9th LuCE REPORT

Empowering voices:

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

An initiative of: Lung Cancer Europe

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TABLE OF CONTENTS:

FOREWORD

In recent years, Lung Cancer Europe (LuCE) has worked to highlight the barriers faced by people affected by lung cancer across Europe. In its 9th report, LuCE focuses on the importance of education and shared decision-making—areas where there is still considerable room for improvement.

This report is particularly relevant for individuals living with ALK-positive lung cancer, a specific subtype that, although relatively rare, often affects younger, non-smoking individuals. Targeted therapies have significantly changed the outlook for many of these patients.

Placing individuals at the center of the care process is not only a guiding principle but a practical necessity. When patients are empowered with the right information, they are better equipped to play an active role in managing their condition, understanding what works best for them, and making informed choices aligned with their personal goals and values.

Some of the key findings from this report highlight critical areas for improvement, including communication with healthcare professionals and the complexity of medical information. Participants impacted by ALK-positive lung cancer in the United Kingdom reported significant barriers in accessing and understanding information, with some expressing a limited understanding of their disease.

It is clear that many people affected by ALK-positive lung cancer wish for their opinions to be heard and respected. Yet, not all feel their perspectives are genuinely valued. Bridging this gap is essential. Healthcare professionals must take the time to clearly explain treatment options, including potential side effects and long-term impacts, so that patients can actively participate in choosing the best course of action—balancing quality of life, treatment goals, and personal values.

Lung Cancer Europe

ALK POSITIVE UK

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 ALK-positive lung cancer in the United Kingdom. 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 Report includes results obtained from 106 participants impacted by ALK-positive lung cancer in the UK. This represented 5.2% of the total number of participants in the 9th LuCE Report[1]. All figures included in this report compare data collected from individuals impacted by ALK-positive lung cancer in the UK with the average of all participants.

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[1] *106 responses from individuals with ALK+ lung cancer in the UK / 2,044 responses from the WHO European Region (including the UK responses)*

Overview of ALK positive participants from the UK characteristics:

85.8% People diagnosed with ALK-positive lung cancer (91)

14.2% Caregivers (15)

65.1% Women (69)

34.9% Men (37)

39.6% 55-64 age group (42)

20.8% 45-54 age group (22)

20.8% 65-74 age group (22

59.4% Tertiary education (63)

32.1% Upper secondary (34)

79.2% People with (or their loved one) NSCLC - adenocarcinoma (84)

82.1% Stage IV (87)

9.4% Stage III (10)

58.5% 3rd level hospital (university) (62)

33.0% 2nd level hospital (regional) (35)

RESULTS

The majority of participants affected by ALK-positive lung cancer in the UK stated that information about lung cancer was very important, but 20% 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 impacted by ALK-positive lung cancer in the UK (86.8%) considered this information was extremely important.

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

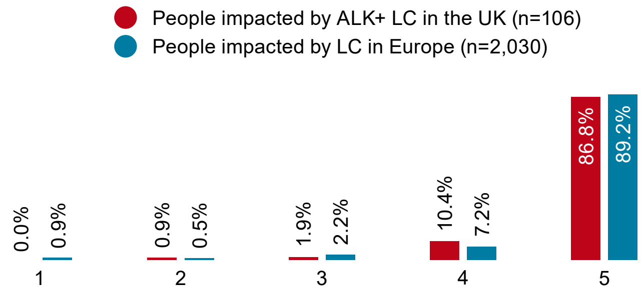
A total of 20.6% of participants highlighted that they did not receive enough information about their diagnosis, treatment and care. However, people impacted by ALK-positive lung cancer in the UK reported receiving all the information they needed at a rate higher than the European average (79.4% vs. 59.8%).

> *The process was basically 'this is what you have, we can't cure you, this is the treatment' and after getting the breadcrumbs of information I've been away and spoken to various people some patients and some healthcare practitioners.*

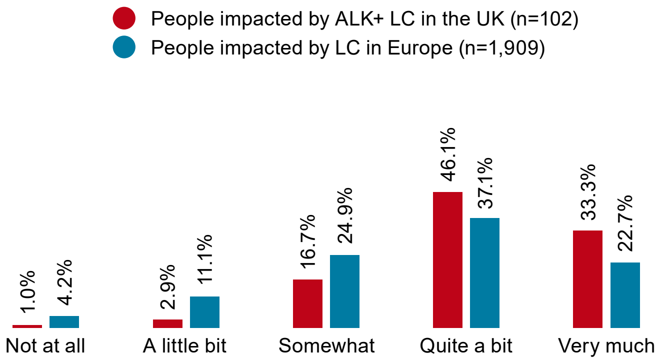
> *Even with the ALK+ diagnosis, I didn't understand what it meant to start with and it took me time to be able to reach out and learn more.*

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



> *A major problem is that most patients' (including mine) level of understanding of lung cancer is so much lower than those of the healthcare professionals treating it, that it can be difficult to have a meaningful dialogue.*

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 55-65% received full diagnostic information and had good access to their healthcare team throughout the diagnostic pathway. Our data shows that around four in ten participants affected by ALK-positive lung cancer in the UK reported having insufficient information or lack of access to the healthcare team during these challenging times.

Around four in ten of participants impacted by ALK-positive lung cancer in the UK reported having insufficient information about the diagnostic pathway.

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

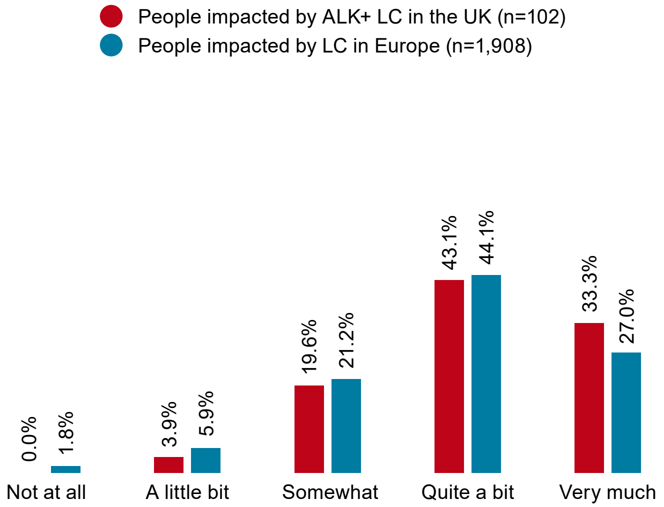
People impacted by ALK+ LC in the UK (n=106) *vs.* **People impacted by LC in Europe (n=2,036)**

	Not at all / A little bit	Somewhat	Quite a bit / Very much
We received information about the next steps along the diagnostic pathway	**23.6%**	**19.8%**	**56.6%**
	17.4%	**26.7%**	**56.0%**
We received information about the procedures relating to the diagnostic tests	**22.6%**	**23.6%**	**53.8%**
	21.4%	**26.1%**	**52.4%**
We were informed about the significance of the results	**14.2%**	**23.6%**	**62.3%**
	17.5%	**23.9%**	**58.6%**
We had proper access to the healthcare team during the diagnostic process	**17.9%**	**18.9%**	**63.2%**
	20.4%	**24.3%**	**55.3%**
We had the opportunity to receive answers to questions about the diagnostic process	**16.0%**	**19.8%**	**64.2%**
	19.6%	**23.8%**	**56.6%**

> *One in four participants reported having difficulty understanding the information they received.*

Our research identifies challenges in understanding the information received throughout the disease journey. A total of 23.5% of participants impacted by ALK-positive lung cancer in the UK stated that they had difficulty understanding the information received about diagnosis, treatment and care. Only 33.3% of participants reported fully understanding all of the information received.

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

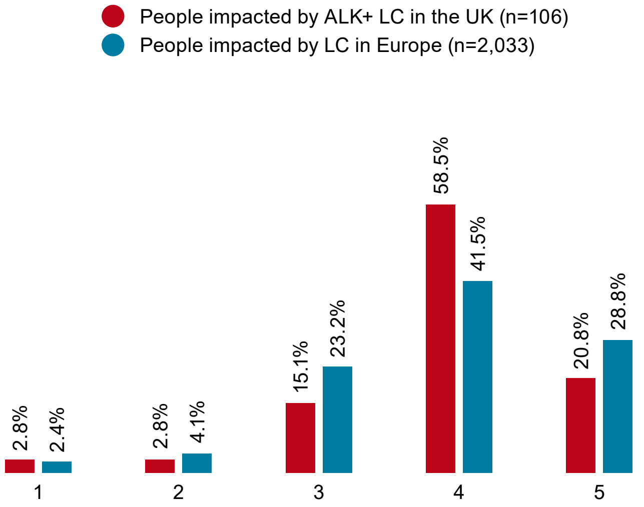


> *Two in ten participants did not have a good level of knowledge about their disease.*

Our data suggest that the level of knowledge about lung cancer among those affected by ALK-positive lung cancer in the UK is higher than the European average. Most participants (79.3%) reported having good understanding of the disease. However, we still find a significant number of participants – 2 out of 10 – 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'

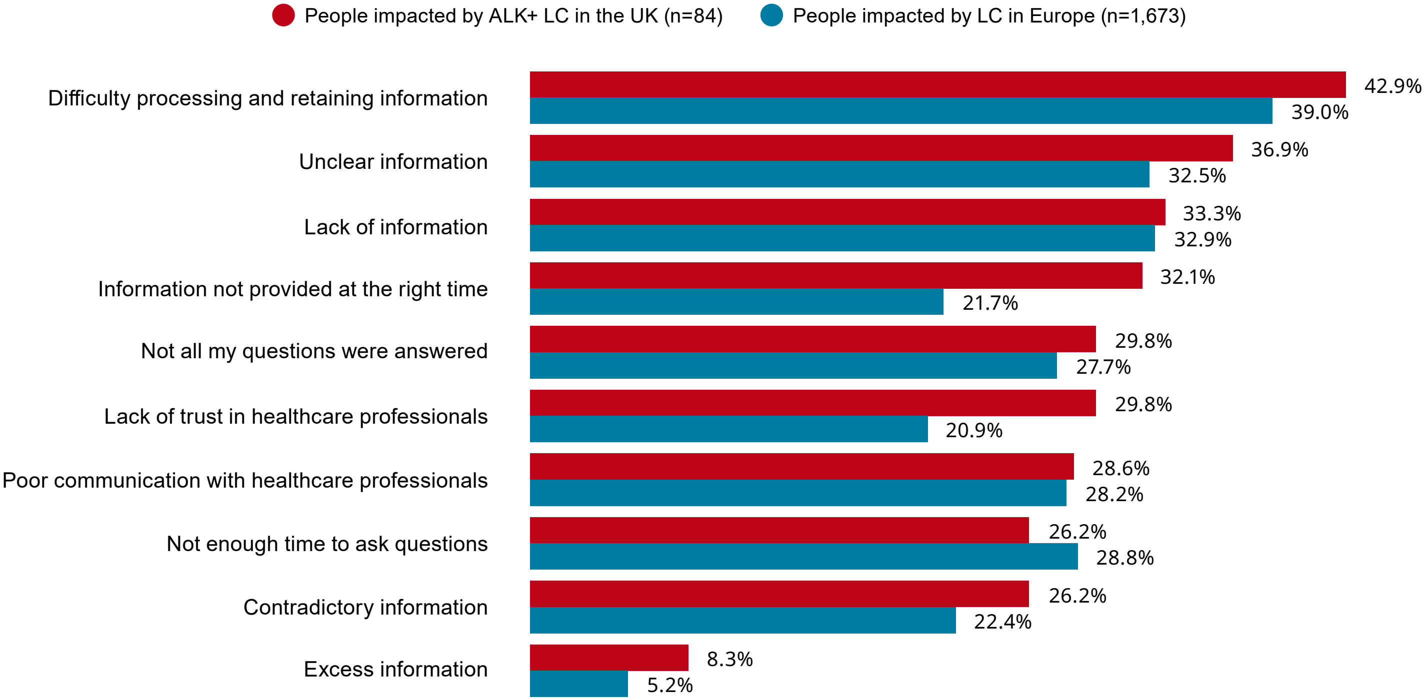


Despite reporting better overall rates of access to and understanding of information compared to the European average, participants affected by ALK-positive lung cancer in the UK experienced more barriers related to information and communication. The most commonly reported barrier was difficulty processing and retaining information (42.9%), followed by unclear information (36.9%) and a lack of information (33.3%).

Around 30% of participants impacted by ALK-positive lung cancer in the UK reported barriers related to communication with healthcare providers, as well as a lack of trust in them.

Communication issues with healthcare providers were also highlighted by a considerable number of respondents. These included information not being provided at the right time (32.1%) and not all questions being answered (29.8%). Notably, 29.8% of participants reported a lack of trust in healthcare professionals—higher than the European average of 20.9%—and a similar percentage (28.6%) cited poor communication with their healthcare providers.

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



Clinical trials were reported as the main informational need by participants impacted by ALK-positive lung cancer in the UK.

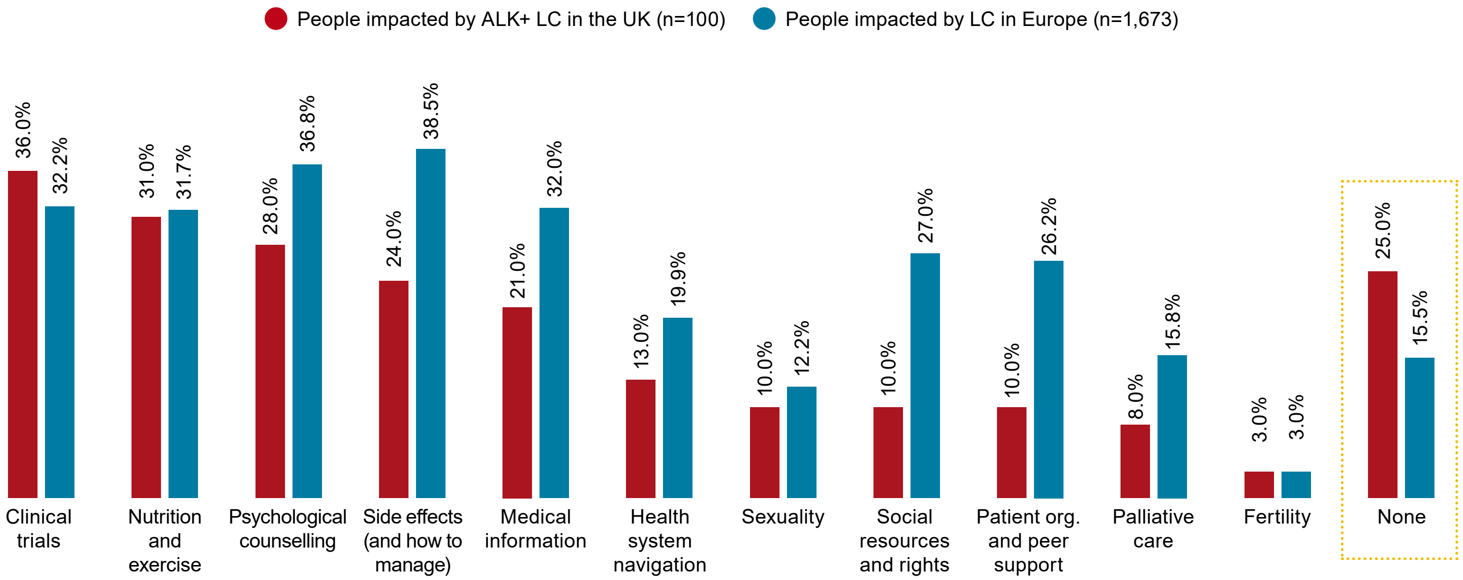
Information and support throughout the disease journey are crucial for appropriate care and well-being. However, 75% of respondents affected by ALK-positive lung cancer in the UK impacted by lung cancer reported lacking some form of support or information. The most frequently reported informational gaps were related to clinical trials (36%), nutrition and exercise (31%) and psychological counselling (28%).

> *We need a more holistic approach to treatment involving medical, nursing, physiotherapy and psychological staff and support.*

> *The emotional distress of diagnosis can feel as hard as any physical symptoms or side effects. Information about exercise and nutrition whilst living with cancer would be very helpful.*

> *If it had not been for ALK+ UK and ALK+ Inc (US) I would not be so well-informed. Real issue is a national standard for MRI and CT scans, particularly when you are away from London, Manchester and Cambridge.*

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



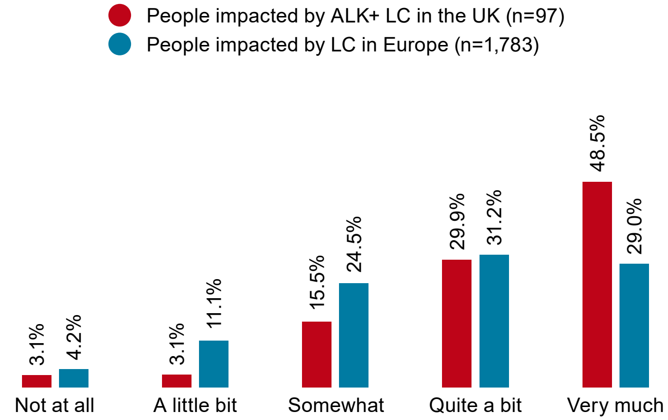
Healthcare providers have traditionally held the decision-making responsibility. However, there is a growing emphasis on shared decision-making, where people living with a disease, or their loved ones, are more actively involved in their healthcare decisions. This approach respects patient autonomy and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

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

Our research finds consensus on the importance of patient engagement in healthcare decisions. Almost all people impacted by ALK-positive lung cancer in the UK (96.9%) believed their opinion must be considered in the decision-making process. Notably, 48.5% of them felt that their opinions must *‘very much’* be incorporated into the conversations ´, compared to 29% 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, 98.8% of ALK-positive lung cancer patients surveyed believed that their opinion should be taken into account, with 83.4% strongly supporting this (`*very much*´ or `*quite a bit*´). On the other hand, 84.6% of caregivers surveyed felt that their opinions should be considered in treatment and care discussions, with almost half (46.1%) believing their voice should be strongly taken into account (‘*very much’* or ‘*quite a bit’*).

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 by
participants affected by ALK-positive lung cancer

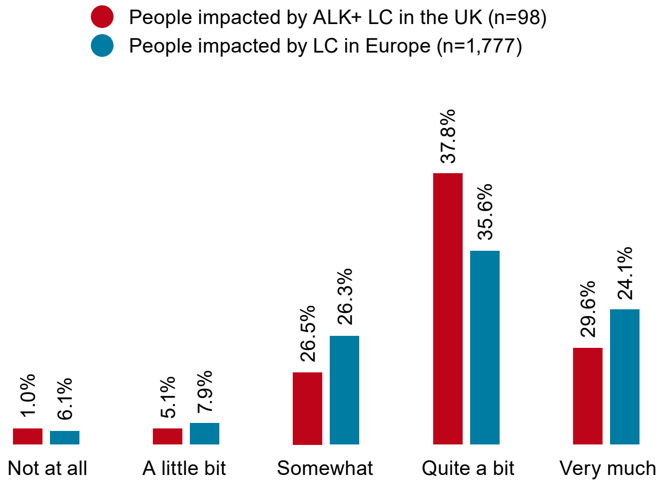
	People with lung cancer	Caregivers
Not at all	1.2%	15.4%
A little bit	1.2%	15.4%
Somewhat	14.3%	23.1%
Quite a bit	29.8%	30.7%
Very much	53.6%	15.4%

Three in four participants were satisfied with their level of involvement in shared decision-making, with only 67.4% felt that treatment and care was aligned with their preferences.

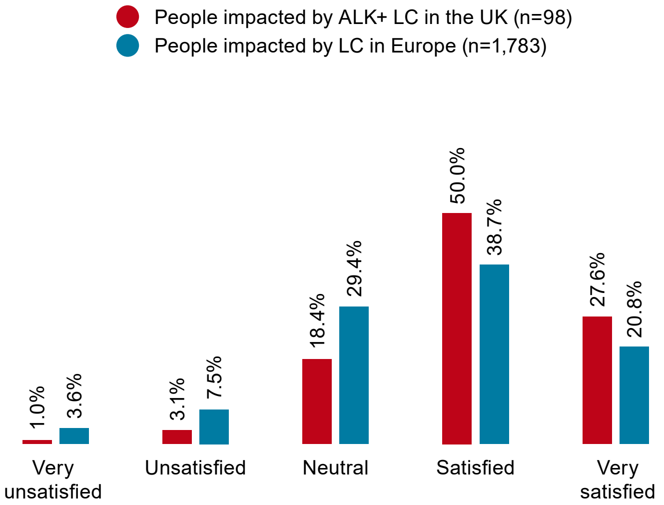
Despite the high interest of people impacted by lung cancer regarding shared decision-making, the data presented in this report highlights an insufficient involvement of patients and caregivers in this process. Consequently, only 67.4% of participants impacted by ALK-positive lung cancer in the UK felt 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 impacted by ALK-positive lung cancer in the UK, 76.6% positively valued their involvement in the decision-making process, which was 17 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]



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[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 impacted by ALK-positive lung cancer in the UK (57%) recognised that the information was too difficult to understand. Complex information was identified as the main obstacle to meaningful participation in decision-making. Emotional difficulties in dealing with decisions and poor communication with healthcare professionals was selected as the second and third 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?

	People impacted by ALK+ LC in the UK (n=93)	People impacted by LC in Europe (n=1,701)
Complex information (difficult to understand)	**57%**	**49.2%**
Emotional difficulties in dealing with important decisions	**35.5%**	**34.0%**
Poor communication with the healthcare team	**31.2%**	**37.6%**
Lack of self-confidence in participating in decision-making	**25.8%**	**18.8%**
Barriers to access to a second opinion	**24.7%**	**20.0%**
Difficulties in finding trustworthy sources of information	**18.3%**	**27.5%**

> *I feel some patients will feel backed into a corner to accept the treatment plan with no second opinions.*

> *Many patients are full of fear and afraid to seen to be difficult or don't want to disagree with their oncologist or team.*

> *We need more open discussion and consistency of care. Rarely talk to same consultant twice.*

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

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, 20.7% reported having a poor understanding of lung cancer, and a similar proportion (23.5%) 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 32.6% 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 key barriers to effective involvement in treatment decisions.

ABOUT US

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**

This report has been made possible thanks to the collaboration of:

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 Europe

Many Faces, One Voice

www.lungcancereurope.eu

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