9th LuCE REPORT

Empowering voices:

Knowledge and decision-making among people impacted by oncogene-driven lung cancers in Europe

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Lung Cancer Europe

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This is an annual initiative led by Lung Cancer Europe (LuCE) with the purpose of raising awareness relating to the main challenges faced by people impacted by this disease.

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Organisations

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- IPOP
- ILCC Irish Lung Cancer Community
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- WALCE Women Against Lung Cancer in Europe
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INTRODUCTION

In recent years, Lung Cancer Europe (LuCE) has identified barriers to care in the European lung cancer community. With its current 9th report, LuCE has focused on the importance of education and shared decision-making, as we believe there is room for improvement within these fields.

Person-centred care 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 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 communication with healthcare professionals and understanding the complexity of medical information.

The need to improve access to information throughout the lung cancer journey remains crucial. Participants impacted by oncogene-driven lung cancers reported significant barriers to obtaining and understanding information, with some expressing a poor understanding of the disease.

Only some of the participants with oncogene driven disease felt that their perspectives were genuinely acknowledged, however, this reports highlights participant’s wishes that their opinions be acknowledged by healthcare providers. This gap must be addressed. Physicians 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 physicians to decide on the best course of action, considering factors like side effects, drug toxicity, and the balance between quality and length of life.

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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 certain types of oncogene-driven lung cancers in Europe[1]. The purpose 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 1,078 participants impacted by oncogene-driven lung cancers in Europe. This represented 52.7% of the total number of participants in the 9th LuCE Report . All figures included in this report compare data collected from individuals impacted by oncogene-driven lung cancers in Europe with the average of all participants (including the oncogene drive cohort).

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[1] *This report includes responses from participants impacted by ALK-, EGFR-, KRAS-, PD-L1-, and ROS1-driven lung cancer in Europe*

[2] *1,078 responses from individuals impacted by certain types of oncogene-driven lung cancers in Europe / 2,044 responses from the WHO European Region*

Overview of participants from the UK characteristics:

This report only includes responses from participants affected by specific oncogene drivers for which we received a minimum number of responses. These are ALK, EGFR, KRAS, PD-L1 and ROS1. Others, such as BRAF or MET, were not included because the low number of responses was insufficient to support a meaningful analysis of these cohorts.

Here are the response percentages based on tumour mutation: EGFR (22.2%), ALK (20.9%), PD-L1 (8.2%), KRAS (5.7%), ROS1 (3.8%), BRAF (1.6%), MET (1.3%), HER2 (0.8%), RET (0.6%), FGFR1 (0.3%), CTLA-4 (0.3%), NTRK (0.3%), NRAS (0.2%) and NRG1 (0.1%).

	ALK	EGFR	KRAS	PD-L1	ROS1
Patient / Caregiver	**79.9%** - Patients **20.1%** - Caregivers	**79.7%** - Patients **20.3%** - Caregivers	**75.0%** - Patients **25.0%** - Caregivers	**74.1%** - Patients **25.9%** - Caregivers	**88.2%** - Patients **11.8%** - Caregivers
Gender	**73.7%** - Women **26.3%** - Men	**82.7%** - Women **17.1%** - Men	**78.4%** - Women **21.6%** - Men	**75.3%** - Women **24.7%** - Men	**78.9%** - Women **21.1%** - Men
Age	**33.6%** - 55-64 **25.6%** - 45-54	**34.2%** - 55-64 **24.1%** - 65-74	**36.5%** - 55-64 **27.8%** - 65-74	**39.2%** - 55-64 **19.9%** - 45-54	**40.8%** - 55-64 **22.4%** - 45-54
Education	**61.4%** - Tertiary education	**57.6%** - Tertiary education	**53.4%** - Tertiary education	**64.5%** - Tertiary education	**61.8%** - Tertiary education
Type of lung cancer	**82.9%** - NSCLC – adenocarcinoma	**87.2%** - NSCLC - adenocarcinoma	**83.5%** - NSCLC - adenocarcinoma	**81.2%** - NSCLC - adenocarcinoma	**85.5%** - NSCLC - adenocarcinoma
Stage of lung cancer	**74.4%** - Stage IV **15.6%** - Stage III	**68.6%** - Stage IV **19.2%** - Stage I-II	**55.7%** - Stage IV **23.5%** - Stage III	**63.0%** - Stage IV **26.7%** - Stage III	**69.7%** - Stage IV **15.8%** - Stage III
Type of hospital	**61.8%** - 3rd level hospital (university) **28.2%** - 2nd level hospital (regional)	**58.3%** - 3rd level hospital (university) **30.5%** - 2nd level hospital (regional)	**64.7%** - 3rd level hospital (university) **19.8%** - 2nd level hospital (regional)	**62.7%** - 3rd level hospital (university) **27.7%** - 2nd level hospital (regional)	**66.7%** - 3rd level hospital (university) **26.7%** - 2nd level hospital (regional)

RESULTS

The majority of participants impacted by oncogene-driven lung cancers stated that information about the disease was very important, but around 4 in 10 did not receive all the information that they needed.

Information about the disease is a key element for 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 oncogene-driven lung cancers considered this information extremely important.

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

Around 35-45% of participants impacted by oncogene-driven lung cancers highlighted that they did not receive enough information about their diagnosis, treatment and care. The group that most frequently reported receiving all the necessary information were those with EGFR positive disease (66%), while those with PD-L1 reported it the least (53.2%). The European average was 59.8%.

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

Where 1 is 'not important at all' and 5 is 'extremely important'

	1	2	3	4	5
ALK (n=421)	0.0%	0.7%	2.1%	6.2%	91.0%
EGFR (n=439)	0.9%	0.0%	1.4%	6.8%	90.9%
KRAS (n=116)	0.9%	0.9%	3.4%	6.0%	88.8%
PD-L1 (n=165)	0.6%	1.2%	0.6%	2.4%	95.2%
ROS1 (n=76)	1.3%	0.0%	1.3%	6.6%	90.8%
All respondents (n=2,030)	0.9%	0.5%	2.2%	7.2%	89.2%

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

	Not at all	A little bit	Somewhat	Quite a bit	Very much
ALK (n=404)	2.7%	9.7%	23.5%	41.6%	22.5%
EGFR (n=421)	1.9%	9.7%	22.3%	43.2%	22.8%
KRAS (n=108)	2.8%	9.3%	31.5%	34.3%	22.2%
PD-L1 (n=158)	5.1%	17.7%	24.1%	39.2%	13.9%
ROS1 (n=75)	4.0%	10.7%	22.7%	45.3%	17.3%
All respondents (n=1,909)	4.2%	11.1%	24.9%	37.1%	22.7%

> *I missed more detailed and better-explained information, as well as ability to listen more to the patient.*

> *We should be better informed by medical teams, with enough time in consultations to understand and decide properly.*

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

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

Our data shows that a significant proportion of participants impacted by oncogene-driven lung cancers reported having insufficient information or lack of access to the healthcare team during these challenging times (the percentage ranges from 37% to 56%, depending on the indicator and the oncogene driven group surveyed).

More than 1 in 3 participants affected by an oncogene-driven lung cancer reported having insufficient information about the diagnostic pathway.

We received information about the next steps along the diagnostic pathway

	Not at all / A little bit	Somewhat	Quite a bit / Very much
ALK (n=422)	17.5%	29.4%	53.1%
EGFR (n=439)	16.2%	25.5%	58.3%
KRAS (n=116)	16.4%	20.7%	62.9%
PD-L1 (n=166)	22.9%	30.7%	46.4%
ROS1 (n=76)	19.7%	32.9%	47.4%
All respondents (n=2,036)	17.4%	26.7%	56.0%

We received information about the procedures relating to the diagnostics tests

	Not at all / A little bit	Somewhat	Quite a bit / Very much
ALK (n=422)	20.9%	30.3%	48.8%
EGFR (n=438)	19.9%	24.0%	56.2%
KRAS (n=116)	22.4%	25.0%	52.6%
PD-L1 (n=166)	26.5%	30.1%	43.4%
ROS1 (n=76)	25.0%	27.6%	47.4%
All respondents (n=2,036)	21.4%	26.1%	52.4%

We were informed about the significance of the results

	Not at all / A little bit	Somewhat	Quite a bit / Very much
ALK (n=422)	14.0%	24.9%	61.1%
EGFR (n=438)	15.6%	22.4%	62.0%
KRAS (n=116)	20.7%	22.4%	56.9%
PD-L1 (n=166)	25.5%	23.6%	50.9%
ROS1 (n=76)	18.4%	23.7%	57.9%
All respondents (n=2,036)	17.5%	23.9%	58.6%

We had proper access to the healthcare team during the diagnostic process

	Not at all / A little bit	Somewhat	Quite a bit / Very much
ALK (n=422)	18.5%	26.1%	55.5%
EGFR (n=438)	18.7%	22.6%	58.7%
KRAS (n=116)	17.2%	25.9%	56.9%
PD-L1 (n=166)	26.5%	24.7%	48.8%
ROS1 (n=76)	23.7%	18.4%	57.9%
All respondents (n=2,036)	20.4%	24.3%	55.3%

We had the opportunity to receive answers to our questions about the diagnostic process

	Not at all / A little bit	Somewhat	Quite a bit / Very much
ALK (n=422)	17.8%	26.3%	55.9%
EGFR (n=439)	16.2%	24.6%	59.2%
KRAS (n=116)	19.0%	25.9%	55.2%
PD-L1 (n=166)	24.7%	26.5%	48.8%
ROS1 (n=76)	22.4%	19.7%	57.9%
All respondents (n=2,036)	19.6%	23.8%	56.6%

Around 1 in 4 participants impacted by oncogene-driven lung cancers reported having difficulty understanding the information they received.

Our research identifies challenges in understanding the information received throughout the disease journey. Around 1 in 4 participants impacted by oncogene-driven lung cancers stated that they did not fully understand the information received about the diagnosis, treatment and care.

The group that most frequently reported a good understanding[3] were those with ROS1 (77.3%), while those with KRAS and PD-L1 reported it the least (69.2% and 69.4% respectively). The European average was 71.1%.

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

	Not at all	A little bit	Somewhat	Quite a bit	Very much
ALK (n=403)	1.0%	3.7%	21.6%	44.9%	28.8%
EGFR (n=423)	0.7%	4.0%	21.3%	45.2%	28.8%
KRAS (n=107)	0.9%	4.7%	25.2%	42.1%	27.1%
PD-L1 (n=157)	2.5%	8.3%	19.7%	49.0%	20.4%
ROS1 (n=75)	0.0%	4.0%	18.7%	52.0%	25.3%
All respondents (n=1,908)	1.8%	5.9%	21.2%	44.1%	27.0%

Only around 1 in 4 participants impacted by oncogene-driven lung cancers had a very good level of knowledge about their disease.

Only around 1 in 4 participants affected by oncogene-driven lung cancers reported fully understanding all the information they received.

Even though most participants reported having a good understanding of the disease, we still find a significant number of participants who did not have a good level of knowledge about their disease: 31.3% for PD-L1; 30.3% for ROS1, 27.8% for KRAS, 27.5% for ALK, and 24.7% for EGFR.

The group that most frequently reported having a good understanding of the disease[4] were those with EGFR (75.3%), while those with PD-L1 reported it the least (68.7%). The European average was 70.3%.

How would you rate your level of understanding about the disease? 1 is ‘very limited understanding’ and 5 is ‘full understanding´

	1	2	3	4	5
ALK (n=422)	1.2%	3.1%	23.2%	45.7%	26.8%
EGFR (n=438)	1.1%	2.3%	21.2%	48.6%	26.7%
KRAS (n=116)	1.7%	1.7%	24.3%	40.0%	32.2%
PD-L1 (n=166)	3.0%	4.8%	23.5%	41.6%	27.1%
ROS1 (n=76)	3.9%	1.3%	25.0%	47.4%	22.4%
All respondents (n=2,036)	2.4%	4.1%	23.2%	41.5%	28.8%

[3] *Responses `Quite a bit´ and `Very much´*
[4] *Responses `4´ and `5´*

Difficulties processing and retaining information was reported as the most frequent barrier related to the information.

Participants impacted by oncogene-driven lung cancers reported specific barriers to information about the disease. The most frequent barriers reported were difficulties processing and retaining information due to emotional distress, unclear information and lack of information.

Issues with communication with healthcare providers were also highlighted by a significant number of participants. These included poor communication with healthcare professionals, a lack of time to ask questions, or not having all their questions answered.

Top 4 difficulties related to the information[5]?

ALK (n=344)	
Difficulty processing and retaining information due to emotional distress	41.3%
Unclear information	34.6%
Lack of information	31.4%
Not all my questions were answered	29.9%

EFGR (n=379)	
Difficulty processing and retaining information due to emotional distress	46.4%
Unclear information	30.3%
Lack of information	28.5%
Not all my questions were answered	26.6%

KRAS (n=95)	
Unclear information	41.3%
Lack of information	33.7%
Difficulty processing and retaining information due to emotional distress	32.6%
Poor communication with healthcare professionals	32.6%

PD-L1 (n=144)	
Lack of information	39.6%
Difficulty processing and retaining information due to emotional distress	36.1%
Poor communication with healthcare professionals	36.1%
Unclear information	34.7%
Not all my questions were answered	34.7%

ROS1 (n=64)	
Difficulty processing and retaining information due to emotional distress	42.2%
Lack of information	39.1%
Unclear information	32.8%
Not enough time to ask questions	29.7%

All survey respondents (n=1,673)	
Difficulty processing and retaining information	39.0%
Lack of information	32.9%
Unclear information	32.5%
Not enough time to ask questions	28.8%

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[5] *The questions asked was `Have you ever experienced any of the following during the disease journey?´*

Clinical trials and side effects were reported as the main informational needs by participants affected by oncogene-driven lung cancers.

Information and support throughout the disease journey are crucial for appropriate care and well-being. However, around 85% of respondents impacted by oncogene-driven lung cancers reported lacking some form of support or information. The most frequently reported informational gaps were related to clinical trials and side effects. Other significant needs were related to nutrition and exercise, medical information, and psychological counselling. Notably, 4 in 10 respondents impacted by ROS1-driven lung cancer reported lacking sufficient information about patient organisations, peer support, and NGOs.

> *Side effects are barely mentioned for fear of frightening the patient. I felt like I was undergoing the treatment process without any choice.*

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

> *Better access to disease-related information, often only available through patient organisations.*

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

ALK (n=398)	
Side effects	39.2%
Nutrition and exercise	38.9%
Clinical trials	36.4%
Psychological counselling	36.2%
None	16.1%

EFGR (n=417)	
Clinical trials	37.2%
Side effects	37.2%
Nutrition and exercise	35.5%
Psychological counselling	35.0%
None	16.5%

KRAS (n=107)	
Clinical trials	40.2%
Side effects	34.6%
Medical information	32.7%
Psychological counselling	32.7%
None	17.8%

PD-L1 (n=157)	
Medical information	41.4%
Side effects	40.1%
Clinical trials	39.5%
Psychological counselling	35.7%
None	12.1%

ROS1 (n=72)	
Patient organisations, peer support, NGOs	40.3%
Clinical trials	37.5%
Medical information	34.7%
Nutrition and exercise	33.3%
None	15.3%

All respondents (n=1,887)	
Side effects	38.5%
Psychological counselling	36.8%
Medical information	32.0%
Nutrition and exercise	31.7%
None	15.5%

Physicians 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 impacted by oncogene-driven lung cancers 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 affected by oncogene-driven lung cancers surveyed believed their opinion must be considered in the decision-making process. Participants impacted by ROS1 and KRAS driven lung cancer reported higher levels of interest compared to other oncogene-driven groups.

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. However, the data did not show significant differences between the two groups. The percentage of patients with oncogene-driven lung cancers who believed that their opinion should be taken into account was around 98%, with 35-43% strongly supporting this (`*very much*´).

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

PATIENT AND CAREGIVER RESPONSES

	Not at all	A little bit	Somewhat	Quite a bit	Very much
ALK (n=388)	4.1%	8.2%	23.5%	29.6%	34.5%
EGFR (n=394)	2.5%	11.7%	20.8%	32.7%	32.2%
KRAS (n=100)	3.0%	5.0%	20.0%	41.0%	31.0%
PD-L1 (n=148)	4.1%	14.2%	16.2%	34.5%	31.1%
ROS1 (n=72)	4.2%	9.7%	13.9%	31.9%	40.3%
All respondents (n=1,783)	4.2%	11.1%	24.5%	31.2%	29.0%

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

PATIENT RESPONSES

	Not at all	A little bit	Somewhat	Quite a bit	Very much
ALK (n=312)	2.6%	5.5%	20.5%	32.1%	39.4%
EGFR (n=312)	1.0%	7.4%	18.6%	34.9%	38.1%
KRAS (n=79)	2.5%	3.8%	20.3%	38.0%	35.4%
PD-L1 (n=110)	2.7%	7.3%	13.6%	39.1%	37.3%
ROS1 (n=65)	3.1%	6.2%	12.3%	35.4%	43.1%

> *40-50% of participants affected by oncogene-driven lung cancers were dissatisfied with their level of involvement in shared decision-making. Overall only 50-70% felt that treatment and care aligned with their preferences.*

Despite the high interest in people impacted by lung cancer regarding shared decision-making, the data presented in this report highlights the insufficient involvement of patients and caregivers in this process. Consequently, only 50-70% of participants affected by oncogene-driven lung cancers felt that the treatment and care plan aligned with patient preferences by `quite a bit´ or `very much´ [6].

The group that most frequently reported their treatment was aligned with their preferences was EGFR, followed by ALK. In contrast, the groups that reported this the least were KRAS and PD-L1.

Patient and caregiver satisfaction is an important factor in the lung cancer pathway. However, only around 50-60% positively valued their involvement in the decision-making process[7].

The groups that reported the highest levels of satisfaction were ROS1 and EGFR, while PD-L1 reported the lowest.

Do you feel that your treatment and care has aligned with your personal preferences?[6]

	Not at all	A little bit	Somewhat	Quite a bit	Very much
ALK (n=387)	4.1%	5.4%	24.3%	38.5%	27.6%
EGFR (n=391)	2.6%	5.4%	23.0%	39.1%	29.9%
KRAS (n=99)	6.1%	11.1%	32.3%	33.3%	17.2%
PD-L1 (n=147)	7.5%	5.4%	33.3%	36.7%	17.0%
ROS1 (n=73)	5.5%	9.6%	23.3%	32.9%	28.8%
All respondents (n=1,777)	6.1%	7.9%	26.3%	35.6%	24.1%

How satisfied are you with your level of involvement in the treatment and care decision process?[7]

	Very unsatisfied	Unsatisfied	Neutral	Satisfied	Very satisfied
ALK (n=387)	3.6%	6.7%	23.3%	46.0%	20.4%
EGFR (n=392)	2.8%	4.3%	26.0%	42.9%	24.0%
KRAS (n=100)	4.0%	7.0%	33.0%	35.0%	21.0%
PD-L1 (n=147)	8.2%	8.8%	27.9%	40.8%	14.3%
ROS1 (n=73)	0.0%	6.8%	27.4%	42.5%	23.3%
All respondents (n=1,783)	3.6%	7.5%	29.4%	38.7%	20.8%

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

[7] *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 in shared decision-making reported was 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, around half of the participants impacted by oncogene-driven lung cancers 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. Thus, there is an urgent need to improve the communication skills of physicians and facilitate open and honest dialogue with clinicans and patients/caregivers.

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

ALK (n=368)		**EGFR** (n=372)		**KRAS** (n=97)		**PD-L1** (n=145)		**ROS1** (n=71)		**All survey respondents (n=1,701)**	
Complex information	56.8%	Complex information	53.8%	Complex information	54.6%	Complex information	52.4%	Complex information	49.3%	Complex information	49.2%
Poor communication with the healthcare team	35.1%	Poor communication with the healthcare team	35.2%	Poor communication with the healthcare team	41.2%	Poor communication with the healthcare team	42.1%	Difficulties in finding trustworthy sources of information	36.6%	Poor communication with the healthcare team	37.6%
Emotional difficulties in dealing with important decisions	30.4%	Emotional difficulties in dealing with important decisions	33.3%	Difficulties in finding trustworthy sources of information	26.8%	Emotional difficulties in dealing with important decisions	34.5%	Poor communication with the healthcare team	35.2%	Emotional difficulties in dealing with important decisions	34.0%

> *A major problem is that most patients' understanding of lung cancer is far below that of the healthcare professionals treating it, making meaningful dialogue difficult.*

> *Communication and honesty in safe relationships is key. Safety brings hope, and hope affects treatment outcomes and the willingness to be involved.*

> *Doctors should have more time with patients, ask for their opinion, allow for questions to the oncology team, and treat them as equals — not in a hierarchical relationship.*

> *It is important to provide clear and simple explanations about the diagnosis and treatments. The lack of information and the speed of consultations stressed me a lot.*

CALL TO ACTION

Healthcare teams 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, approximately 1 in 4 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 around 30-50% 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**

Oncogene-driven LuCE Members supporting this Report

ALK POSITIVE
Belgium

ALK Positive Belgium

www.alkpositivebelgium.be

We are committed to Alk lung cancer patients and everyone close to them. We strive to provide the best Alk lung cancer care.

It is important to us that this care always takes into account the wishes of the patient. We provide information about the disease Alk-lung cancer and bring fellow sufferers into contact with each other. We do this, for example, by giving information meetings and by offering closed Facebook groups.

ALKPOSITIV
DEUTSCHLAND

ALK Positiv Deutschland

www.alkpositiv-deutschland.org

ALKpositiv Deutschland is a patient network with an associated online group. In our network, ALK-positive patients as well as caregivers exchange information on all topics relating to the disease.

We organise online meetings several times a year and also organise regional, face-to-face meetings. We are the voice of ALK-positive patients in Germany. Our aim is to support each other in the group and provide health literacy through webinars and talks. We are advocating for state-of-the-art diagnostics as well as access to treatments and clinical trials in Germany.

Oncogene-driven LuCE Members 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

ALK Positive Europe (APEU)

www.alkpositiveeurope.org

ALK Positive Europe (APEU) is a European umbrella non-profit organization dedicated to supporting and advocating for people living with ALK-positive lung cancer.

The organization provides a platform for ALK+ patient organizations, support groups and individuals across Europe to promote better outcomes and quality of life for ALK+ patients. It aims to ensure that every person diagnosed with ALK+ lung cancer in Europe has access to the best possible care and the latest treatment innovations, regardless of their country of residence. Another area of focus is accelerating research.

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

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impacted by or at risk of lung cancer

info@lungcancereurope.eu