9th LuCE REPORT

Empowering voices:

Knowledge and decision-making among people impacted by lung cancer in the United Kingdom

An initiative of: LuCE Lung Cancer Europe

With the support of: ALK Positive UK, Lung Cancer Nursing UK, Oncogene Cancer Research

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FOREWORD

In recent years, Lung Cancer Europe (LuCE) has provided an overview of the barriers that we need to overcome in the European lung cancer community. With its 9th report, LuCE has focused on the importance of education and shared decision-making, as we believe there is room for improvement in this field.

Placing individuals at the centre of the care process is essential. When those impacted by lung cancer are empowered to take an active role in managing their disease, they are in the best position to understand what works for them. With the right information, they can make more informed decisions about their treatment options and ensure that it is aligned with their treatment goals. Some key findings from our report highlight several areas of importance such as the communication with healthcare professionals and the complexity of the medical information.

The need to improve access to information throughout the lung cancer journey remains crucial. Participants from the United Kingdom (UK) reported significant barriers to obtaining and understanding information, with some expressing a poor understanding of the disease.

This report highlights that most respondents from the UK impacted by lung cancer wish for their opinions to be acknowledged by healthcare providers; however, some feel that their perspectives are genuinely valued. This gap must be addressed. Healthcare providers should clearly explain the rationale behind treatment choices, even if it requires additional time. Documenting available treatment options is also important, so individuals can work collaboratively with their healthcare providers to decide on the best course of action, considering factors like side effects, drug toxicity, and the balance between quality and length of life.

DESCRIPTION AND METHODOLOGY

DESCRIPTION:

This report is a descriptive research analysis that explores the level of information, knowledge and decision-making involvement among those impacted by lung cancer in the UK. The purpose of this report is to gain a deeper understanding of their preferences and needs, and to explore measures that could better support people impacted by lung cancer. This project is part of a wider pan-European 9th LuCE Report `Empowering voices: Knowledge and decision-making among people impacted by lung cancer in Europe´.

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

METHODOLOGY:

An online survey was self-filled by people impacted by lung cancer in the WHO European Region. The survey, which was confidential and did not include questions related to personal information, was active from May 24th until July 7th, 2024.

This Country Report includes results obtained from 233 participants from the UK. This represented 11.4% of the total number of participants in the 9th LuCE Report[1]. All figures included in this report compare data collected from participants from the UK with the average of all participants.

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[1] *233 responses from the UK / 2,044 responses from the WHO European Region (including the UK responses)'*

Overview of participants from the UK characteristics:

80.7% People diagnosed with lung cancer (188)

19.3% Caregivers (45)

78.9% People with (or their loved one) NSCLC - adenocarcinoma (183)

72.5% Women (169)

27.5% Men (64)

45.5% ALK (106)

40.8% EGFR (95)

36.5% 55-64 age group (85)

27.5% 65-74 age group (64)

66.4% Stage IV (154)

19.0% Stage I-II (44)

51.5% Tertiary education (120)

39.5% Upper secondary (92)

58.8% 3rd level hospital (university) (137)

30.9% 2nd level hospital (regional) (72)

RESULTS

The majority of participants from the UK stated that information about lung cancer was very important, but 1 in 5 did not receive all the information that they needed.

Information about the disease is a key element to a better quality of life. Results from our research show high interest among people impacted by lung cancer in having access to medical and healthcare information. The majority of participants from the UK (84.5%) considered this information was extremely important.

However, participants reported significant barriers to getting information and being actively involved in their disease management.

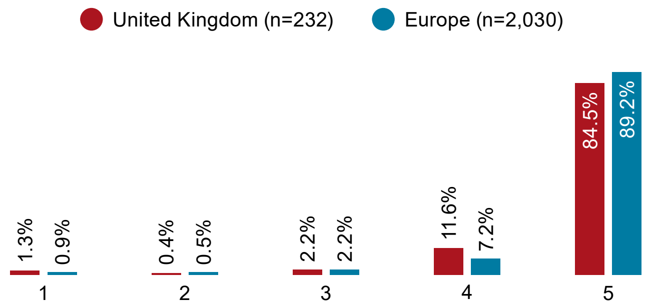
A total of 22.6% of participants highlighted that they did not receive enough information about their diagnosis, treatment and care. However, people impacted by lung cancer in the UK reported receiving all the information they needed (by *´quite a bit´* or *`very much´*) at a rate higher than the European average (77.4% *vs.* 59.8%).

> *I did not receive information about EGFR positive or detailed information about EGFR mutations from medics. I found it myself.*

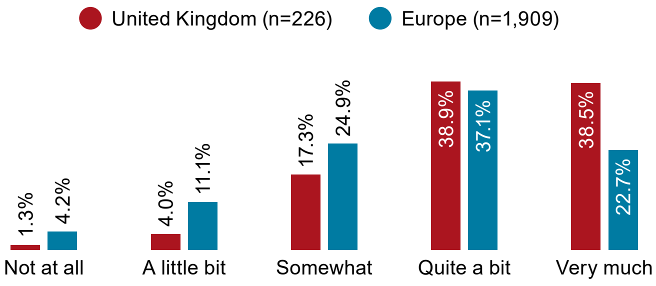
> *We do not have full access to clinical discussions about our case. Test results are not always discussed properly.*

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

1 is ‘not important at all’ and 5 is ‘extremely important´



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



> *We need clarity and simplicity of information, and ensuring patient understands each step before proceeding further*

The diagnostic pathway can be an emotionally intense time for people impacted by lung cancer. During challenging times, receiving information and empathy are crucial both physically and psychologically for diagnosis and treatment.

Approximately 60-70% received full diagnostic information and had good access to their healthcare team throughout the diagnostic pathway. Our data shows that around one-third of participants from the UK reported having insufficient information or lack of access to the healthcare team during these challenging times.

Around one-third of participants from the UK reported having insufficient information about the diagnostic pathway.

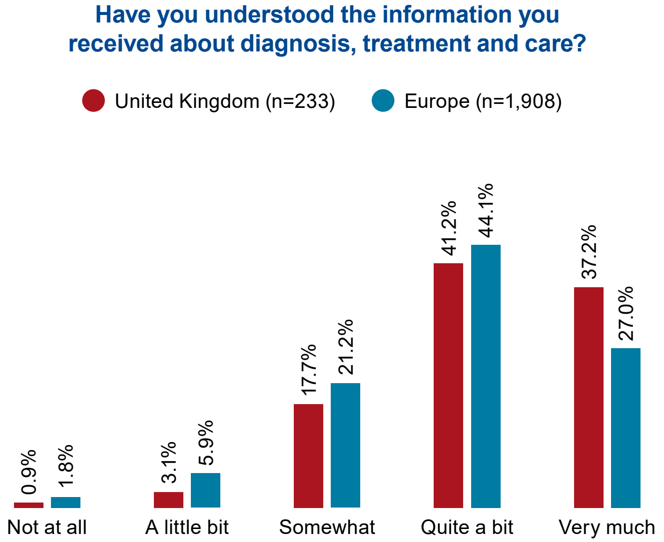
Which best describes your experience regarding the information you received along the diagnostic pathway?

United Kingdom (n=233) *vs.* **European average (n=2,036)**

	Not at all / A little bit	Somewhat	Quite a bit / Very much
We received information about the next steps along the diagnostic pathway	**14.6%**	**21.0%**	**64.4%**
	17.4%	**26.7%**	**56.0%**
We received information about the procedures relating to the diagnostic tests	**15.0%**	**21.5%**	**63.5%**
	21.4%	**26.1%**	**52.4%**
We were informed about the significance of the results	**12.0%**	**21.5%**	**66.5%**
	17.5%	**23.9%**	**58.6%**
We had proper access to the healthcare team during the diagnostic process	**12.9%**	**19.3%**	**67.8%**
	20.4%	**24.3%**	**55.3%**
We had the opportunity to receive answers to questions about the diagnostic process	**12.1%**	**19.8%**	**68.1%**
	19.6%	**23.8%**	**56.6%**

One in five participants from the UK reported having difficulty understanding the information they received.

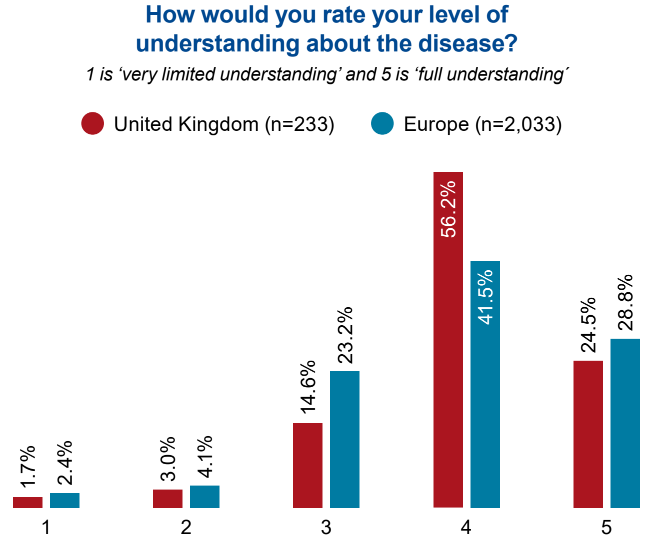
Our research identifies challenges in understanding the information received throughout the disease journey. A total of 21.7% of participants from the UK stated that they did not fully understand the information received about diagnosis, treatment and care. Only 37.2% of participants reported fully understanding all of the information received.



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

One in five participants from the UK did not have a good level of knowledge about their disease.

Our data suggest that the level of knowledge about lung cancer among those impacted by the disease in the UK is higher than the European average. Most participants from the UK (80.7%) reported having good understanding of the disease. However, we still find a significant number of participants – 1 out of 5 – who did not have a good level of knowledge about their disease.



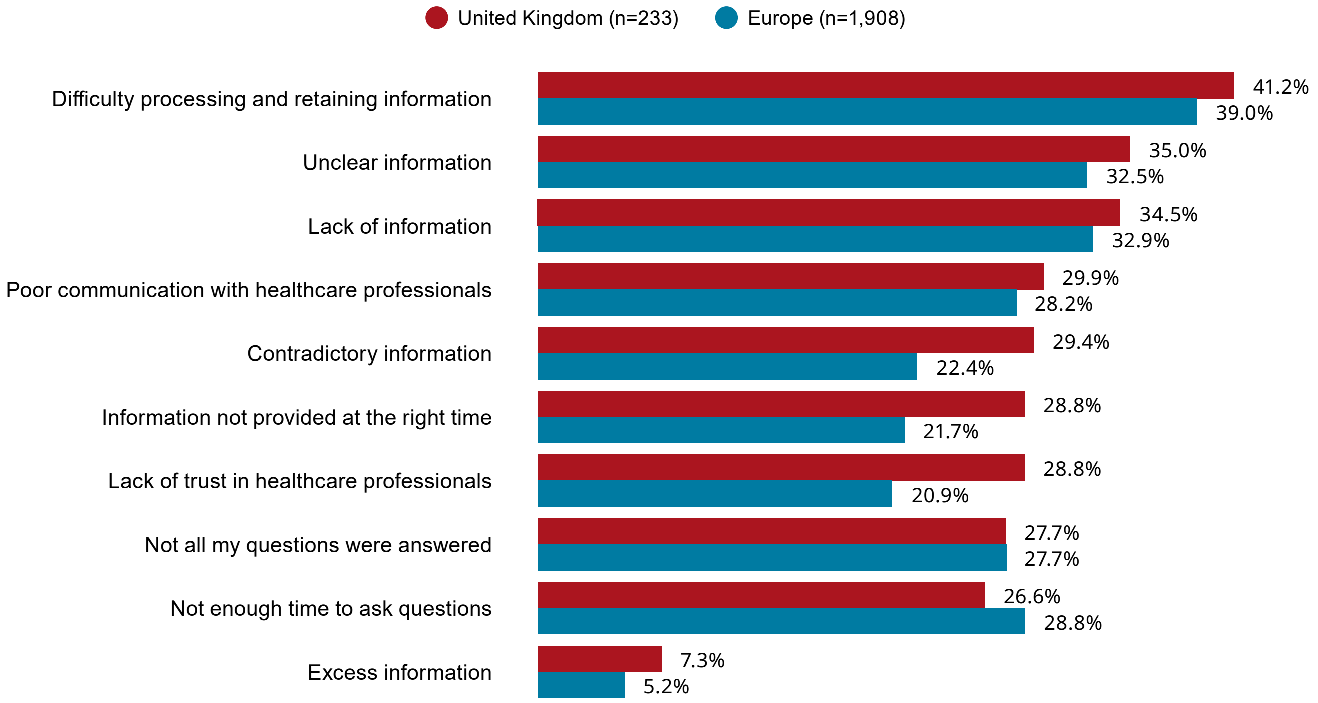
How would you rate your level of understanding about the disease?

1 is 'very limited understanding' and 5 is 'full understanding´

Despite having better rates of access to and understanding of information in the UK compared to the European average, participants from the UK reported more barriers to information and communication. Approximately, 1 out of 3 reported difficulties processing and retaining information (41.2%), unclear information (35.0%) or lack of information (34.5%).

Around 1 out of 4 participants from the UK reported barriers related to communication with healthcare providers, as well as a lack of trust in them.

Issues with communication with healthcare providers were also highlighted by a significant number of participants from the UK: poor communication with healthcare professionals (29.9%), contradictory information (29.4%), and information not provided at the right time (28.8%), among others. It is remarkable that 28.8% of participants from the UK reported a lack of trust in healthcare professionals, compared to 20.9% at the wider European level.



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

Clinical trials were reported as the main informational need by participants from the UK.

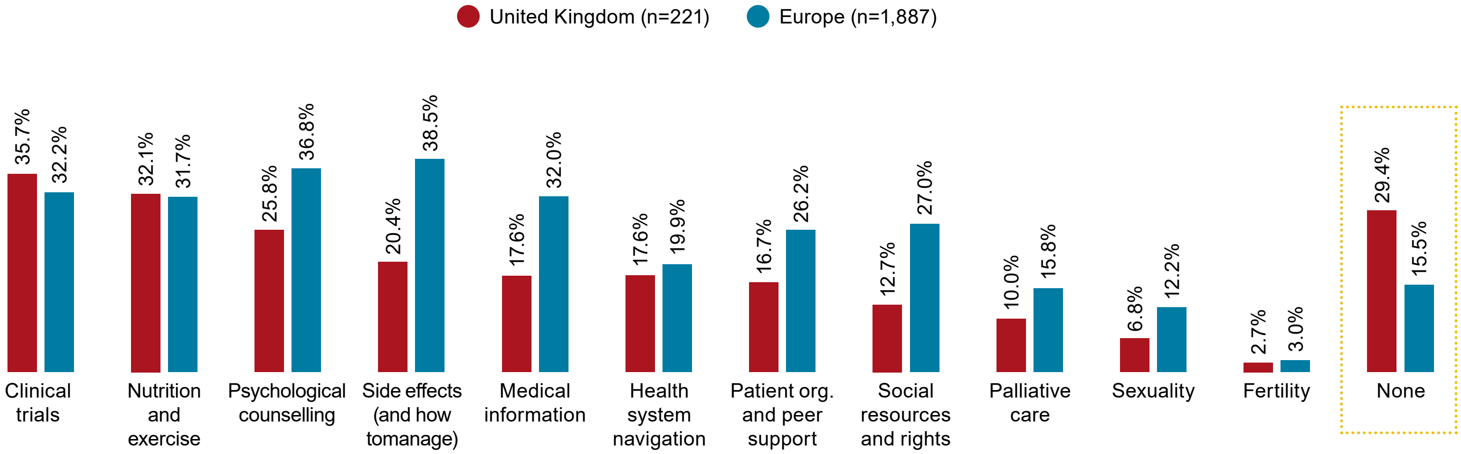
Information and support throughout the disease journey are crucial for appropriate care and well-being. However, 70.6% of respondents from the UK impacted by lung cancer reported lacking some form of support or information. The most frequently reported informational gaps were related to clinical trials (35.7%), nutrition and exercise (32.1%) and psychological counselling (25.8%).

> *Mental health, anxiety, panic attacks, and scan anxiety are not dealt with very well, yet they have a huge impact on your life when trying to cope with a cancer diagnosis.*

> *Very little information given or discussed about genetic mutations and their impact on the cancer, outcomes and different options available.*

> *Information about exercise and nutrition whilst living with cancer would be very helpful.*

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



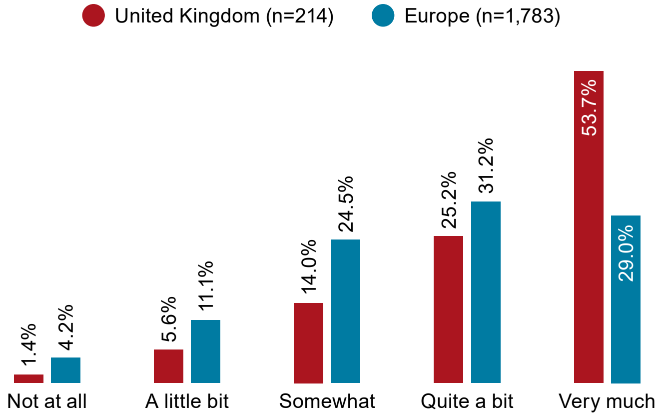
Healthcare providers have traditionally held the decision-making responsibility. However, there is a growing emphasis on shared decision-making, where people living with a disease, or their loved ones, are more actively involved in their healthcare decisions. This approach respects patient autonomy and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

> *Almost all participants from the UK believed that their opinions should be considered in the decision-making.*

Our research finds consensus on the importance of patient engagement in healthcare decisions. Almost all people surveyed in the UK (98.6%) believed their opinion must be considered in the decision-making process. Notably, 53.7% of UK respondents felt that their opinions must *'very much'* be incorporated into the conversations compared to 29.0% at the European level.

The person diagnosed with lung cancer has the right to make decisions about their treatment and care. Therefore, it is important to explore the differences between patients and caregivers. Notably, 99.4% of people from the UK with lung cancer surveyed believed that their opinion should be taken into account, with 87.8% strongly supporting this (`*very much*´ or `*quite a bit*´). On the other hand, 95.3% of caregivers surveyed also felt that their opinions should be considered in treatment and care discussions, with half (52.4%) believing their voice should be taken into account to some extent (`*a little bit*´ or `*somewhat*´).

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



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

Responses collected in the United Kingdom

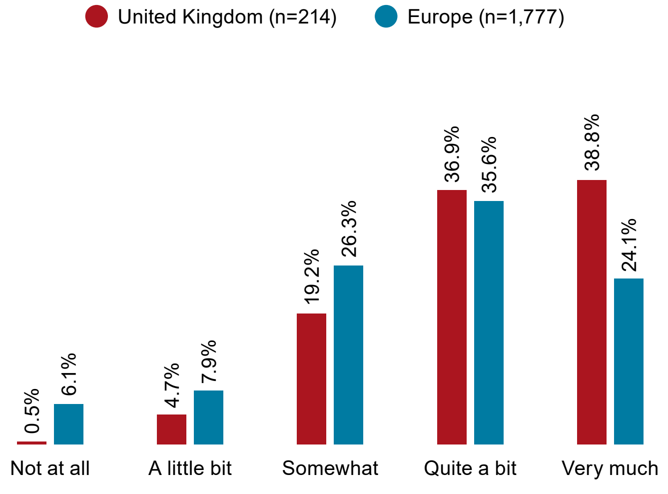
	People with lung cancer	Caregivers
Not at all	0.6%	4.7%
A little bit	2.3%	19.1%
Somewhat	9.3%	33.3%
Quite a bit	25.0%	26.2%
Very much	62.8%	16.7%

Eight out of ten participants from the UK were satisfied with their level of involvement in shared decision-making, with only 75.7% felt that treatment and care was aligned with their preferences.

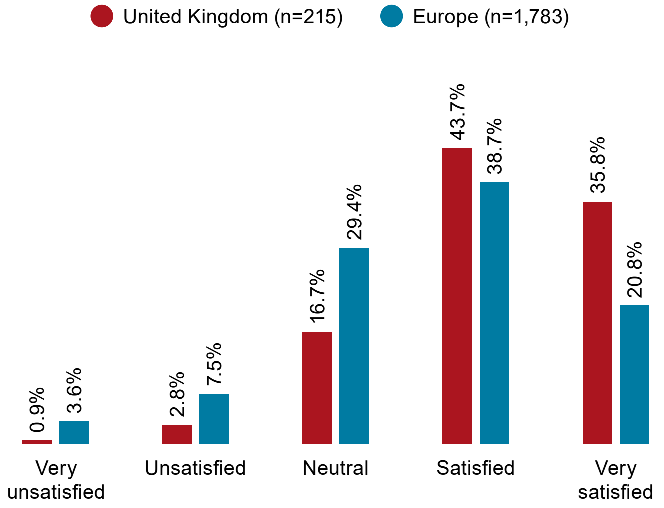
Despite the high interest of people impacted by lung cancer regarding shared decision-making, the data presented in this report highlights an insufficient involvement of patients and caregivers in this process. Consequently, only 75.7% of participants from the UK felt that the treatment and care plan aligned with patient preferences by *`quite a bit´* or *`very much´*[2].

Patient and caregiver satisfaction is an important factor in the healthcare journey. Out of all of the participants from the UK, 79.5% positively valued their involvement in the decision-making process, which was 20 percentage points higher that the European average (59.5%)[3].

Do you feel that your treatment and care has aligned with your personal preferences?[2]



How satisfied are you with your level of involvement in the treatment and care decision process?[3]



[2] *Question for caregivers was: `Do you feel that the treatment has aligned with the personal preferences of your loved one?´*

[3] *The question for caregivers stated: "Please respond based on their satisfaction with your level of involvement, rather than the patient's level of involvement"*

The main obstacle reported for participation in decision-making was the complex information.

It is crucial to have a good understanding of the disease and the various treatment and care options to effectively participate in decision-making. However, more than half of the participants from the UK (55.4%) recognised that the information was too difficult to understand. Complex information was identified as the main obstacle to meaningful participation in decision-making. Poor communication with healthcare professionals was selected as the second most common obstacle for meaningful participation in decision-making. Thus, there is an urgent need to improve the communication skills of healthcare providers and facilitate open and honest dialogue with patients and caregivers.

Based on your experience, what are the key obstacles to achieving meaningful participation in the decision-making processes?

	United Kingdom (n=202)	Europe (1,701)
Complex information (difficult to understand)	55.4%	49.2%
Poor communication with the healthcare team	31.2%	37.6%
Emotional difficulties in dealing with important decisions	29.7%	34.0%
Lack of self-confidence in participating in decision-making	22.8%	18.8%
Difficulties in finding trustworthy sources of information	21.8%	27.5%
Barriers to access to a second opinion	20.8%	20.0%

> *We should have information about the options and guidance and time to make a decision.*

> *You can’t advocate for yourself if you don’t know the questions to ask.*

> *The patients need support in engaging with the detailed and complex information about their diagnosis, prognosis and treatment options.*

> *We need more psychological support generally and those aimed at building confidence in the patient’s own wishes. Many patients are full of fear and afraid to seen to be difficult or don’t want to disagree with their oncologist or team.*

CALL TO ACTION

Healthcare professionals should offer complete, clear and comprehensive information about the disease and the treatment and supportive services available based on an individual´s preferences and needs.

Despite most participants considering health information to be very important, 1 in 5 reported having a poor understanding of lung cancer, and a similar proportion stated that they did not understand information about diagnosis and treatments.

Healthcare professionals should develop and implement a communication strategy to encourage and support shared decision-making.

Participation in decision-making is highly valued, but 1 in 4 did not feel that treatments were sufficiently aligned with their preferences. The complexity of the information and difficulties in communication with healthcare professionals have been identified as the main obstacles to effective participation in decision-making.

ABOUT US

LuCE
Lung Cancer Europe

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

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.

✉ **info@lungcancereurope.eu** **www.lungcancereurope.eu**

LuCE members in UK supporting this report

ALK Positive UK

www.alkpositive.org.uk

A registered charity established by patients, their families and friends.

Our Vision: People with ALK-positive lung cancer in the UK will thrive and live a long and fulfilling life unhindered by their disease. ALK Positive UK exists to:

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

Lung Cancer Nursing UK (LCNUK)

www.lcnuk.org

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

Oncogene Cancer Research

www.oncogeneresearch.org

Our mission at Oncogene Cancer Research is to extend both the length and quality of life of people living with oncogene-driven lung cancers.

We do this by focusing on three key areas:

- Accelerating research by funding promising projects, advocating at every stage—from trial design to access—and pushing for more clinical trials to open in the UK.
- Empowering patients and caregivers with knowledge and resources so they can make informed decisions about their care.
- Champion advocacy to ensure the patient voice is heard at every level.

Lung Cancer Europe

Many Faces, One Voice

www.lungcancereurope.eu

Lung Cancer Europe (LuCE) is the voice of Europeans
impacted by or at risk of lung cancer

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