	58.6
I don't know (n=156)	12.2	28.2	59.6

Overall, participants' mental health scores at the time of the survey were similar across different biomarker groups (Table 10). Most (60.1%) rated their mental health as good (7–10 out of 10), 31.0% of participants scored their mental health as moderate (4–6 out of 10), and a smaller number (8.9%) rated it as poor (1–3 out of 10).

Participants who reported EGFR, ALK, PD-L1, or 'other' biomarkers had similar mental health scores. In each of these groups, 62.5–68.4% scored their mental health as good, 26.2–31.6% as moderate, and 5.3–6.7% as poor. In comparison, slightly more participants in the KRAS group reported poor mental health (13.8%).

Participants who reported no biomarker testing reported the poorest mental health overall. This group had the highest proportion of poor scores (17.2%) and the lowest proportion of good scores (44.6%) among all biomarker groups, suggesting a more vulnerable psychological profile that may, in part, reflect uncertainty associated with not having biomarker information.

Table 10: Mental health today across biomarker groups

Biomarker group	How would you rate your mental health today? Please rate it from 1 to 10, where 1 is 'very poor', and 10 is 'excellent' (%)		
	Poor (1–3) (n=215)	Moderate (4–6) (n=747)	Good (7–10) (n=1447)
EGFR (n=504)	6.5	31.0	62.5
ALK (n=469)	5.3	26.2	68.4
PD-L1 (n=152)	5.9	31.6	62.5
KRAS (n=130)	13.8	28.5	57.7
Other (n=253)	6.7	30.4	62.8
No biomarker (n=228)	10.1	35.1	54.8
I don't know (includes in the process of testing) (n=487)	11.9	31.8	56.3
Have not been tested for biomarker (n=186)	17.2	38.2	44.6

When asked to rate their mental health at the time of the survey on a scale from 1 to 10, most participants reported high scores (7–10). However, there were meaningful differences across lung cancer type and biomarker group.

3.2.2 IMPACT OF LUNG CANCER ON MENTAL HEALTH

When asked about the impact of living with lung cancer on their mental health, participants reported a predominantly negative-to-neutral impact, with the majority of scores falling within the negative (scores 1–3) or neutral (scores 4–6) categories (32.1% and 38.1%, respectively) across most lung cancer types (Table 11).

The number of participants reporting a negative impact varied across lung cancer types. Negative scores were most common among participants impacted by SCLC (40.3%), followed by NSCLC squamous carcinoma (39.8%) and NSCLC adenosquamous carcinoma (36.4%) and least common among participants impacted by 'another type' of lung cancer (22.4%).

Neutral impact scores were also frequently reported, lowest among those impacted by NSCLC squamous carcinoma (27.6%) and highest among those impacted by NSCLC sarcomatoid carcinoma (50.0%).

Overall, positive impact scores (7–10) were slightly less common, reported by 29.7% of participants across lung cancer types. The highest proportions were observed among participants reporting 'another type' of lung cancer (38.8%), those who did not know their lung cancer type (36.1%), and those impacted by NSCLC squamous carcinoma (32.7%). By contrast, NSCLC sarcomatoid carcinoma was linked to the lowest proportion of positive scores (16.7%).

Table 11: Impact of lung cancer on mental health across lung cancer types

Lung cancer type	How would you rate the impact of lung cancer on your mental health? Please rate it from 1 to 10, where 1 is 'very negative', and 10 is 'very positive' (%)		
	Negative (1–3) (n=694)	Neutral (4–6) (n=823)	Positive (7–10) (n=624)
NSCLC adenocarcinoma (n=1521)	31.5	39.5	29.0
NSCLC squamous carcinoma (n=98)	39.8	27.6	32.7
NSCLC large cell carcinoma (n=44)	34.1	38.6	27.3
NSCLC adenosquamous carcinoma (n=33)	36.4	39.4	24.2
NSCLC sarcomatoid carcinoma (n=12)	33.3	50.0	16.7
NSCLC other subtype (n=72)	34.7	37.5	27.8
SCLC (n=139)	40.3	32.4	27.3
Another type of lung cancer (n=85)	22.4	38.8	38.8
I don't know (n=155)	29.0	34.8	36.1

Across biomarker groups, participant scoring of the impact of lung cancer on mental health was distributed relatively evenly across the negative (1–3), neutral (4–6), and positive (7–10) categories (31.9%, 37.8%, and 30.3%, respectively; Table 12).

Participants who reported no biomarker testing showed the most negative pattern overall. This group reported the highest proportion of negative scores (43.2%) and the lowest proportion of positive scores (22.2%), suggesting that they experience the greatest mental health burden among all biomarker groups. In contrast, participants in the KRAS group reported the highest proportion of positive scores (33.8%), although differences between biomarker groups were generally modest.

Table 12: Impact of lung cancer on mental health across biomarker groups

Biomarker group	How would you rate the impact of lung cancer on your mental health? Please rate it from 1 to 10, where 1 is 'very negative', and 10 is 'very positive' (%)		
	Negative (1–3) (n=765)	Neutral (4–6) (n=908)	Positive (7–10) (n=728)
EGFR (n=504)	30.6	38.9	30.6
ALK (n=469)	34.5	36.7	28.8
PD-L1 (n=150)	30.0	39.3	30.7
KRAS (n=130)	33.1	33.1	33.8
Other (n=253)	29.2	38.3	32.4
No biomarker (n=227)	27.8	38.8	33.5
I don't know (includes in the process of testing) (n=483)	29.8	39.1	31.1
Have not been tested for biomarker (n=185)	43.2	34.6	22.2

Lung cancer had a mixed impact on mental health overall. The most negative effects were reported by people affected by SCLC, NSCLC squamous carcinoma, and by participants without biomarker testing.

3.2.3 IMPACT OF EMOTIONAL DIFFICULTIES ON DAILY LIFE

Following their lung cancer diagnosis, most participants (89.3%) reported experiencing emotional difficulties that greatly affected daily life, and the extent of this burden varied by lung cancer type (Table 13). The percentage of participants who stated they had not experienced emotional difficulties (10.7%; range: 0.0% to 30.3%) also varied by lung cancer type.

Across lung cancer types, the most common response was that participants occasionally experienced emotional difficulties that greatly impacted daily life, but were able to manage them (43.1%). Participants impacted by NSCLC sarcomatoid carcinoma reported a particularly high emotional burden: although a small group (n=12), all participants reported some level of emotional difficulties, and 25.0% described these as constant and severely disruptive to daily life. In contrast, participants impacted by NSCLC adenosquamous carcinoma (n=33) reported a comparatively lower emotional burden, with 30.3% reporting no significant emotional difficulties and none (0.0%) reporting constant, severely disruptive difficulties.

Table 13: Prevalence of emotional difficulties impacting daily life across lung cancer types

Lung cancer type	Prevalence of emotional difficulties with a great impact on daily life (%)				
	Yes, almost constantly, and they have severely disrupted my daily life (n=161)	Yes, very often, and they have significantly impacted my daily life (n=318)	Yes, frequently, and they have somewhat affected my daily life (n=524)	Yes, occasionally, but I have been able to manage them (n=935)	No, I have not experienced significant emotional difficulties (n=232)
NSCLC adenocarcinoma (n=1529)	6.5	14.5	24.7	44.7	9.7
NSCLC squamous carcinoma (n=99)	13.1	22.2	21.2	28.3	15.2
NSCLC large cell carcinoma (n=43)	2.3	16.3	32.6	39.5	9.3
NSCLC adenosquamous carcinoma (n=33)	0.0	9.1	27.3	33.3	30.3
NSCLC sarcomatoid carcinoma (n=12)	25.0	0.0	33.3	41.7	0.0
NSCLC other subtype (n=72)	9.7	12.5	20.8	44.4	12.5
SCLC (n=139)	10.1	18.7	25.9	37.4	7.9
Another type of lung cancer (n=86)	10.5	18.6	23.3	40.7	7.0
I don't know (n=157)	9.6	8.9	17.2	45.9	18.5

Across biomarker groups, participants most often reported experiencing occasional emotional difficulties that greatly impacted daily life but were generally able to manage them (42.2%; Table 14). This was noted most often by participants reporting ALK biomarkers (48.7%), and least often by those reporting KRAS biomarkers (20.9%). KRAS was the only biomarker group where this was not the most common response.

In the KRAS group, the most frequent response was "very often, with a significant impact on daily life" (40.3%), which was the highest proportion across all biomarker groups. The KRAS group also had the lowest proportion of participants reporting no significant emotional difficulties (6.2%). Together, these findings suggest that participants in the KRAS group experienced meaningful emotional difficulties more often than those in other biomarker groups.

Table 14: Prevalence of emotional difficulties impacting daily life across biomarker groups

Biomarker group	Prevalence of emotional difficulties with a great impact on daily life (%)				
	Yes, almost constantly, and they have severely disrupted my daily life (n=177)	Yes, very often, and they have significantly impacted my daily life (n=389)	Yes, frequently, and they have somewhat affected my daily life (n=570)	Yes, occasionally, but I have been able to manage them (n=1017)	No, I have not experienced significant emotional difficulties (n=259)
EGFR (n=507)	5.7	13.8	23.7	45.4	11.4
ALK (n=470)	5.7	12.1	23.6	48.7	9.8
PD-L1 (n=152)	4.6	17.1	21.1	44.7	12.5
KRAS (n=129)	9.3	40.3	23.3	20.9	6.2
Other (n=255)	3.9	18.8	23.9	45.5	7.8
No biomarker (n=228)	10.5	15.8	26.3	35.5	11.8
I don't know (includes in the process of testing (n=485)	9.1	13.6	22.9	41.4	13.0
Have not been test for biomarker (n=186)	12.9	18.3	24.2	34.9	9.7

Since the lung cancer diagnosis, many participants reported experiencing emotional difficulties that affected daily life, most often at an occasional but manageable level.

3.2.4 IMPACT OF MENTAL HEALTH ON FAMILY, SOCIAL LIFE, AND FINANCES

Across lung cancer types, social life and lifestyle emerged as the areas of daily life most affected by mental health, with relatively few participants selecting "not at all" as the reported impact. Participants affected by NSCLC sarcomatoid carcinoma reported the most severe impacts across all three life areas.

Family Life

The impact of mental health on family life was clear across all lung cancer types. Most participants indicated that their mental health harmed their family life "somewhat" (25.2%), "a little bit" (24.0%) or "quite a bit" (23.8%) (Table 15).

Family life was most severely affected among participants in the NSCLC sarcomatoid carcinoma group, with 41.7% reporting the highest level of impact ("very much"), considerably higher than the level reported across all cancer types (12.4%).

Reports of no family impact ("not at all") were generally less common (14.6%), but were highest among the NSCLC adenosquamous carcinoma group (21.2%).

Table 15: Impact of mental health on family life across lung cancer types

Lung cancer type	Reported impact of mental health on family (%)				
	Very much (n=268)	Quite a bit (n=512)	Somewhat (n=542)	A little bit (n=516)	Not at all (n=315)
NSCLC adenocarcinoma (n=1513)	10.0	22.8	26.1	25.6	15.5
NSCLC squamous carcinoma (n=98)	19.4	23.5	22.4	21.4	13.3
NSCLC large cell carcinoma (n=44)	11.4	27.3	20.5	31.8	9.1
NSCLC adenosquamous carcinoma (n=33)	18.2	24.2	27.3	9.1	21.2
NSCLC sarcomatoid carcinoma (n=12)	41.7	16.7	33.3	0.0	8.3
NSCLC other subtype (n=71)	16.9	23.9	23.9	18.3	16.9
SCLC (n=140)	19.3	32.9	18.6	19.3	10.0
Another type of lung cancer (n=86)	23.3	23.3	22.1	19.8	11.6
I don't know (n=156)	14.1	25.0	26.3	21.8	12.8

Social life and lifestyle

Most participants, regardless of lung cancer type, reported that their social life and lifestyle had been negatively impacted by their mental health. Only a small proportion (9.2%) reported no impact ("not at all"), suggesting that social life and lifestyle are particularly vulnerable to mental health impacts among the patients and caregivers surveyed (Table 16).

The most severe impact on social life and lifestyle ("very much") was most commonly reported by participants in the NSCLC sarcomatoid carcinoma (36.4%) and NSCLC squamous carcinoma (34.3%) groups. For all other lung cancer types, the impact was reported as less severe, more commonly affecting them "quite a bit" (28.0%).

Table 16: Impact of mental health on social life across lung cancer types

Lung cancer type	Reported impact of mental health on social life/lifestyle (%)				
	Very much (n=407)	Quite a bit (n=627)	Somewhat (n=505)	A little bit (n=418)	Not at all (n=199)
NSCLC adenocarcinoma (n=1518)	16.9	28.9	24.4	20.2	9.7
NSCLC squamous carcinoma (n=99)	34.3	26.3	11.1	19.2	9.1
NSCLC large cell carcinoma (n=44)	13.6	34.1	20.5	20.5	11.4
NSCLC adenosquamous carcinoma (n=32)	18.8	34.4	28.1	9.4	9.4
NSCLC sarcomatoid carcinoma (n=11)	36.4	9.1	18.2	18.2	18.2
NSCLC other subtype (n=72)	16.7	31.9	26.4	15.3	9.7
SCLC (n=140)	25.0	31.4	21.4	15.7	6.4
Another type of lung cancer (n=86)	26.7	29.1	26.7	8.1	9.3
I don't know (n=154)	20.1	28.6	20.8	24.7	5.8

Finances and work

Across all lung cancer types, almost half of participants (44.8%) reported that their mental health affected their finances and work either "very much" or "quite a bit" (Table 17). However, when looking at the different groups, the impact appears to be quite polarised. The NSCLC sarcomatoid carcinoma group reported the greatest impact on finances, with 63.6% selecting "very much" and none (0.0%) selecting "not at all." For these participants, finances and work were the most severely affected of the three aspects of daily life.

In contrast, participants impacted by 'other' NSCLC subtypes reported the lowest financial impact, with only 12.7% selecting "very much" and the highest proportion selecting "not at all" (32.4%).

Table 17: Impact of mental health on finances and work across lung cancer types

Lung cancer type	Reported impact of mental health on finances/work (%)				
	Very much (n=548)	Quite a bit (n=405)	Somewhat (n=341)	A little bit (n=348)	Not at all (n=483)
NSCLC adenocarcinoma (n=1497)	25.7	19.3	14.7	17.4	23.0
NSCLC squamous carcinoma (n=97)	30.9	17.5	15.5	13.4	22.7
NSCLC large cell carcinoma (n=44)	27.3	22.7	18.2	13.6	18.2
NSCLC adenosquamous carcinoma (n=32)	28.1	21.9	21.9	15.6	12.5
NSCLC sarcomatoid carcinoma (n=11)	63.6	18.2	9.1	9.1	0.0
NSCLC other subtype (n=71)	12.7	16.9	21.1	16.9	32.4
SCLC (n=139)	27.3	19.4	20.9	12.2	20.1
Another type of lung cancer (n=83)	28.9	20.5	14.5	14.5	21.7
I don't know (n=151)	23.2	15.9	22.5	14.6	23.8

Family life

When asked about the impact of their mental health on family life, most participants across all biomarker groups selected the responses "quite a bit" (23.9%), "somewhat" (25.0%), and "a little bit" (24.1%), suggesting a low-to-moderate impact of mental health on family life (Table 18). However, participants reporting no biomarker testing (17.9%) and those unsure of the biomarker group (17.0%) were more likely to report a severe impact ("very much").

Overall, 14.9% of participants said that the lung cancer diagnosis had no impact at all on their family life. This response was least common among participants who reported no identified biomarker or were unsure of the biomarker profile (both 12.9%) and most common in the KRAS group (22.7%). The KRAS group also reported the lowest level of severe impact, suggesting that people impacted by KRAS-positive lung cancer experience less impact on family life.

Table 18: Impact of mental health on family life across biomarker groups

Biomarker group	Reported impact of mental health on family (%)				
	Very much (n=288)	Quite a bit (n=572)	Somewhat (n=597)	A little bit (n=576)	Not at all (n=357)
EGFR (n=504)	8.9	21.6	25.6	27.0	16.9
ALK (n=465)	11.2	22.6	25.4	27.3	13.5
PD-L1 (n=151)	7.3	23.8	27.8	25.8	15.2
KRAS (n=128)	4.7	26.6	26.6	19.5	22.7
Other (n=251)	12.7	25.5	23.1	23.5	15.1
No biomarker (n=225)	12.0	27.1	25.8	22.2	12.9
I don't know (includes in the process of testing) (n=482)	17.0	24.5	23.4	22.2	12.9
Have not been tested for biomarker (n=184)	17.9	24.5	24.5	17.9	15.2

Social life and lifestyle

Social life was the most commonly affected domain of daily life, with few participants (9.3%) reporting that their mental health had no impact (Table 19).

Overall, almost one-fifth of participants (18.7%) said that their social life and lifestyle were severely affected ("very much"). This response was most common among those reporting an unknown biomarker status (23.3%) and those reporting no biomarker testing (23.1%), suggesting greater social disruption where biomarkers are unknown or not tested for.

Participants across biomarker groups reported their social life to be "quite" impacted by their mental health (29.3%), highest in the KRAS group (36.2%). Together, these data indicate a moderate impact on social life across biomarker groups.

Table 19: Impact of mental health on social life across biomarker groups

Biomarker group	Reported impact of mental health on social life/lifestyle (%)				
	Very much (n=447)	Quite a bit (n=703)	Somewhat (n=553)	A little bit (n=471)	Not at all (n=222)
EGFR (n=500)	15.6	27.0	24.0	24.0	9.4
ALK (n=467)	16.5	28.7	24.4	19.1	11.3
PD-L1 (n=151)	17.9	31.1	23.2	18.5	9.3
KRAS (n=130)	17.7	36.2	17.7	19.2	9.2
Other (n=255)	15.7	30.6	25.9	19.2	8.6
No biomarker (n=227)	20.7	25.6	26.4	18.9	8.4
I don't know (includes in the process of testing) (n=480)	23.3	30.2	19.4	18.5	8.5
Have not been tested for biomarker (n=186)	23.1	31.7	22.6	15.1	7.5

Finances and work

Mental health was reported as impacting finances and work "very much" or "quite a bit" by 25.7% and 19.1% of participants across all biomarker groups, respectively (Table 20). The greatest impact of mental health on finances and work was reported by participants who had not been tested for a biomarker (34.6% reported their finances were impacted "very much"). Overall, around one in five participants (22.7%) did not experience any impact of their mental health on their finances or work.

Table 20: Impact of mental health on finances and work across biomarker groups

Biomarker group	Reported impact of mental health on finances/work (%)				
	Very much (n=606)	Quite a bit (n=452)	Somewhat (n=379)	A little bit (n=388)	Not at all (n=537)
EGFR (n=500)	23.0	20.0	15.6	16.8	24.6
ALK (n=462)	25.3	17.1	18.8	16.0	22.7
PD-L1 (n=151)	26.5	21.9	14.6	14.6	22.5
KRAS (n=128)	28.9	21.1	9.4	16.4	24.2
Other (n=252)	27.0	18.3	16.3	21.0	17.5
No biomarker (n=219)	28.8	21.0	14.6	15.1	20.5
I don't know (includes in the process of testing) (n=471)	22.1	20.2	16.6	16.8	24.4
Have not been tested for biomarker (n=179)	34.6	14.5	16.2	12.3	22.3

Across all biomarker groups, the impact of mental health was generally low-to-moderate on family life and moderate on social life and lifestyle. As with lung cancer types, reports of financial and work impacts were polarised, with most participants reporting either severe financial burdens or none at all.

Mental health impacted participants' daily life, including their family life, social life, and finances. For some participants, these impacts were severe. Social life and lifestyle were most consistently affected across lung cancer and biomarker types, while financial impacts were more mixed.

3.2.5 COPING WITH THE EMOTIONAL IMPACT OF LUNG CANCER

Across lung cancer types, most participants (41.7%) reported feeling "quite" capable of managing the emotional impact of their disease (Table 21). This was most common among those impacted by 'other' NSCLC subtypes (47.9%), NSCLC squamous carcinoma (44.4%), and NSCLC adenocarcinoma (43.3%). In contrast, participants impacted by NSCLC sarcomatoid carcinoma reported the lowest confidence, with only 16.7% stating they felt "quite" capable.

There was wide variation in participants feeling "somewhat" capable across lung cancer types (32.5%; range: 25.4–50.0%). Participants reporting feeling "very" capable were slightly dominated by those unsure of the lung cancer type (18.7%) and those impacted by NSCLC adenosquamous carcinoma (18.2%).

Only a minority reported feeling "not at all" capable across lung cancer types (2.7%). However, NSCLC sarcomatoid carcinoma was a notable outlier, with 16.7% reporting they were "not at all" capable of managing the emotional challenges associated with lung cancer.

Table 21: Perceived ability to manage the emotional impact of lung cancer across lung cancer types

Lung cancer type	To what extent have you felt capable of managing the emotional repercussions of lung cancer? (%)				
	Very much (n=304)	Quite a bit (n=904)	Somewhat (n=704)	A little bit (n=196)	Not at all (n=58)
NSCLC adenocarcinoma (n=1525)	13.7	43.3	31.9	8.8	2.2
NSCLC squamous carcinoma (n=99)	9.1	44.4	26.3	14.1	6.1
NSCLC large cell carcinoma (n=44)	13.6	40.9	40.9	4.5	0.0
NSCLC adenosquamous carcinoma (n=33)	18.2	42.4	33.3	3.0	3.0
NSCLC sarcomatoid carcinoma (n=12)	16.7	16.7	50.0	0.0	16.7
NSCLC other subtype (n=71)	11.3	47.9	25.4	11.3	4.2
SCLC (n=140)	17.1	31.4	37.1	12.9	1.4
Another type of lung cancer (n=87)	12.6	33.3	43.7	10.3	0.0
I don't know (n=155)	18.7	37.4	31.0	6.5	6.5

Across biomarker groups, most participants reported feeling "quite" capable of managing the emotional effects of lung cancer (41.9%) (Table 22). This was most common among participants in the PD-L1 (49.0%), 'other' biomarkers (46.7%), and KRAS (45.0%) groups.

Feeling "somewhat" capable was also commonly reported (31.9%), particularly among participants in the ALK (33.5%) and EGFR groups (33.4%). The proportion reporting feeling "very" capable was relatively similar across biomarker groups (14.5%; range: 12.6–16.7%), with the highest values seen in the no biomarker (16.7%) and 'other' biomarker (16.1%) groups.

> *Fear of inability to function normally as a parent, spouse, employee.*

> *Seeing my family suffer emotionally is harder than the disease itself.*

Table 22: Perceived ability to manage the emotional impact of lung cancer across biomarker groups

Biomarker group	To what extent have you felt capable of managing the emotional repercussions of lung cancer? (%)				
	Very much (n=349)	Quite a bit (n=1009)	Somewhat (n=769)	A little bit (n=213)	Not at all (n=68)
EGFR (n=506)	14.0	40.9	33.4	8.9	2.8
ALK (n=469)	12.6	43.3	33.5	8.7	1.9
PD-L1 (n=151)	15.2	49.0	25.8	7.3	2.6
KRAS (n=129)	13.2	45.0	29.5	7.0	5.4
Other (n=255)	16.1	46.7	27.8	7.1	2.4
No biomarker (n=228)	16.7	38.2	33.3	9.2	2.6
I don't know (includes in the process of testing) (n=487)	14.8	39.4	32.2	9.7	3.9
Have not been tested for biomarker (n=183)	15.3	37.7	33.9	11.5	1.6

Most participants reported feeling reasonably capable of managing the emotional effects of lung cancer, while relatively fewer felt very confident in their ability to manage them. These findings highlight the need for greater psychological support and targeted interventions for individuals affected by lung cancer.

> *People disappeared from my life after the diagnosis. I feel abandoned.*

> *Even when surrounded by others, I feel completely alone.*

3.2.6 HEALTHCARE FACTORS IMPACTING MENTAL HEALTH

A substantial majority of participants identified at least one aspect of their care or treatment journey that influenced their well-being (Table 23). The healthcare-related issues most frequently reported as having the greatest impact on mental health across lung cancer types were receiving the diagnosis (selected by 63.6% of participants) and managing physical symptoms or treatment side effects (45.6%). When looking more closely at these factors, the impact of receiving the diagnosis was highest among participants with 'other' NSCLC subtypes (79.2%) and NSCLC sarcomatoid carcinoma (75.0%). Managing symptoms or side effects was most commonly selected by those impacted by NSCLC adenosquamous carcinoma (51.5%) and 'other' NSCLC subtypes (50.0%).

Other commonly reported issues impacting mental health included receiving additional news beyond the initial diagnosis (39.5% of participants), the diagnostic process (32.7%), and undergoing treatment (24.1%).

Challenges related to healthcare delivery were reported less often overall, but were notable in specific lung cancer types. Waiting times were a key concern among participants impacted by SCLC (35.0%) and 'another type' of lung cancer (32.6%). Difficulties communicating with healthcare professionals were also reported across lung cancer types (17.8%), with the highest proportions among those impacted by NSCLC squamous carcinoma (29.3%) and NSCLC large cell carcinoma (27.3%).

Table 23: Healthcare-related issues with the greatest impact on mental health across lung cancer types

Lung cancer type	Which of the following healthcare-related issues has had the greatest impact on your mental health? (Please, select all that apply) (%)													
	The diagnostic process (n=709)	Receiving the lung cancer diagnosis (n=1381)	Receiving additional news beyond the diagnosis (prognosis, recurrence, etc.) (n=857)	Attending medical consultations (n=347)	Undergoing treatment (n=523)	Facing barriers to accessing treatments or care (n=329)	Waiting times (n=586)	Lack of trust in the medical team (n=235)	Difficulties communicating with healthcare professionals (n=386)	Accessing information about lung cancer (n=179)	Difficulties with health insurance (n=156)	Managing physical symptoms or side effects (n=990)	None (n=79)	Other (please specify) (n=83)
NSCLC adeno carcinoma (n=1528)	34.2	65.2	42.1	16.2	22.8	14.4	26.9	10.5	17.1	7.7	7.3	47.1	3.2	4.2
NSCLC squamous carcinoma (n=99)	36.4	57.6	42.4	26.3	35.4	16.2	27.3	17.2	29.3	12.1	7.1	43.4	4.0	4.0
NSCLC large cell carcinoma (n=44)	38.6	54.5	25.0	18.2	34.1	22.7	18.2	15.9	27.3	6.8	4.5	43.2	6.8	2.3
NSCLC adenosquamous carcinoma (n=33)	27.3	57.6	30.3	18.2	15.2	3.0	18.2	6.1	9.1	6.1	3.0	51.5	3.0	6.1
NSCLC sarcomatoid carcinoma (n=12)	33.3	75.0	16.7	16.7	25.0	25.0	25.0	16.7	25.0	8.3	8.3	41.7	0.0	0.0
NSCLC other subtype (n=72)	22.2	79.2	36.1	11.1	23.6	16.7	23.6	11.1	16.7	8.3	2.8	50.0	4.2	6.9
SCLC (n=140)	27.1	54.3	36.4	13.6	25.7	26.4	35.0	11.4	18.6	10.7	7.9	40.7	3.6	2.1
Another type of lung cancer (n=86)	31.4	68.6	29.1	14.0	27.9	11.6	32.6	7.0	17.4	8.1	12.8	38.4	2.3	1.2
I don't know (n=157)	24.8	53.5	29.3	12.1	25.5	12.7	23.6	10.8	15.9	9.6	5.7	38.9	7.6	1.9

Across biomarker groups, very few participants noted no healthcare-related issues affecting their mental health (3.8%; Table 24). The factor most often reported as having the greatest impact on mental health across the biomarker groups was receiving the lung cancer diagnosis (63.2%). Managing physical symptoms and side effects was also a major concern (45.8%), particularly among participants in the KRAS group.

Other experiences that commonly affected mental health included receiving additional news after the initial diagnosis (39.8%), going through the diagnostic process itself (32.3%), waiting times (26.9%), and undergoing treatment (24.3%). Across all groups, participants associated with positive PD-L1 status were most likely to report difficulties communicating with healthcare professionals (25.8%) and challenges accessing lung cancer information (13.9%).

> *Dealing with side effects of cancer treatment is also part of the picture. This can have a much bigger effect on mental health but is not considered important as the person is meant to be grateful the cancer is under control despite any debilitating effects of treatment.*

Table 24: Healthcare-related issues with the greatest impact on mental health across biomarker groups

Biomarker group	Which of the following healthcare-related issues has had the greatest impact on your mental health? (Please, select all that apply) (%)													
	The diagnostic process (n=779)	Receiving the lung cancer diagnosis (n=1525)	Receiving additional news beyond the diagnosis (prognosis, recurrence, etc.) (n=961)	Attending medcal consultations (n=379)	Undergoing treatment (n=587)	Facing barriers to accessing treatments or care (n=362)	Waiting times (n=650)	Lack of trust in the medical team (n=268)	Difficulties communicating with healthcare professionals (n=434)	Accessing information about lung cancer (n=201)	Difficulties with health insurance (n=179)	Managing medical symptoms or side effects (n=1105)	None (n=91)	Other (pleae specify) (n=76)
EGFR (n=506)	34.6	68.6	44.1	18.0	23.9	15.0	30.0	12.1	16.0	7.7	7.9	50.4	3.8	4.9
ALK (n=470)	36.2	69.6	40.9	18.3	16.4	12.1	22.8	11.3	16.2	6.8	8.9	42.8	1.7	4.7
PD-L1 (n=151)	31.8	62.9	38.4	13.9	25.8	19.2	31.8	12.6	25.8	13.9	7.3	43.7	4.0	4.6
KRAS (n=130)	22.3	53.8	46.2	10.0	27.7	16.2	28.5	7.7	20.0	6.9	7.7	52.3	2.3	5.4
Other (n=255)	35.3	65.1	45.5	13.3	21.6	16.1	24.7	15.3	19.2	7.8	9.0	46.3	2.4	5.1
No biomarker (n=229)	31.0	61.1	39.3	13.1	31.4	13.5	27.5	10.9	17.5	10.5	3.9	43.7	4.8	2.6
I don't know (includes in the process of testing) (n=487)	28.7	56.3	32.9	13.8	28.1	14.8	25.7	8.6	18.1	9.0	6.4	45.4	6.0	2.9
Have not been tested forbiomarker (n=185)	30.3	57.3	33.5	20.0	27.0	18.9	29.7	10.3	18.9	6.5	7.0	41.1	4.9	2.2

Most participants reported at least one healthcare-related experience that had affected their mental health. The greatest impacts were linked to receiving the lung cancer diagnosis and managing physical symptoms or side effects.

> *Cancer becoming resistant to targeted therapy, new treatments not working, health and energy declining. This has had an impact on my mental health.*

> *The diagnosis hit me like a punch in the stomach. I couldn't believe it.*

3.2.7 MENTAL HEALTH SUPPORT OFFERED DURING CARE

Overall, mental health support for people impacted by lung cancer diagnoses was not routinely offered. Across lung cancer types, 31.2% of participants reported receiving no mental health support related to the diagnosis at any point in their care pathway. This was most commonly reported by participants impacted by SCLC (43.9%), those who did not know their lung cancer type (41.7%), and those reporting 'another type' of lung cancer (37.9%). Echoing this, almost one-fifth of participants (19.2%) reported seeking mental health support independently, rather than having it offered.

Where support was offered, it most often occurred at the time of diagnosis (28.8%) and during treatment (27.9%). Notably, participants with NSCLC sarcomatoid carcinoma were most likely to report being offered support during treatment (41.7%). Across lung cancer types, support offered after completion of treatment was less common (7.2%), suggesting a potential gap in ongoing psychological support during survivorship and follow-up.

Table 25: Mental health support offered in the care pathway across lung cancer types

Lung cancer type	As part of your care pathway, were you offered any mental health support in relatio to your lung cancer diagnosis? (Please, select all that apply) (%)				
	Yes, at the time of diagnosis (n=623)	Yes, while receiving treatment (n=605)	Yes, after the treatment (n=156)	No, but I sought this out myself (n=415)	No (n=675)
NSCLC adenocarcinoma (n=1525)	30.0	27.5	6.4	20.8	28.5
NSCLC squamous carcinoma (n=97)	21.6	30.9	7.2	22.7	28.9
NSCLC large cell carcinoma (n=44)	22.7	34.1	11.4	18.2	31.8
NSCLC adenosquamous carcinoma (n=33)	36.4	39.4	12.1	12.1	27.3
NSCLC sarcomatoid carcinoma (n=12)	8.3	41.7	16.7	16.7	25.0
NSCLC other subtype (n=72)	30.6	26.4	6.9	18.1	37.5
SCLC (n=139)	26.6	21.6	7.9	15.1	43.9
Another type of lung cancer (n=87)	28.7	33.3	4.6	13.8	37.9
I don't know (n=156)	24.4	28.2	12.8	10.3	41.7

Across biomarker groups, mental health support was most often offered during treatment or at the time of diagnosis, and less often after treatment had ended (Table 26).

For those participants who were offered support, during treatment was most common (29.3%) and was particularly high in the KRAS group (45.4%). Support at the time of diagnosis was also frequently reported (29.1%). In contrast, support after treatment was limited across all biomarker groups (7.2%; range: 4.3–8.7%).

Overall, 30.7% of participants noted they had received no mental health support at any stage of their care, although this varied considerably across biomarker groups (ranging from 17.7% to 47.0%). This response was most common in participants who reported no biomarker testing (47.0%) and an unknown biomarker status (37.9%). Furthermore, 18.8% of participants said they had sought mental health support themselves when it was not offered.

> *"Access to mental health support would have been useful at diagnosis, but now 28 months on, I have found my own way."*

Table 26: Mental health support offered in the care pathway across biomarker groups

Biomarker group	As part of your care pathway, were you offered any mental health support in relation to your lung cancer diagnosis? (Please, select all that apply) (%)				
	Yes, at the time of diagnosis (n=701)	Yes, while receiving treatment (n=705)	Yes, after the treatment (n=174)	No, but I sought this out myself (n=453)	No (n=740)
EGFR (n=504)	32.7	29.0	6.7	21.6	24.4
ALK (n=468)	35.3	27.1	7.9	16.2	31.4
PD-L1 (n=151)	26.5	31.8	4.6	17.2	33.8
KRAS (n=130)	26.9	45.4	7.7	20.0	17.7
Other (n=254)	37.0	34.6	6.3	20.1	20.9
No biomarker (n=229)	24.0	24.9	8.7	21.8	31.4
I don't know (includes in th process of testing) (n=486)	22.2	28.0	8.6	16.9	37.9
Have not been tested for biomarker (n=185)	21.1	23.8	4.3	17.8	47.0

Mental health support was most often offered during treatment or at diagnosis, with fewer participants reporting support after treatment. However, many noted they were not offered support at all, and some had to seek help themselves. Gaps in mental health support were notably greater in certain lung cancer types and biomarker groups.

"There was no psychological support offered. I had to manage on my own."

"I was not referred to the hospital psychologist when I was diagnosed, I think I should have been but have been referred to them recently after recurrence."

3.2.8 REFERRAL TO PATIENT OR NON-PROFIT ORGANISATIONS BY HEALTHCARE PROVIDERS

Across lung cancer types, 37.4% of participants reported having never received a referral to a patient or non-profit organisation from a healthcare professional (Table 27). The proportion reporting no referral ranged from 33.3% (NSCLC adenosquamous carcinoma) to 66.7% (NSCLC sarcomatoid carcinoma).

Overall, 28.6% of participants reported seeking out patient or non-profit organisations on their own. Notably, the three groups most likely to report no referral (participants with NSCLC sarcomatoid carcinoma, those who did not know their lung cancer type, and those impacted by SCLC) were also the least likely to report seeking out patient organisations independantly (16.7%, 16.0%, and 21.4%, respectively). This pattern highlights potential support gaps for these groups. Where referrals were reported, they most often occurred earlier in the care pathway.

Participants with NSCLC sarcomatoid carcinoma reported particularly low levels of provider-led referral, both at diagnosis and during treatment (both 8.3%), alongside the highest proportion reporting no referral at any point (66.7%). This group represents a clear outlier and may indicate a particular lack of provider-led referral to patient organisations within this group.

Referrals after treatment were uncommon across most lung cancer types (5.1%; range: 1.4–16.7%). An exception was NSCLC sarcomatoid carcinoma, where 16.7% reported a post-treatment referral, although numbers in this group are limited.

Table 27: Referral to patient organisations or non-profit organisations across lung cancer types

Lung cancer type	Have you ever been referred to patient organisations or non-profit organisations by a healthcare provider? (Please, select all that apply) (%)				
	Yes, at the time of diagnosis (n=378)	Yes, while receiving treatment (n=433)	Yes, after the treatment (n=111)	No, but I sought this out myself (n=619)	No (n=810)
NSCLC adenocarcinoma (n=1525)	18.0	20.2	5.0	31.0	33.5
NSCLC squamous carcinoma (n=98)	23.5	19.4	6.1	23.5	37.8
NSCLC large cell carcinoma (n=44)	15.9	22.7	2.3	29.5	40.9
NSCLC adenosquamous carcinoma (n=33)	18.2	24.2	9.1	27.3	33.3
NSCLC sarcomatoid carcinoma (n=12)	8.3	8.3	16.7	16.7	66.7
NSCLC other subtype (n=72)	20.8	22.2	1.4	25.0	38.9
SCLC (n=140)	14.3	14.3	3.6	21.4	52.9
Another type of lung cancer (n=87)	13.8	17.2	4.6	29.9	43.7
I don't know (n=156)	12.2	23.1	8.3	16.0	54.5

The proportion of participants who had never been referred to a patient or non-profit organisation by a healthcare professional varied considerably across biomarker groups, ranging from 27.1% to 52.0% (average: 37.2%). Participants unsure of their biomarker status and those reporting no biomarker testing were less likely to have been referred to patient organisations, with over half reporting never having been referred (52.0% and 51.1%, respectively).

When referrals were reported, they most commonly occurred while receiving treatment (20.5%) and at the time of diagnosis (17.8%). In both cases, referrals were most common among participants in the EGFR and 'other' biomarker groups. Being referred after treatment was uncommon across biomarker groups (5.4%).

Over one-quarter (28.2%) sought support from patient organisations independently, after not being referred by a healthcare provider. This was most common among those in the KRAS biomarker group (39.2%).

Table 28: Referral to patient organisations or non-profit organisations across biomarker groups

Biomarker group	Have you ever been referred to patient organisations or non-profit organisations by a healthcare provider? (Please, select all that apply) (%)				
	Yes, at the time of diagnosis (n=428)	Yes, while receiving treatment (n=494)	Yes, after the treatment (n=131)	No, but I sought this out myself (n=679)	No (n=896)
EGFR (n=506)	25.5	25.1	5.1	27.9	27.1
ALK (n=467)	21.4	22.5	5.4	29.3	31.0
PD-L1 (n=152)	14.5	21.7	5.9	28.9	38.2
KRAS (n=130)	9.2	15.4	6.2	39.2	33.8
Other (n=254)	24.0	26.8	5.1	28.3	27.2
No biomarker (n=229)	10.9	11.8	6.6	34.5	41.5
I don't know (includes in the process of testing) (n=487)	10.9	18.3	5.7	22.2	52.0
Have not been tested for biomarker (n=186)	14.0	13.4	3.8	25.3	51.1

Participants most commonly reported that they had not been referred to patient or non-profit organisations by a healthcare provider, and many reported seeking support themselves. When referrals occurred, they were most common during treatment or at diagnosis.

> *The information provided by patient associations like AEACaP is very useful to me.*

> *Satisfied thanks to the ALK+ROS1 association, which let me talk with patients with the same cancer and gene.*

3.2.9 EMOTIONAL SUPPORT FROM THE HEALTHCARE TEAM

When participants were asked whether they felt that their healthcare team had given them appropriate emotional support to manage their disease, the most frequent response across lung cancer types was "yes, but only to some extent" (30.1%: Table 29). Only one-quarter (24.0%) responded "yes, completely", suggesting that while emotional support may be provided, it may not fully meet the needs of most people living with lung cancer.

Participants impacted by NSCLC adenosquamous carcinoma reported the highest satisfaction with the emotional support provided by their healthcare team, with 73.3% responding "yes, completely" or "yes, but only to some extent."

A notable number of participants indicated they had to seek emotional support independently rather than receiving it from their healthcare team. Overall, the percentage selecting "no, I had to find support myself" was 21.0%, highest among those impacted by NSCLC squamous carcinoma (23.9%). In addition, 10.4% reported that they had not received emotional support but would like it, particularly participants reporting 'another type' of lung cancer (18.4%) and 'other' NSCLC subtypes (15.4%).

Only a small minority reported that they had not received emotional support and did not need it (4.6%). This response was not selected at all in the NSCLC sarcomatoid carcinoma group (0.0%), suggesting that, when support was lacking, it was more likely to be perceived as a gap in care for this group.

Table 29: Emotional support provided by participants' healthcare teams across lung cancer types

Lung cancer type	Do you feel your healthcare team has given you appropriate emotional support to help you manage the disease? If you are a caregiver, 'your healthcare team' refers to your own team, not your loved one's (%)					
	Yes, completely (n=474)	Yes, but only to some extent (n=595)	No, but I would like support (n=205)	No, I had to find support myself (n=416)	No, but this is not necessary (n=197)	Don't know / not sure (n=91)
NSCLC adenocarcinoma (n=1412)	22.7	30.7	10.0	21.7	10.3	4.6
NSCLC squamous carcinoma (n=92)	26.1	26.1	8.7	23.9	12.0	3.3
NSCLC large cell carcinoma (n=38)	26.3	23.7	13.2	18.4	10.5	7.9
NSCLC adenosquamous carcinoma (n=30)	33.3	40.0	3.3	10.0	6.7	6.7
NSCLC sarcomatoid carcinoma (n=10)	20.0	50.0	10.0	20.0	0.0	0.0
NSCLC other subtype (n=65)	20.0	35.4	15.4	16.9	7.7	4.6
SCLC (n=119)	27.7	22.7	11.8	20.2	10.9	6.7
Another type of lung cancer (n=76)	22.4	35.5	18.4	17.1	5.3	1.3
I don't know (n=136)	32.4	25.0	8.1	20.6	9.6	4.4

Across biomarker groups, participants received varying levels of support from their healthcare team to help them manage their lung cancer. Overall, 54.8% of participants felt they had received appropriate support, either completely or to some extent.

The EGFR biomarker group reported the highest level of emotional support, with 23.9% noting complete support ("yes, completely") and 33.8% reporting some support ("yes, but only to some extent"). In contrast, the KRAS group had the lowest proportion of participants reporting complete support (15.7%) but the highest proportion reporting "some" support (38.0%).

As with different lung cancer types, unmet needs and self-sourcing of support were also common across biomarker groups. Around one-fifth of participants (20.6%) reported not receiving appropriate emotional support from their healthcare team and having to find it themselves ("no, I had to find support myself"), with the highest rate in the KRAS biomarker group (26.4%).

A desire for support, but not received ("no, but I would like support") was reported by 10.3% of participants. This was most common among those with no biomarker testing (15.1%) and the 'other' biomarkers group (12.4%). The opinion that emotional support was not necessary from their healthcare teams was relatively low across all biomarker groups (9.5%).

Table 30: Emotional support provided by participants' healthcare teams across biomarker groups

Biomarker group	Do you feel your healthcare team has given you appropriate emotional support to help you manage the disease? If you are a caregiver, 'your healthcare team' refers to your own team, not your loved one's (%)					
	Yes, completely (n=532)	Yes, but only to some extent (n=678)	No, but I would like support (n=228)	No, I had to find support myself (n=455)	No, but this is not necessary (n=210)	Don't know / not sure (n=105)
EGFR (n=468)	23.9	33.8	7.3	20.9	10.5	3.6
ALK (n=433)	22.4	31.9	10.6	20.8	9.9	4.4
PD-L1 (n=142)	27.5	28.9	9.2	19.0	7.7	7.7
KRAS (n=121)	15.7	38.0	8.3	26.4	9.1	2.5
Other (n=242)	21.5	33.9	12.4	18.6	9.1	4.5
No biomarker (n=203)	25.6	28.1	11.3	21.7	9.9	3.4
I don't know (included in the process of testing) (n=433)	28.2	26.6	10.9	19.6	9.5	5.3
Have not been tested for biomarker (n=166)	23.5	24.7	15.1	20.5	7.8	8.4

While many participants felt their healthcare team provided at least some emotional support, almost one-third indicated a need for additional support or reported having to find support themselves. This reveals an opportunity to improve psychosocial care for people impacted by lung cancer.

> *My diagnosis was delivered with no empathy, in a hallway.*

3.2.10 MEASURES THAT COULD HELP IMPROVE MENTAL HEALTH

Participants identified several measures that could help improve their mental health. Across lung cancer types, the top priority was increased access to information about the disease, treatment, and care options (49.5%; Table 31). This was selected by 38.5% of participants impacted by NSCLC squamous carcinoma and NSCLC adenosquamous carcinoma, rising to 80.0% among those impacted by NSCLC sarcomatoid carcinoma. This suggests that measures aiming to reduce uncertainty about lung cancer may improve the mental health of those impacted by the disease.

Support for managing side effects was another measure frequently selected (44.0%), most often among participants in the NSCLC large cell carcinoma group (47.4%) and those unsure of the lung cancer type (46.5%). In addition, a need for improved communication with healthcare professionals was noted (37.8%), particularly among participants impacted by NSCLC sarcomatoid carcinoma (60.0%).

Participants also emphasised the value of support to help with financial and work-related challenges (29.8%), and peer support (30.4%), highlighting the potential benefits of connecting with others facing similar challenges. Some participants (16.0%) felt that digital resources (like apps and websites) could help improve their mental health. However, responses varied across lung cancer types, from 3.8% in NSCLC adenosquamous carcinoma to 26.6% in 'other' NSCLC subtypes group, suggesting differing preferences and needs for online tools across lung cancer groups.

Requests for access to palliative care were generally lower (15.9%), but were highest among those impacted by SCLC (24.6%).

> *"No one gave me support in healthcare, only my family!"*

Table 31: Measures identified as helpful for improving mental health, across lung cancer types

Lung cancer type	Which of the following measures do you think could help improve your mental health? (please, select all that apply) (%)								
	More information about the disease, treatment and care options (n=956)	Access to mental health services (n=665)	Support to deal with side effects (n=850)	Access to palliative care (n=307)	Better communication with healthcare professionals (n=729)	Peer support (other people living with a similiar situation) (n=587)	Digital resources (apps, websites, etc.) (n=308)	Support to deal with financial and work-related repercussions (n=576)	Other (please specify) (n=160)
NSCLC adenocarcinoma (n=1377)	49.2	34.7	44.6	15.4	37.4	32.3	16.5	30.4	8.5
NSCLC squamous carcinoma (n=91)	38.5	41.8	42.9	16.5	40.7	23.1	11.0	28.6	8.8
NSCLC large cell carcinoma (n=38)	57.9	34.2	47.4	18.4	36.8	34.2	13.2	34.2	7.9
NSCLC adenosquamous carcinoma (n=26)	38.5	23.1	30.8	19.2	38.5	38.5	3.8	46.2	3.8
NSCLC sarcomatoid carcinoma (n=10)	80.0	30.0	40.0	20.0	60.0	10.0	10.0	20.0	0.0
NSCLC other subtype (n=64)	54.7	40.6	45.3	10.9	40.6	26.6	26.6	15.6	6.3
SCLC (n=118)	50.8	32.2	44.9	24.6	44.9	24.6	15.3	33.1	14.4
Another type of lung cancer (n=77)	58.4	40.3	32.5	22.1	28.6	26.0	19.5	35.1	3.9
I don't know (n=129)	48.8	24.8	46.5	10.1	35.7	24.0	10.9	21.7	5.4

Across biomarker groups, the most commonly selected measure to improve mental health was more information about the disease, treatment, and care options (Table 32). This measure was selected by half of all participants (50.0%), and was most common among those in the unknown biomarker (53.7%) and ALK (51.5%) groups.

Support for managing side effects was also selected by almost half of participants (44.1%) as a measure to improve mental health. Better communication with healthcare professionals was reported by 37.8% of participants across biomarker groups, with the highest rate in the KRAS group.

Approximately one-third of participants selected improved access to mental health services (34.3%), peer support (30.6%) and financial and work-related support (29.3%). Digital resources and access to palliative care were selected by a smaller but still notable proportion of participants (16.3% and 16.1%, respectively).

Table 32: Measures identified as helpful for improving mental health, across biomarker groups

Biomarker group	Which of the following measures do you think could help improve your mental health? (Please, select all that apply) (%)								
	More information about the disease, treatment and care options (n=1077)	Access to mental health services (n=738)	Support to deal with side effects (n=950)	Access to palliative care (n=346)	Better communication with healthcare professionals (n=813)	Peer support (other people living with a similar situation) (n=659)	Digital resources (apps, websites, etc.) (n=350)	Support to deal with financial and work-related repercussions (n=630)	Other (please specify) (n=179)
EGFR (n=454)	50.2	35.2	45.2	15.4	36.6	32.4	17.0	27.8	10.4
ALK (n=421)	51.5	34.9	43.0	15.4	39.0	36.3	20.0	34.4	9.3
PD-L1 (n=135)	45.9	39.3	47.4	19.3	37.8	34.8	18.5	35.6	6.7
KRAS (n=120)	50.0	32.5	38.3	15.8	45.0	26.7	19.2	25.0	9.2
Other (n=235)	47.2	34.9	46.0	17.0	36.2	34.5	20.4	25.1	8.1
No biomarker (n=201)	48.8	31.3	50.7	13.4	35.3	25.4	13.4	32.3	4.0
I don't know (includes in the process of testing) (n=423)	53.7	34.3	43.3	17.7	37.1	24.6	10.4	24.8	6.9
Have not been tested for biomarker (n=164)	45.1	29.9	37.2	14.6	39.6	26.8	13.4	31.7	10.4

Participants identified several key measures that could improve their mental health: more information about the disease, treatment, and care options; enhanced communication; support for managing side effects; and improved access to mental health services.

> *As a caregiver, [I found] receiving information and psychological support to be effective in caring for the person who was ill.*

> *It would be good to have an assistant to answer our questions.*

> *Psychological support should be standard after diagnosis.*

3.2.11 PREVIOUS DIAGNOSIS OF DEPRESSION

Depression is a mental health condition characterised by a consistently low mood, or a loss of pleasure or interest in activities.[4] Among individuals with cancer, depression is the most common psychiatric disorder, with the highest prevalence of major depression observed in those diagnosed with lung cancer.[5,6]

Across lung cancer types, 63.2% indicated they had not been diagnosed with depression (Table 33). Where respondents had been diagnosed, depression was reported more frequently as a pre-existing diagnosis (17.7%) than as a post-diagnosis outcome (5.4%). This pattern was particularly marked in NSCLC squamous carcinoma (26.4% before vs 5.5% after) and NSCLC adenosquamous carcinoma (20.7% before vs 3.4% after). The highest overall prevalence of a depression diagnosis (either before or after a lung cancer diagnosis) was among those with NSCLC sarcomatoid carcinoma. In this group, diagnoses were evenly split, with 20.0% reporting a diagnosis of depression before and 20.0% after lung cancer detection.

Some participants (13.7%) reported they were not aware of having received a diagnosis of depression. This uncertainty was highest among those impacted by 'other' NSCLC subtypes (20.0%) and SCLC (18.1%), suggesting potential gaps in the recognition, communication, or assessment of depression within these groups.

Table 33: Depression diagnoses across lung cancer types

Lung cancer type	Have you ever been diagnosed with depression? (If you have been diagnosed with depression both before and after the lung cancer detection, please select 'Yes, before the lung cancer diagnosis') (%)			
	Yes, before the lung cancer diagnosis (n=347)	Yes, after the lung cancer diagnosis (n=106)	No (n=1243)	Not that I am aware of (n=270)
NSCLC adenocarcinoma (n=1407)	17.6	5.0	63.6	13.8
NSCLC squamous carcinoma (n=91)	26.4	5.5	57.1	11.0
NSCLC large cell carcinoma (n=38)	15.8	7.9	68.4	7.9
NSCLC adenosquamous carcinoma (n=29)	20.7	3.4	72.4	3.4
NSCLC sarcomatoid carcinoma (n=10)	20.0	20.0	50.0	10.0
NSCLC other subtype (n=65)	13.8	9.2	56.9	20.0
SCLC (n=116)	15.5	6.9	59.5	18.1
Another type of lung cancer (n=76)	14.5	6.6	65.8	13.2
I don't know (n=134)	17.9	3.7	65.7	12.7

Across biomarker groups, nearly two-thirds of participants reported they had not received a diagnosis of depression (63.4%) (Table 34).

Participants in the KRAS biomarker group reported the highest rate of pre-existing depression, i.e., before lung cancer detection (29.8%). Relatively high levels of pre-existing depression were also reported by participants unsure of the biomarker status (20.6%) and those reporting no biomarkers (19.6%).

Few participants reported being diagnosed with depression after the lung cancer diagnosis (5.5%), but this was most commonly reported in the PD-L1 group (7.8%) and those unsure of the biomarker status (7.1%).

Participants reporting no identified biomarkers were most likely to select the response "not that I am aware of" (21.1%) when asked if they had ever been diagnosed with depression, suggesting potential uncertainty in this group.

Table 34: Depression diagnoses across biomarker groups

Biomarker group	Have you ever been diagnosed with depression? (If you have been diagnosed with depression both before and after the lung cancer detection, please select 'Yes, before the lung cancer diagnosis') (%)			
	Yes, before the lung cancer diagnosis (n=385)	Yes, after the lung cancer diagnosis (n=121)	No (n=1392)	Not that I am aware of (n=297)
EGFR (n=469)	16.2	4.3	65.5	14.1
ALK (n=431)	13.2	6.3	70.3	10.2
PD-L1 (n=141)	17.0	7.8	66.0	9.2
KRAS (n=121)	29.8	4.1	52.1	14.0
Other (n=242)	16.5	4.5	67.4	11.6
No biomarker (n=204)	19.6	4.4	54.9	21.1
I don't know (includes in the process of testing) (n=423)	20.6	7.1	56.0	16.3
Have not been tested for biomarker (n=164)	15.2	4.9	69.5	10.4

While most participants had not been diagnosed with depression, diagnoses were slightly more common among those impacted by NSCLC sarcomatoid carcinoma and those in the KRAS biomarker group. These diagnoses primarily occurred before lung cancer detection. Given that over one-third had received a diagnosis of depression, improving support for these individuals is fundamental to reduce the burden of managing both conditions simultaneously and improve clinical outcomes in lung cancer care.

> *"There were moments when I no longer wanted to live."*

> *"I've lost all hope for the future; I feel completely defeated."*

3.2.12 PREVIOUS DIAGNOSIS OF AN ANXIETY DISORDER

Anxiety disorders are mental health conditions characterised by persistent and unresolved feelings of anxiety that may get worse over time.[7] Research indicates that individuals impacted by cancer, particularly those with lung cancer, experience higher rates of anxiety compared to the general population.[8,9]

Most participants across lung cancer types reported they had never been diagnosed with an anxiety disorder, with two-thirds answering "No" (66.4%) (Table 35).

A diagnosis of an anxiety disorder was most likely to be reported before lung cancer detection (15.1%) than after (6.3%), with two exceptions: 10.0% of the NSCLC sarcomatoid carcinoma group reported being diagnosed with anxiety before their lung cancer diagnosis, compared to 20.0% after. Similarly, 7.9% of the NCLC (large cell carcinoma) group reported a 'before' diagnosis compared to 13.2% 'after'.

A notable proportion of participants (12.3%) reported they were not aware of whether they had been diagnosed with an anxiety disorder, suggesting that anxiety may be challenging to recognise among people impacted by lung cancer.

Table 35: Anxiety disorder diagnoses across lung cancer types

Lung cancer type	Have you ever been diagnosed with an anxiety disorder? (If you have been diagnosed with an anxiety disorder both before and after the lung cancer detection, please select 'Yes, before the lung cancer diagnosis') (%)			
	Yes, before the lung cancer diagnosis (n=295)	Yes, after the lung cancer diagnosis (n=123)	No (n=1300)	Not that I am aware of (n=240)
NSCLC adenocarcinoma (n=1402)	15.5	5.8	66.6	12.1
NSCLC squamous carcinoma (n=91)	17.6	9.9	57.1	15.4
NSCLC large cell carcinoma (n=38)	7.9	13.2	71.1	7.9
NSCLC adenosquamous carcinoma (n=29)	13.8	6.9	79.3	0.0
NSCLC sarcomatoid carcinoma (n=10)	10.0	20.0	60.0	10.0
NSCLC other subtype (n=65)	10.8	4.6	73.8	10.8
SCLC (n=116)	11.2	6.9	65.5	16.4
Another type of lung cancer (n=73)	9.6	6.8	68.5	15.1
I don't know (n=134)	20.1	6.0	62.7	11.2

Almost two-thirds of participants (66.5%) have not been diagnosed with an anxiety disorder across all biomarker groups (Table 36).

KRAS was linked to the highest proportion of participants reporting a pre-existing anxiety diagnosis (23.1%), higher than other biomarker groups (14.5%; range: 11.2-23.1%). Diagnoses occurring after lung cancer detection were generally low across participants (6.3%).

Uncertainty around receiving an anxiety disorder diagnosis was observed, with 12.2% of participants selecting the response, "not that I am aware of", highest among participants with unknown biomarker status (16.2%).

Table 36: Anxiety disorder diagnoses across biomarker groups

Biomarker group	Have you ever been diagnosed with an anxiety disorder? (If you have been diagnosed with an anxiety disorder both before and after the lung cancer detection, please select 'Yes, before the lung cancer diagnosis') (%)			
	Yes, before the lung cancer diagnosis (n=328)	Yes, after the lung cancer diagnosis (n=137)	No (n=1456)	Not that I am aware of (n=267)
EGFR (n=467)	15.4	6.6	66.8	11.1
ALK (n=430)	12.8	4.7	71.4	11.2
PD-L1 (n=141)	14.9	6.4	68.1	10.6
KRAS (n=121)	23.1	4.1	61.2	11.6
Other (n=241)	11.2	4.6	71.8	12.4
No biomarker (n=204)	15.2	10.3	63.2	11.3
I don't know (includes in the process of testing) (n=421)	16.6	6.2	61.0	16.2
Have not been tested for biomarker (n=163)	14.7	8.6	66.3	10.4

Across all lung cancer types and biomarker groups, most participants reported no anxiety disorder diagnosis. Among those who were diagnosed, pre-existing anxiety was generally more common than a diagnosis occurring after lung cancer detection. Given that around one-third of respondents reported an anxiety diagnosis, strengthening psychosocial support for people affected by lung cancer, particularly those with psychological vulnerabilities, is essential.

> *Scan days fill me with unbearable anxiety, fearing bad news.*

> *Anxiety due to lack of access to tests and medicines.*

3.2.13 MENTAL HEALTH IMPACTS EXPERIENCED

Many participants (60.5%) reported experiencing at least one impact on their mental health since their lung cancer diagnosis (Table 37) . People affected by NSCLC sarcomatoid carcinoma were least likely to report an absence of listed mental health impacts (20.0%), while those who didn't know their lung cancer type were most likely to report no impacts (40.5%).

Of the mental health impacts reported, feeling extremely sad was the most common experience, particularly in the NSCLC sarcomatoid carcinoma (60.0%), NSCLC adenosquamous carcinoma (55.2%), and NSCLC large cell carcinoma (52.8%) types.

Other common impacts included feeling trapped, particularly among those impacted by NSCLC squamous carcinoma (32.6%) and NSCLC large cell carcinoma (30.6%). Persistent feelings of hopelessness or worthlessness, as well as a significant loss of interest in life, were selected more often among 'another type' of lung cancer (31.4% and 22.9%, respectively) and NSCLC sarcomatoid carcinoma (20.0% and 30.0%, respectively).

When looking at more severe emotional burdens among the groups, suicidal thoughts were reported by 8.0% of participants on average, highest in NSCLC sarcomatoid carcinoma (20.0%), NSCLC squamous carcinoma (14.0%), and NSCLC large cell carcinoma (13.9%). Thoughts of self-harm were less common (2.0%), although most frequently reported by people impacted by NSCLC large cell carcinoma (5.6%) and those unsure of the lung cancer type (4.6%).

Table 37: Mental health impacts experienced since the lung cancer diagnosis, across lung cancer types

Lung cancer type	Since the lung cancer diagnosis, have you experienced any of the following in relation to your mental health? (Please, select all that apply) (%)								
	Persistent feelings of hopelessness or worthlessness (n=404)	Feeling extremely sad (n=838)	Feeling trapped (n=471)	Unbearable pain or suffering (n=243)	Significant loss of interest in life (n=292)	Thoughts of self-harm (n=39)	Suicidal thoughts (n=152)	None of the above (n=691)	Prefer not to answer (n=64)
NSCLC adenocarcinoma (n=1376)	20.4	43.0	23.8	11.6	14.2	1.5	7.5	37.8	3.4
NSCLC squamous carcinoma (n=86)	25.6	48.8	32.6	22.1	20.9	3.5	14.0	26.7	2.3
NSCLC large cell carcinoma (n=36)	30.6	52.8	30.6	16.7	19.4	5.6	13.9	25.0	2.8
NSCLC adenosquamous carcinoma (n=29)	17.2	55.2	17.2	17.2	10.3	3.4	6.9	37.9	3.4
NSCLC sarcomatoid carcinoma (n=10)	20.0	60.0	30.0	20.0	30.0	0.0	20.0	20.0	10.0
NSCLC other subtype (n=59)	27.1	42.4	30.5	13.6	20.3	3.4	6.8	35.6	3.4
SCLC (n=114)	21.1	45.6	29.8	7.9	13.2	1.8	7.0	28.1	5.3
Another type of lung cancer (n=70)	31.4	47.1	22.9	15.7	22.9	2.9	10.0	28.6	1.4
I don't know (n=131)	16.0	40.5	21.4	18.3	16.8	4.6	6.9	40.5	2.3

Mental health impacts were similar across different biomarker groups. Feelings of extreme sadness were reported by almost half of participants (43.6%), and nearly one-quarter felt trapped (24.6%) (Table 38). Additionally, 21.1% experienced persistent feelings of hopelessness or worthlessness, and 16.0% experienced a significant loss of interest in life.

Suicidal thoughts were reported by 8.3% of participants across biomarker groups, increasing to 11.1% in the KRAS group. Thoughts of self-harm were less common (2.3%), but also reported most often in the KRAS group (4.3%).

The PD-L1 group was most likely to report no mental health-related experiences since the lung cancer diagnosis (42.8%), and those who reported no biomarker testing were least likely (30.4%). This suggests a greater emotional burden where biomarker testing has not been performed.

Table 38: Mental health impacts experienced since the lung cancer diagnosis, across biomarker groups

Biomarker group	Since the lung cancer diagnosis, have you experienced any of the following in relation to your mental health? (Please, select all that apply) (%)								
	Persistent feelings of hopelessness or worthlessness (n=450)	Feeling extremely sad (n=931)	Feeling trapped (n=526)	Unbearable pain or suffering (n=277)	Significant loss of interest in life (n=341)	Thoughts of self-harm (n=50)	Suicidal thoughts (n=177)	None of the above (n=770)	Prefer not to answer (n=76)
EGFR (n=458)	17.9	45.2	22.5	10.3	12.4	1.1	5.9	37.8	2.2
ALK (n=421)	21.4	47.3	26.4	10.0	15.7	2.4	7.6	35.4	2.9
PD-L1 (n=138)	19.6	40.6	25.4	15.2	19.6	2.9	10.9	42.8	2.9
KRAS (n=117)	23.1	41.9	23.1	15.4	17.9	4.3	11.1	39.3	4.3
Other (n=233)	23.2	45.5	23.6	18.5	10.7	2.1	9.0	35.2	3.9
No biomarker (n=196)	24.0	42.3	30.6	13.3	18.9	2.6	8.7	35.7	3.1
I don't know (includes in the process of testing (n=410)	22.7	39.0	24.1	15.4	18.3	2.2	8.8	34.6	4.9
Have not been tested for biomarker (n=161)	18.6	44.1	22.4	10.6	20.5	4.3	9.9	30.4	6.2

Since the lung cancer diagnosis, participants reported experiencing emotional burdens, in particular, extreme sadness and feeling trapped. Although less common, several groups reported concerning levels of suicidal thoughts, highlighting the importance of incorporating psychosocial assessment, support, and counselling in lung cancer care to closely monitor mental health disorders and suicide risk.

> *I constantly wonder what the point of everything is now.*

> *I no longer recognise myself. I feel like a shadow of who I was.*

3.3 THE IMPACT OF LUNG CANCER ON MENTAL HEALTH ACROSS EUROPEAN COUNTRIES

On the day of survey completion, the 2,148 participants reported moderate mental health. On a 1–10 scale (1 = very poor; 10 = excellent), the mean score across 21 countries was 6.68.

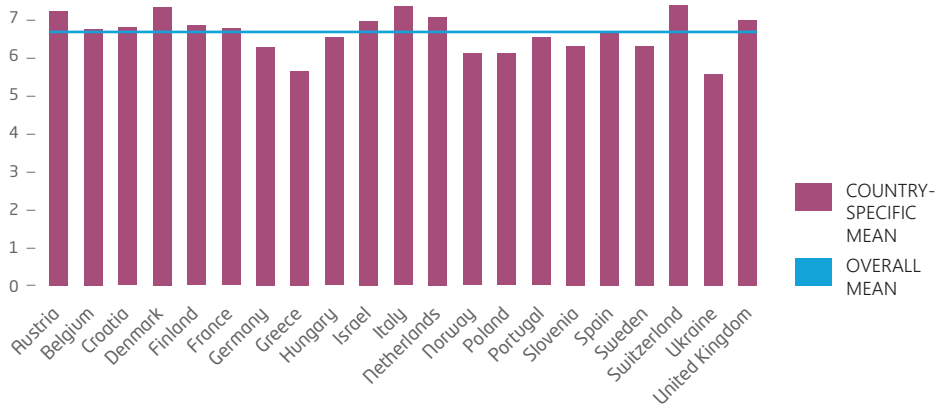
The mean (often called the average) is a simple way to describe the "typical" value in a set of numbers using a single summary number. You calculate it by adding all the numbers together and dividing by how many numbers there are.

For example, if five people rate their mental well-being on a scale from 1 (very poor) to 10 (excellent) as 6, 7, 7, 8, and 9, you add them together (6+7+7+8+9 = 37) and divide by 5. This gives a mean (average) of 7.4.

Mean scores varied across countries. The highest mean mental health scores were reported by participants in Italy, Switzerland, and Denmark (Figure 1). Participants in the Netherlands, Austria, and the United Kingdom also reported comparatively better mental health, with average scores above 7.

At the other end of the scale, participants in Slovenia, Ukraine, and Greece reported the lowest average mental health scores. Participants in Germany and Poland also reported mean scores below the overall survey average, suggesting poorer perceived mental health in these countries compared with others in the sample.

Figure 1. Self-rated mental health scores by country

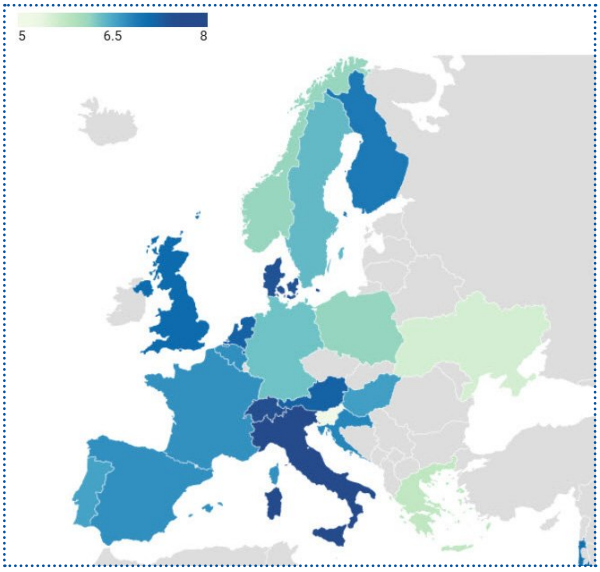


Note: Only countries with five or more survey participants were included in this analysis. All statistical analyses have been adjusted to account for uneven sample sizes across regions.

Mental health experiences related to lung cancer vary widely, not only between countries, but also within them. Even people living in the same country can experience different mental and psychological effects of lung cancer.

More detailed statistical analysis confirmed that self-rated mental health differed significantly by country. In general, people impacted by lung cancer in several Western and Northern European countries reported better current mental health than those living in parts of Southern and Eastern Europe. Participants in Italy, Denmark, the Netherlands, Switzerland, and the United Kingdom consistently reported higher scores, while Ukraine, Greece, and Slovenia most frequently reported lower scores. However, the differences between the higher-scoring countries themselves were generally small and not statistically meaningful. These patterns of participant current mental health scores are shown in Figure 2: lighter green indicates poorer mental health, and darker blue indicates better mental health.

Figure 2. Self-rated mental health scores across Europe

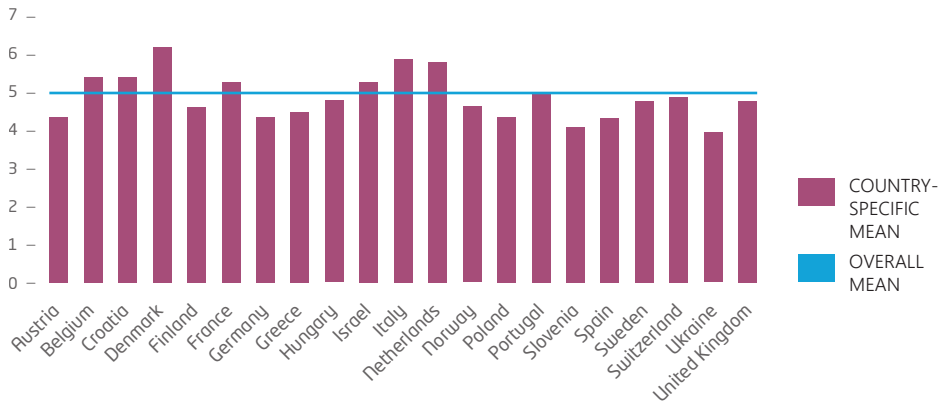


The geographical variations in Figure 2 suggest that self-rated mental health in people impacted by lung cancer likely reflects country-specific influences, such as the availability of psychological and supportive care, health system capacity and resources, access to social and community support, and broader financial or political conditions. Nonetheless, the overall differences between countries were relatively modest, suggesting that country of residence is only one part of the picture. Individual circumstances and the socio-cultural environment are also likely to play a major role in shaping mental health.

Survey participants (n=2,139) across the 21 European countries described the impact of lung cancer on their mental health as predominantly negative, with a mean score of 4.94 on a 1–10 scale (1 = very negative; 10 = very positive).

The smallest negative impact (i.e., higher mean mental health scores) was reported by participants in Denmark, Italy, and the Netherlands (Figure 3). Belgium and Croatia also reported scores above the overall average. Participants in Ukraine and Slovenia reported the greatest negative impact of lung cancer on their mental health. Lower-than-average scores were also observed in Austria, Spain, Germany, and Greece, suggesting a greater psychological burden associated with lung cancer in these countries.

Figure 3. Self-rated impact of lung cancer on mental health by country

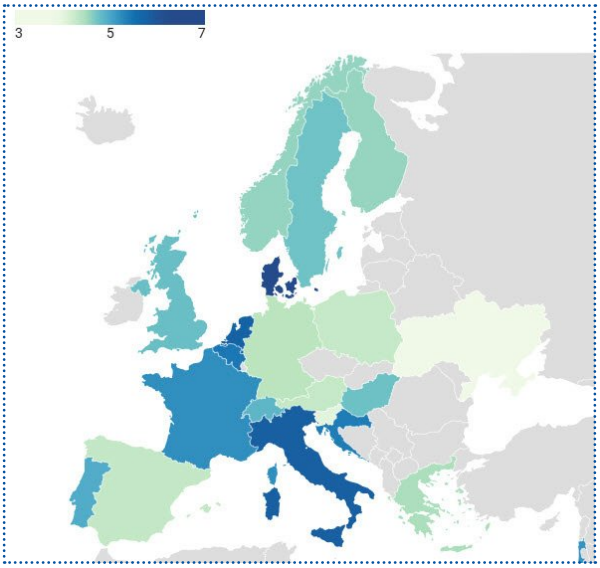


Responses varied widely within countries, highlighting that individual experiences of the psychological impact of lung cancer can differ substantially between those living in the same country.

Statistical analysis confirmed that cross-country differences in the perceived impact of lung cancer on mental health were significant. Overall, participants in several Western and Northern European countries (most notably Denmark, Italy, and the Netherlands) reported a significantly smaller negative impact of lung cancer on their mental health compared with participants in parts of Southern and Eastern Europe (particularly Ukraine, Greece, Germany, and Spain). As with overall mental health scores, differences among the countries reporting the impact of lung cancer on their mental health were generally small and not statistically meaningful.

These patterns are illustrated in Figure 4: lighter green indicates a more negative perceived impact on mental health, while darker blue indicates a more positive perceived impact.

Figure 4. Self-rated impact of lung cancer on mental health across Europe



These findings highlight cross-country variation in the mental and psychological burden of lung cancer across Europe. While lung cancer was widely perceived to negatively affect mental health, this impact appeared to be more pronounced in parts of Southern and Eastern Europe. Such differences likely reflect broader country-level factors, such as access to survivorship and supportive care services, the quality of communication and emotional support at diagnosis, financial pressures and social protection, and cultural norms around illness, coping, and expressing distress.

The fact that there is no access to euthanasia in Finland and that unbearable suffering through suffocation could lie ahead.

In Slovenia, palliative care is very poor, except a few ones.

The depressing situation of the Hungarian health system, the systematic unpreparedness and indifference of doctors.

The healthcare system where my relative was treated is of an unacceptable standard.

I can't afford private mental health care, and in public hospitals you can't get clear answers or suitable doctors.

I received significant psychological support from my parish priest.

I had to lose my job because I had to take my mother for infusions. Why? To stand in queues for paperwork, beds, to be infused, to see doctors. Why? Because the process is unorganised and you spend half a day at the hospital every week. Also tests and diagnostics outside the center had to be done on other days.

While measuring the psychological impact of lung cancer is highly informative, it does not fully capture a person's overall mental health. Taken together, the results reinforce the need for comprehensive assessments of both general mental well-being and lung cancer-specific psychological burden, so that everyone impacted by lung cancer can access support that addresses every aspect of their well-being.

4. CALL TO ACTION

Healthcare systems and policymakers must treat mental health support as a fundamental part of lung cancer care.

Supporting the results of the 10th LuCE Report, further analysis of the survey findings demonstrate the widespread emotional burden of lung cancer that can severely disrupt daily life across all disease types and biomarker groups. While impacts were felt differently between these types and groups, overall support remains uneven, with many receiving no help at all. We call for psychosocial services to be embedded across the lung cancer pathway, including routine distress screening, clear referral routes, and timely access to evidence-based psychological care (including counselling, peer support, and crisis support) from diagnosis through treatment, survivorship, and end-of-life care.

Healthcare professionals must proactively identify distress, communicate clearly, and equip people to manage both symptoms and mental well-being.

Participants consistently highlight the same priorities: better information, stronger support to manage symptoms and side effects, improved communication, and easier access to mental health services. We call on healthcare teams to:

- Deliver clear, consistent explanations of diagnosis, treatment options, and what to expect.
- Normalise conversations about mental health.
- Signpost those affected by lung cancer to trusted resources and patient organisations, so that no one is left to navigate the psychological toll of lung cancer alone.

5. GLOSSARY

Patients	People with a diagnosis of lung cancer.
Caregivers	People caring for, or have cared for, someone with lung cancer, such as family, friends, or partners (not healthcare professionals).
Participants	Patients and caregivers impacted by lung cancer who took part in this survey.
People impacted by lung cancer	We refer to both patients and caregivers in this report as being "impacted by" lung cancer (whether the disease is impacting themselves directly or the person they care for).
Diagnosis	The point at which a doctor confirms a person has lung cancer, usually based on scans and laboratory tests.
Stage 1–2 / Localised disease	Lung cancer that has not spread outside the lung.
Stage 3 / Locally advanced disease	Lung cancer that has spread to tissues surrounding the lungs, but not to other parts of the body.
Stage 4 / Metastatic disease	Lung cancer that has spread beyond the lungs to other parts of the body.
Small cell lung cancer (SCLC)	A type of lung cancer. Compared to non-small cell lung cancer (NSCLC), SCLC is a faster-growing, less common type of lung cancer that behaves differently from NSCLC and is treated differently.
Non-small cell lung cancer (NSCLC)	A type of lung cancer. It includes several lung cancer subtypes. In this survey, participants selected the type of NSCLC that they are impacted by, including: • **NSCLC adenocarcinoma:** This type of lung cancer starts in the mucus-producing gland cells, and is typically the most common NSCLC type.

	• **NSCLC squamous carcinoma:** This type of lung cancer starts in the squamous cells, which line the airways. • **NSCLC adenosquamous carcinoma:** This type of lung cancer has both adenocarcinoma and squamous carcinoma cells. • **NSCLC large cell carcinoma:** This type of lung cancer has larger-appearing cancer cells. • **NSCLC sarcomatoid carcinoma:** This type of lung cancer has more mixed cell features.
'Other' NSCLC subtype	A type of NSCLC other than those listed in the survey options. Participants were able to select this option and then describe what type of lung cancer they were impacted by.
'Another type' of lung cancer	A type of lung cancer other than those listed in the survey options. Participants were able to select this option and then describe what type of lung cancer they were impacted by.
Biomarker	A measurable feature (such as a protein or a gene change) that can be found in a sample of a person's blood or tissue. Doctors can test for biomarkers by sending it to a laboratory. Knowing which biomarkers a cancer is associated with can help doctors understand how the cancer behaves and which treatments may work best. In this survey, participants selected whether the cancer they are impacted by has been associated with any biomarkers, including EGFR, ALK, PD-L1, KRAS, and 'other' biomarkers.
'Other' biomarker	A type of biomarker other than those listed in the survey options. Participants were able to select this option and then describe what type of biomarker their lung cancer was positive for.
EGFR	EGFR is a protein found on the surface of cells that helps them grow and divide. In some lung cancers, a genetic mutation causes the EGFR protein to make cells grow too much, which can lead to cancer.

ALK	ALK refers to both a gene and a protein involved in development of the nervous system. In some lung cancers, a genetic mutation causes lung cells to grow abnormally, which can lead to cancer.
PD-L1	PD-L1 is a protein found on the surface of some cancer cells. It can act like a "shield", helping cancer hide from the immune system.
KRAS	KRAS refers to both a gene and a protein involved in controlling cell growth. If the KRAS gene is mutated, it can send constant growth signals to cells and cause cancer to develop.
Survivorship	Cancer survivorship is a complex state of being. It includes the perspectives, needs, health, and the physical, psychological, social, and economic challenges experienced by people and caregivers after a cancer diagnosis.
Healthcare team	The group of healthcare professionals involved in someone's care. This team may include oncologists, nurses, psychologists, and general practitioners.
Care pathway	The overall journey through the healthcare system, from first symptoms and diagnosis through treatment, and follow-up.
Patient organisation	A group that provides information, advocacy, community, and support services for patients and caregivers.
Palliative care	Care that focuses on improving the quality of life for people living with serious illness. It aims to prevent and relieve symptoms and side effects.
Anxiety disorders	Anxiety disorders are mental health conditions involving persistent and ongoing feelings of anxiety and worry that interfere with daily life.
Depression	Depression is a mental health condition characterised by a consistently low mood, or a loss of pleasure or interest in activities, that interfere with daily life.

6. ABOUT LUCE

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

Our vision

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

Our mission

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

Lung Cancer Europe

lungcancereurope.eu info@lungcancereurope.eu

7. ABOUT OUR MEMBERS

LuCE provides a platform for organisations and individuals working for people impacted by lung cancer. As of February 2026, there are 47 members (43 organisations and 4 individuals), representing 28 countries.

Thank you all for your great support and unwavering commitment to the lung cancer community across Europe. Together, we are building a stronger, more compassionate future for all those impacted by lung cancer. We encourage you to support and learn more about our member organisations.

www.lungcancereurope.eu/our-members

Associations

Österreichische Lungenunion
www.lungenunion.at

Association of Patients with Respiratory Failure and Lung Transplantation

ALK Positive Belgium
www.alkpositivebelgium.be

Prolong VZW
www.prolong.be

Šance pro plíce
www.sanceproplice.cz

Jedra
www.jedra.toraks.hr

Patientforeningen Lungekræft
www.lungekraeft.com

Pulmones - Suomen Keuhkosyöpäyhdistys ry
www.pulmones.fi/ajankohtaista

Suomen Syöpäpotilaat
www.syopapotilaat.fi

ALK FRANCE cancer poumon
www.alkros1francecancerpoumon.wordpress.com

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

ALK Positive Deutschland
www.alkpositiv-deutschland.org

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

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

zielGENau
www.zielgenau.org

Fairlife Lung Cancer Care
www.fairlifelcc.com

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

Lélek-zet Egyesület
www.lelekzetegyesulet.hu

Irish Lung Cancer Community
www.ilcc.ie

Israel Lung Cancer Foundation
www.ilcf.org.il

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

European School of Oncology
www.eso.net

Women Against Lung Cancer in Europe
www.womenagainstlungcancer.eu

Dzivibas Koks
www.dzivibaskoks.lv

Longkanker Nederland
www.longkankernederland.nl

Lungekreftforeningen
www.lungekreftforeningen.no

Pulmonale
www.pulmonale.pt

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

Punim plućima
www.punimplucima.rs

Društvo onkoloških bolnikov Slovenije
www.onkologija.org

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

Fundación MÁS QUE IDEAS
www.fundacionmasqueideas.org

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

ETOP IBCSG Partners Foundation
www.etop.ibcsg.org

Lungcancerförening
www.lungcancerforeningen.se

ALK Positive UK
www.alkpositive.org.uk

EGFR Positive UK
www.egfrpositive.org.uk

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

Oncogene Cancer Research
www.oncogeneresearch.org

ROS1der UK
www.ros1ders-cancer.uk

Athena Women against Cancer
www.athena-wac.com

ALK Positive Europe
www.alkpositiveeurope.org

8. ABOUT OUR SUPPORTERS AND FUNDING

We would like to thank our funding partners for their support of this project and LuCE, which is instrumental in driving our mission forward. Thank you for your commitment to people impacted by lung cancer.

Amgen, AstraZeneca, Bayer, Bristol Myers Squibb, Boehringer Ingelheim, Daiichi Sankyo, GenMab, Gilead, Johnson & Johnson, Lilly, Merck, MSD, Novartis, Pfizer, PharmaMar, Pierre Fabre, Regeneron, Roche, Takeda, and Thermo Fisher.

9. ANNEX

DETAILED BREAKDOWN OF PARTICIPANT CHARACTERISTICS

GENDER (%)

	All participants (n=2,180)
Female	78.4
Male	21.0
Non-binary	0.1
Prefer not to say	0.5
Prefer to self-describe	0.0

AGE (%)

	All participants (n=2,179)
18–24	0.5
25–34	2.6
35–44	8.8
45–54	21.7
55–64	35.9
65–74	24.2
75 or older	6.3

LEVEL OF EDUCATION (%)

	All participants (n=2,179)
Less than primary	0.3
Primary or lower secondary	6.9
Upper secondary / Post-secondary	35.7
Tertiary	57.1

STAGE AT DIAGNOSIS (%)

	All participants (n=2,176)
Localised (thorax): Stage 1-2	25.6
Locally advanced: Stage 3	16.7
Advanced: Stage 4	56.2
I don´t know	1.6

COUNTRY OF RESIDENCE (%)

		All participants (n=2,204)
1	France	17.2
2	United Kingdom	17.0
3	The Netherlands	11.3
4	Germany	8.6
5	Greece	6.6
6	Spain	5.7
7	Ukraine	5.3
8	Italy	5.0
9	Croatia	4.4
10	Hungary	2.4
11	Finland	2.2
12	Belgium	2.2
13	Portugal	2.1
14	Denmark	1.6
15	Israel	1.6
16	Sweden	1.5
17	Norway	1.4
18	Slovenia	1.2
19	Ireland	1.0
20	Austria	0.5
21	Poland	0.3
22	Switzerland	0.3
23	Latvia	0.2
24	Romania	0.2
25	Cyprus	0.1
26	Czech Republic (Czechia)	0.1
27	Estonia	0.1
28	Luxembourg	0.1
29	Malta	0.1
30	North Macedonia	0.1
31	Turkey	0.1

TUMOUR BIOMARKER (%)

	All participants (n=2,160)
EGFR	23.5
ALK	21.8
HER	21.3
I don´t know	21.1
PD-L1	17.0
ROS	13.8
FGFR	10.3
KRAS	6.0
BRAF	1.5
MET	1.4
RET	1.3
CTLA-4	0.2
NRAS	0.2
NTRK	0.2
NRG1	0.1
Other	2.8
No, the tumour is not positive for any biomarkers	10.6
The tumour has not been tested for biomarkers	8.6
Still in the process of biomarker testing	1.6

TYPE OF LUNG CANCER (%)

	All participants (n=2,176)
NSCLC adenocarcinoma	70.4
I don't know	7.3
SCLC	6.4
NSCLC squamous carcinoma	4.6
NSCLC other subtype	4.0
Another type of lung cancer	3.3
NSCLC large cell carcinoma	2.0
NSCLC adenosquamous carcinoma	1.5
NSCLC sarcomatoid carcinoma	0.6

TIME SINCE DIAGNOSIS (%)

	All participants (n=2,194)
Less than one year	24.5
1 to 3 years	36.2
Between 3 and 5 years	19.1
5 years or more	20.2

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Lung Cancer Europe

Many Faces, One Voice

www.lungcancereurope.eu

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