7th LuCE REPORT ON LUNG CANCER

Challenges in the care pathway and preferences of people with lung cancer in Europe

November 2022

Lung Cancer Europe

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7th

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WELCOME TO THE 7th EDITION OF THE LuCE REPORT

This is an annual initiative led by lung cancer patient organisations, across Europe with the purpose of raising awareness relating to the main challenges faced by people impacted by this disease.

In this edition, we invite you to better understand the needs and priorities along the care pathway of people with lung cancer.

This report is especially dedicated to the 991 people with lung cancer who participated and helped us to explore key matters along the disease journey.

Many faces, one voice.

Cutting-edge research for the development of more effective drugs is essential, but *per se* not sufficient in lung cancer. Equally important is the ability of our health care system to render medical innovations accessible for all, so that every person can benefit from the latest scientific advances.

Day to day, the experience of each person impacted by lung cancer is shaped by the skills and professionalism of health care workers, especially by their ability to identify the particular physical, cognitive and emotional challenges arising from individual personality traits, social circumstances, comorbidities and the evolving disease status, in order to provide support in a personalised manner. Hence, an individual's satisfaction with their care is a very complex and highly dynamic variable.

With its current 7th report, LuCE becomes once again a genuine communication channel that captures and publicizes the perspective of those affected by lung cancer throughout their disease trajectory. Using a compact questionnaire of 47 items between June and July 2022 in 25 European countries, the clinical reality, but also feelings, concerns, expectations, preferences, challenges and wishes for change of 991 survey participants were collected with respect to a wide array of medical measures and psychosocial aspects along their diagnostic and treatment pathways. The aim is to provide a comprehensive assessment of the current status quo, highlight recent progress, but also reveal weaknesses and facilitate a roadmap for future interventions in the lung cancer care pathway.

LuCE looks forward to your continued support in order to improve the experience of people with lung cancer, during their entire care pathway along the lines set out by this report. **Together we can make a difference!**

The aim of this report is to facilitate a roadmap for future interventions in the lung cancer care pathway.

Korina Pateli – Bell

Treasure of Lung Cancer Europe (LuCE)

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1. ABOUT THIS REPORT

1.1. DESCRIPTION AND OBJECTIVES

Lung Cancer Europe (LuCE) is an independent non-profit organization, committed to make lung cancer a European health priority. Our aim is to advocate for policies that lead to improvements in early detection, treatment and care.

As the voice of people affected by lung cancer in Europe, LuCE promotes a **patient-centered and multidisciplinary approach to healthcare delivery.** Previous LuCE reports showed significant difficulties experienced by people with lung cancer along the care pathway. For this reason, we advocate for a **model of lung cancer care that puts the individual's needs first,** along with the best of care.

A person centred approach requires an understanding of how people with lung cancer go through the healthcare system, what challenges they face along the way and their preferences regarding the care they receive. Gathering real-world data helps to design and implement optimal pathways focused on their needs, improving quality of care, increasing the efficient use of resources and increasing patient satisfaction[1-2].

This report titled **`Challenges in the care pathway and preferences of people with lung cancer in Europe´** is a descriptive research analysis that explores the experiences and recommendations of people diagnosed with lung cancer from disease presentation to diagnosis to treatment and follow-up.

The purpose of this report was to **identify barriers and areas of improvement to enhance the care pathway.** Even when there are differences in the structure and provision of care across Europe, the findings of this report stress the need of person-centered models that improves the partnership between individuals and their healthcare providers.

RESEARCH OBJECTIVES:

- To explore the experiences of people with lung cancer regarding the care pathway from first medical suspicion of the disease to diagnosis, to treatment and follow-up.

- To identify preferences and opinions of people with lung cancer regarding the healthcare services and resources along the care pathway.

- To obtain preliminary data to explore specific challenges in the lung cancer care pathway in two European countries: The Netherlands and Romania, as case examples.

1.2. METHODOLOGY

a) Literature review

A comprehensive literature review was conducted in March – May 2022, using the electronic database Pubmed. Search terms were concentrated on cancer care pathways and healthcare challenges, as reported by people diagnosed with lung cancer. Publications were limited to the English language.

Previous findings reported in the literature were used to aid in the design of an online survey aimed at people diagnosed with lung cancer. These findings were also used to design an online survey for lung cancer experts (clinicians, healthcare professionals and patient advocates) from The Netherlands and Romania.

A list of references are provided at the end of this report.

b) Online surveys

ONLINE SURVEY FOR PEOPLE DIAGNOSED WITH LUNG CANCER	ONLINE SURVEY FOR EXPERTS FROM THE NETHERLANDS AND ROMANIA
SURVEY DESIGN	
Surveys were drafted in conjunction with Fundación MÁS QUE IDEAS (Spain) and reviewed by a committee of eleven advocates (members of the LuCE Report Working Group). Data was collected thought a self-filled online survey via the Surveymonkey^{R} platform.	
This survey was open to people diagnosed with lung cancer in the WHO European Region. The objective was to understand their experiences and preferences regarding the care pathway.	This survey was open to lung cancer experts (clinicians, healthcare professionals and patient advocates) from The Netherlands and Romania. The objective was to collect preliminary data to explore challenges in the lung cancer care pathway in two European countries, as case examples.
It was confidential and did not include questions relating to personal information.	The data of participants was public and included questions about name and affiliation.
The survey was translated into 17 languages: Croatian, Danish, Dutch, English, Finnish, French, German, Greek, Hebrew, Hungarian, Italian, Latvian, Polish, Portuguese, Romanian, Slovenian and Spanish.	The survey was translated into 3 languages: Dutch, English and Romania.

ONLINE SURVEY FOR PEOPLE DIAGNOSED WITH LUNG CANCER	ONLINE SURVEY FOR EXPERTS FROM THE NETHERLANDS AND ROMANIA
The survey contained 47 questions: 1 question acted as a filter (mandatory) to determine if the respondent was a person with lung cancer and agreed to participate in the survey. 4 questions acted as a filter (mandatory), so specific questions were asked to explore their experiences and preferences in the case of being treated with surgery, radiotherapy or pharmacotherapy, or in the case of having completed their active treatment. 8 questions were about participant characteristics and 34 questions were asked to explore their experiences and preferences. These questions did not require a mandatory answer, therefore, the number of responses per question varies. Three were open questions, and the rest were closed.	The survey contained 25 questions: 1 question acted as a filter (mandatory) to determine if the respondent agreed to participate in the survey. 2 questions were about the name and affiliation of the participant. 22 questions were asked to explore their knowledge and assessment regarding the lung cancer patient pathway in their country. Six were open questions and the rest were closed.

SURVEY DISSEMINATION

The survey was active from May 3rd until July 10th 2022. It was disseminated through the communication channels of LuCE and LuCE members, including websites, direct email and social media channels.	The survey was active from June 20th until July 20th 2022. It was disseminated through the LuCE members from The Netherlands and Romania, via internal communication channels.

DATA ANALYSIS

A quality control check of the data was performed to identify and remove invalid answers. A survey response was considered valid when the participant had completed, at least, the first series of questions about the diagnostic pathway and resided in the WHO European region.	A quality control check of the data was performed to identify and remove invalid answers. A survey response was considered valid when the participant had completed the entire survey.
Data generated from the different language versions were integrated together using SurveyMonkey^{R} analytic tools.	Data generated from the different language versions were compared using SurveyMonkey^{R} analytic tools.

Data from both online surveys and the literature review, were combined to create a draft of this report, which was reviewed by the LuCE Board, the LuCE Working Group and Fundación MÁS QUE IDEAS. A finalised version of the report was then prepared.

> *If you see this box in the text, it includes a transcribed quote from the online survey for people diagnosed with lung cancer.*

C) Research limitations

This report has two different types of research limitations:

- **Online survey, as a technique to collect data from people with lung cancer.**

  Online surveys are widely used in research, but they do give rise to some limitations. There are difficulties to reach some participants, such as those who do not have internet access, are not regular internet users, are not digitally literate or have a poor health status to complete an online survey.

- **Research participants characteristics.**

  The most relevant limitation is the high female over-representation in the survey participants (70.3%). Furthermore, there may be an underrepresentation of those who are older. While most people with lung cancer are over 65, this group represented only 30.3% of the survey participants.

  Another limitation is regarding the countries of residence of participants. People from 25 countries have completed the survey, but 4 out of 10 of them (39.0%) lived in two countries: France and Germany.

1.3. REPORT COLLABORATORS

This report has been possible thanks to to the many people who have contributed their time to provide their insights, opinions and knowledge. We are indebted to each and every one of them.

LuCE Report Working Group members:

- Anne-Marie Baird
- Karen Clayton
- Alina Comanescu
- Nicoline Ehrhard
- Merel Hennink
- Annette Hans
- Sandra Karabatic
- Leslie Manot
- Debra Montague
- Korina Pateli-Bell
- Shani Shilo
- Diego Villalón

Experts surveyed from The Netherlands:

- Lidia Barberio. Patient advocate. Longkanker Nederland
- Franz Custers. Pulmonologist. Zuyderland Medisch Centrum
- Renée Dubois. Patient advocate. Longkanker Nederland
- Michiel Gronenschild. Pulmonologist, Zuyderland Medisch Centrum
- Lizza Hendriks. Pulmonologist. Maastricht University Medical Center
- Merel Hennink. Patient advocate. Longkanker Nederland
- Jeroen Hiltermann. Pulmonologist. University Medical Center Groningen
- Marleen Slotboom. Patient advocate. University Medical Center Groningen
- Wouter van Geffen. Pulmonologist. Medisch Centrum Leeuwarden
- Mirjam Willemsen. Patient advocate. Longkanker Nederland
- Ellie. Patient advocate

Experts surveyed from Romania:

- Alexandru Aurelia. Oncologist. Institutul Oncologic București
- Agavriloaie Carmen. Nurse. Spital Municipal de Urgență Pașcani, secția Îngrijiri paliative
- Alina Comanescu. Patient advocate. Adociatia Sanatate pentru Comunitate
- Razvan Curca. Oncologist. Spitalul Judetean de Urgenta Alba Iulia
- Onutu Angela Daniela. Nurse. Penitenciar Spital Bucuresti Rahova
- Gheorghita Alina Elena. Nurse. Hospice Casa Sperantei- Brasov
- Muncelean Gabriela Elisabeta. Nurse. Spitalul Municipal Dej Compartimentul de Ingrijiri Paliative
- Crucianu Liliana. Nurse. Romanian Oncological Institute. Iași Îngrijiri Paliative
- Nicoleta Mitrea. Patient advocate. Nurse. Hospice Casa Sperantei
- Doina Moise. Nurse. Spitalul vlinic de.pneumoftiziologie si boli infectioase brasov
- Nadia Melania Pop. Nurse. Spitalul de Pneumoftiziologie și Boli Infectioase, Îngrijire paliativă
- Ganescu Radu. Patient advocate. Presedinte Coalitia Organizatiilor Pacientilor cu Afectiuni Cronice
- Dutescu Vlad. Patient advocate

1.4. OVERVIEW OF PARTICIPANTS CHARACTERISTICS

The total number of survey participants was 991. Aside from the mandatory questions, participants could decide which questions they wanted to respond to. Therefore, the number of valid responses per question varies.

70.3% women
29.7% men

The majority were people between 55-64 years of age (39.4%) and 65-74 years of age (24.9%).

42.7% had attained tertiary education and 35.8% upper secondary education.

Half of respondents (50.1%) stated that they lived in an urban area, followed by rural (27.4%) and suburban (21.2%).

75.2% were diagnosed with non-small cell lung cancer (adenocarcinoma) and 57.7% confirmed that their tumour was positive for a molecular marker, mainly ALK (19.3%) and EGFR (15.1%).

People from 25 European countries completed the survey. Most respondents came from France (21.1%), Germany (17.9%), The United Kingdom (8.2%), Poland (6.8%), Greece (6.3%), Spain (5.2%) and Italy (5.0%).

54.4% had Stage IV disease, 25.9% Stage I-II and 17.7% Stage III.

2. KEY FINDINGS: report summary

DIAGNOSTIC PATHWAY

TIME INTERVAL

- 40.3% waited more than one month since they experienced their first symptoms until they contacted their doctor.
- 19.9% had to wait for more than one month to get a primary healthcare appointment.
- 27.3% waited for more than one month since their first medical consultation until they were able to attend a lung specialist.
- 28.2% stated that they had waited more than one month since first consultation with a specialist to the diagnosis of lung cancer.
- 43.2% did not receive treatment within the first month of diagnosis.

WHAT IS NEEDED TO OBTAIN AN EARLIER DIAGNOSIS?

64.0%	39.3%	37.3%	35.1%
Screening programmes	Education for primary care doctors about lung cancer	Shortening waiting times	Education for the public about lung cancer

HOW TO IMPROVE THE DIAGNOSTIC PROCESS?

PROPOSALS

83.5%	73.4%	72.1%
Fast track services that reduce waiting times	Provide a name from the healthcare team and number of a direct contact if needed	Provide a roadmap and clear information about the diagnostic process

SUGGESTIONS TO IMPROVE COMMUNICATION WITH DOCTORS

51.0% Clear plan for next steps

46.7% Empathy and sensitivity

40.4% Clarity of the message

PRIORITIES IN THE PERIOD DIAGNOSIS-TREATMENT

80.1% Education about side effects and how to reduce the risk of complications

73.4% Access to the medical treatment plan

TREATMENT PATHWAY

TREATMENT DECISION

INFORMED CONSENT

Only **52.7%** received and understood all of the information they needed before signing the informed consent document.

PRIORITIES

56.0% Lay language: common words and terms, not medical jargon

51.1% Conversation with specialist to better understand the informed consent

INFORMATION NEEDED FOR THE TREATMENT DECISION

79.3%	**73.8%**	**69.8%**
Treatment options available	Advantages and disadvantages of treatment options	Associated potential side effects and risks

DIFFICULTIES AND PREFERENCES

WHAT IS MOST DIFFICULT TO MANAGE?

SURGERY	**47.5%** Anxiety before surgery	**44.9%** Pain	**43.0%** Doubts about life after surgery
RADIOTHERAPY	**45.8%** Weakness / Fatigue	**29.8%** Stress and anxiety during radiotherapy	**23.5%** Difficulties about visiting hospital
PHARMACOTHERAPY	**72.0%** Weakness / Fatigue	**33.6%** Nausea / Vomiting	**31.6%** Constipation

PRIORITIES DURING AND AFTER TREATMENT

- Support for side effects management (especially pain management), through referral to allied health professionals, education about self-management and improvement of accessibility to the medical and nursing team.
- Guidance to reduce risk of complications.

SUPPORTIVE CARE

SUPPORT NEEDS

35.4% recognized that their overall needs were not addressed enough.

Spheres not addressed enough by healthcare teams:

Emotional **(52.5%)**, physical **(39.7%)** and social **(31.3%).**

INFORMATION ABOUT SUPPORTIVE SERVICES

According to 3 out of 4 participants **(74.9%)**, healthcare teams should inform people about supportive services before starting treatment. Healthcare professionals should not wait until people explicitly report their needs before informing them about the support services available.

COMMUNICATION

INFORMATION FROM HEALTHCARE TEAM TO PEOPLE WITH LUNG CANCER

What information have they missed the most?

48.2%	Clinical trials
40.3%	Emotional / social issues
38.6%	Advanced care planning

INFORMATION FROM PEOPLE WITH LUNG CANCER TO HEALTHCARE TEAM

Half of participants **(49.2%)** stated not to have shared all aspects of their health status with their healthcare team.

HOW TO IMPROVE THE COMMUNICATION BETWEEN PEOPLE WITH LUNG CANCER AND HEALTHCARE PROFESSIONALS?

44.1%	**43.9%**	**43.5%**	**42.9%**
Access to specialised cancer nurse consultations	Longer medical consultations	Having a central point of contact	Better communication skills

FOLLOW-UP CARE

Around 1 out of 3 **(30.8%)** were not satisfied with the support received as part of follow-up care.

85.3% of participants who completed their active treatment acknowledged to have missed information and support.

PRIORITIES

What type of information/ support have they missed the most?

44.2%	Information about the symptoms of recurrence
39.0%	Management of the consequences of lung cancer and treatments
31.1%	Rapid access to health services, when needed
29.1%	Designing a follow-up plan with the person with lung cancer
28.7%	Psychosocial support

3. RESULTS

3.1. DIAGNOSTIC PATHWAY

3.1.1. Time interval in the lung cancer diagnostic pathway

From the first signs / suspicion of lung cancer to the diagnosis of the disease, people experienced **difficulties getting through the diagnostic pathway.** Emotional distress, physical symptoms or stigma are some of the challenges people with lung cancer face at this time[3]. In addition, **time matters in terms of prognosis and survival.**

Implementing a rapid lung cancer diagnostic pathway is a priority for shortening this stressful period of time and getting an early and accurate diagnosis. According to the literature, median overall survival improves by reducing the diagnostic pathway from an average of 30 days to 14 days[4]. Also, previous studies show that people who wait for surgery for more than 5 weeks since diagnosis have worse survival than people who have surgery earlier[5]. This relates to those for who surgery is a treatment option.

The following are the main intervals during the diagnostic pathway: Individual seeking investigation, primary care, referral and diagnostic intervals[6].

INDIVIDUAL
INTERVAL

PRIMARY CARE
INTERVAL

REFERRAL
INTERVAL

DIAGNOSTIC
INTERVAL

Time point 1: INDIVIDUAL INTERVAL

From first symptoms until you contacted your doctor or went to emergency services →

< 14 days: 28.9%

14-28 days: 17.8%

1-2 months: 14.2%
2-4 months: 10.4%
4-6 months: 5.7%
6-12 months: 5.0%
>12 months: 5.0%

Asking for medical investigation is essential when experiencing symptoms in order to get a diagnosis as early as possible. However, **40.3% waited more than one month since they experienced their first symptoms until they contacted their doctor.**

There were **variations in the delay in reporting symptoms by gender.** Our data shows that men reported high self-seeking behavior compared to women. A total of 33.3% of men asked for a medical consultation in the first two weeks of experiencing symptoms, whilst this fell to 26.8% in women. In addition, 18.3% of women stated that they waited more than four months (men: 10.1%).

Previous research has shown that people may delay reporting symptoms for reasons such as low perception that symptoms might be serious, lack of knowledge about lung cancer signs and belief that this disease only affects people who have a smoking history[7]. **Raising awareness about the risk of lung cancer and its symptoms is crucial** to empower people to recognize these symptoms and encourage early presentation to primary care.

Time point 2: PRIMARY CARE INTERVAL

From you contacted your doctor until you had your first medical consultation

< 14 days: 54.1%

14-28 days: 16.3%

1-2 months:	9.1%
2-4 months:	4.8%
4-6 months:	2.3%
6-12 months:	1.6%
>12 months:	2.1%

More than a half of participants reported a high accessibility to primary care - 54.1% had their first medical consultation in less than two weeks from when they requested it. However, **1 out of 5 participants (19.9%), had to wait for more than one month to get a primary healthcare appointment.**

Early diagnosis requires improving accessibility to health systems and avoiding long waiting times in getting medical appointments. There must be pathways to facilitate attendance at primary care physicians as soon as possible.

Time point 3: REFERRAL INTERVAL

From your first medical consultation to referral to lung specialist

< 14 days:
44.9%

14-28 days:
19.7%

1-2 months:	11.6%
2-4 months:	7.7%
4-6 months:	3.1%
6-12 months:	2.6%
>12 months:	2.3%

In most European countries the most common route of referral is through the primary care physician[8]. The first medical consultation is usually due to lung cancer symptoms and this is the first delay in the pathway. However, this does not mean that the time frame from this point onwards is rapid for all people. According to our survey, **27.3% of respondents waited for more than one month since their first medical consultation until they were able to attend a lung specialist.**

The following have been identified as the main reasons for delays in referral: misinterpretation or misattribution of symptoms by primary care physicians, referrals to the wrong specialists and long waiting times for referral to these specialists[7-9].

It is crucial to improve primary care physicians' recognition of lung cancer symptoms as well as the pathways they have open to them for referral. Previous evidence has shown that more efficient administrative workload, straight-to CT pathway and immediate reporting of chest x-rays by a radiographer could improve this pathway and reduce the delay in diagnosis[2].

Rapid referral pathways have been implemented in some different countries, such as Denmark, Ireland, Norway, and the United Kingdom, to reduce delays for people with suspected lung cancer[10-11]. Some of the outcomes of these rapid referral pathways have been: reduction from 43.5 days to 21 days in the time between referral and first appointment in Ireland; decrease from 52% to 45% in the proportion of people diagnosed with metastatic lung cancer in Norway; and reduction from 56 to 42 days between first referral and treatment initiation in Denmark[11].

Time point 4: DIAGNOSTIC INTERVAL

From your first consultation with the specialist to your lung cancer diagnosis

< 14 days: 39.9%

14-28 days: 26.2%

1-2 months:	14.4%
2-4 months:	8.1%
4-6 months:	2.6%
6-12 months:	1.4%
>12 months:	1.7%

The most frequent time interval from referral to a lung specialist to diagnosis was less than 14 days (39.9%). However, **28.2% stated that they had waited more than one month since first consultation with specialist to the diagnosis of lung cancer*.**

Delays may happen because of resource limitation and diagnostic capacity, especially during summer months and the COVID-19 pandemic. Some people with lung cancer are referred to other hospitals, because there are no PET-CT scans or endobronchial ultrasounds, or have to wait because of daily limitations in the number of CT scans or biopsies that can be undertaken[2]. Furthermore, not all hospitals perform every test required for a lung cancer diagnosis or staging[12]. Another reason is the need for multiple specialties as the diagnosis and staging of lung cancer requires multiple specialists including radiologists, pulmonologists, pathologists and nuclear medicine specialists[13].

3.1.2. How can we improve the lung cancer diagnostic pathway?

Data from the previous section shows that a substantial number of participants experienced significant delays at different steps of the diagnostic pathway. Reasons for these delays are multifactorial with an ultimate impact on prognosis and survival. These delays worsen the experience of people affected by lung cancer and erode trust in the health system. Delays during early presentation and diagnosis of the disease may be reduced through the following actions.

According to survey participants, the key priority is to implement **screening programmes** (Figure 1). Low-dose CT (LDCT) screening for lung cancer has been shown to be effective in reducing lung cancer mortality in asymptomatic people[2]. This screening test would help to identify lung cancer in an apparently healthy target population.

[*] This refers to receiving the lung cancer diagnosis (molecular tests not included).

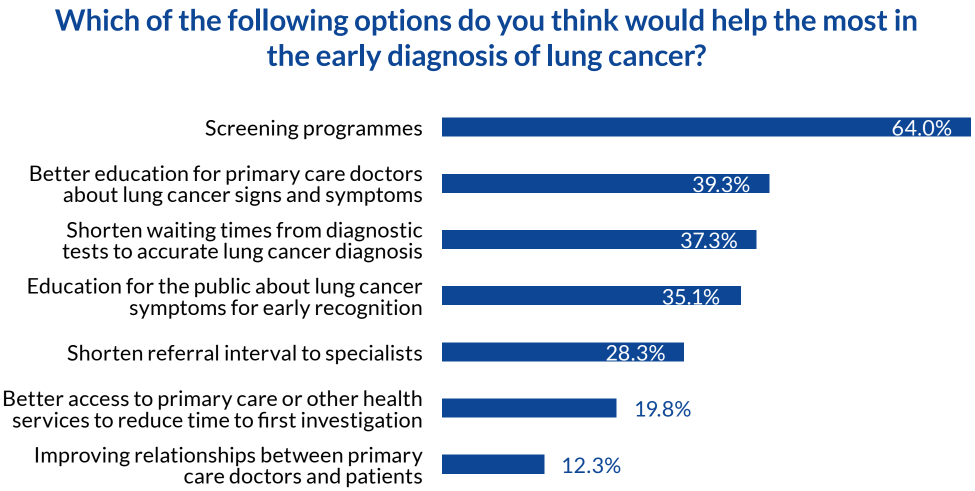

FIGURE 1. Options for early diagnosis (n=991).

Lung cancer screening

Cancer screening programmes exist throughout most of Europe for cervical, breast and colorectal cancer but as of yet there are few national lung cancer screening programmes[14] with the exception of Croatia, Poland and Czech Republic. However, evidence suggests that LDCT screening is more efficient in lung cancer than other types of cancer, as it requires fewer people to be screened to prevent one cancer death[15].

We urge everyone in the lung cancer community to come together to lobby for lung cancer screening to be included in the updated EU Council Recommendations on cancer screening; and in parallel work collectively to promote education and awareness of lung cancer screening across Europe.

Additionally, more than **1 out of 3 people surveyed highlighted the necessity of improving education for primary care doctors and society regarding the signs and symptoms of lung cancer.**

Furthermore, 37.3% of participants noted the importance of shortening waiting times in the diagnostic pathway. In this sense, rapid access pathways are needed to improve this process.

> *Handling tests in parallel rather than one after the other with a physical meeting with doctor at every stage. This added weeks and months to getting the diagnosis. Also, I was not in a risk group. It should be highlighted that non risk groups can be affected by lung cancer too. (Sweden)*

> *Specialists and general practitioners often do not have an overall, holistic view of symptoms, they only recognize the pathology of their specialty. (Italy)*

Figure 2 shows how important rapid diagnostic pathways are for people with lung cancer. **Fast track services that reduce waiting times were considered by participants as a key priority measure to improve the diagnostic process.** There was a consensus (83.5%) that speeding up the diagnostic pathway is a high priority (Table 1).

Furthermore, the majority of participants agreed that **accessibility along the pathway needed to be improved,** for example providing a contact name within the healthcare team. This is of great importance, as it is critical that everyone is aware of who to contact, how to contact, and when to make contact about their healthcare needs.

A high percentage of participants also valued **information** (providing a roadmap and clear data), **communication** (related to professional's skills) and a **friendly environment** as high priorities. Information and support from healthcare professionals can empower people with lung cancer and help them to manage anxiety by setting out what can be expected from the diagnostic pathway[16].

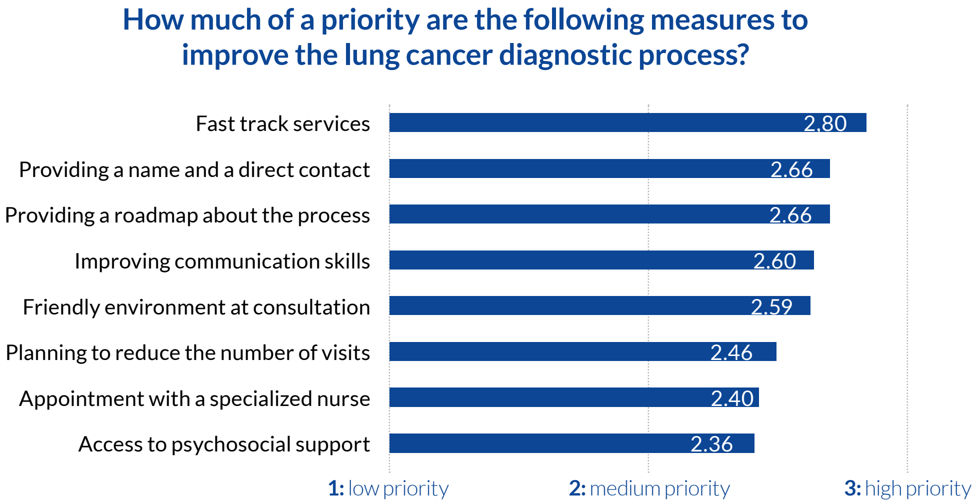

FIGURE 2. Priority measures to improve diagnosis (n=984).

MEASURES TO IMPROVE LUNG CANCER DIAGNOSIS PROCESS	HIGH PRIORITY	LEVEL OF AGREEMENT
Fast track services that reduce waiting times	83.5%	**CONSENSOUS**
Providing a name from the healthcare team and number of a direct contact if needed	73.4%	**MAJORITY**
Providing a roadmap and clear information about the diagnostic process	72.1%	**MAJORITY**
Improving healthcare professionals' communication skills	66.5%	**MAJORITY**
Friendly environment at consultation	65.0%	**MAJORITY**
Better planning to reduce the number of visits to hospital for diagnostic tests	55.7%	**DISAGREEMENT**
Appointment and follow-up with a specialized nurse	52.0%	**DISAGREEMENT**
Access to psychosocial support	50.2%	**DISAGREEMENT**

TABLE 1. High priority measures to improve diagnosis (n=984).

> *Even if diagnosis was fast, we felt very lonely and uninformed. We needed support and especially someone to talk to, other than family. (France)*

> *Being accompanied from the beginning by a specialized psychologist would be a plus... the announcement of these "abnormalities" plunges us into a tsunami... (France)*

> *Oncologists should be very careful about what they say to the patient. Several words that they have said affected me psychologically. (Spain)*

> *We should be able to contact our doctor or nurse any time we need it, even between appointments. (Germany)*

Providing a roadmap of the diagnostic process is very important because people with lung cancer need to undergo many different tests. Table 2 suggests some access disparities to diagnostic tests across Europe, as well as a lack of knowledge among some people about the diagnostic tests they underwent. For example, **1 out of 4 people surveyed did not know if a biomarker test was performed** on their tumour sample.

	Yes	No	Unsure
Chest x-ray	**88.4%**	**10.3%**	**1.4%**
CT of the chest	**96.7%**	**2.3%**	**1.0%**
PET-CT scan	**84.1%**	**13.8%**	**2.1%**
Bronchoscopy	**77.7%**	**19.0%**	**3.3%**
CT scans of upper abdomen	**76.5%**	**17.9%**	**5.6%**
CT or MRI of the brain	**78.7%**	**19.6%**	**1.8%**
Ultrasound-guided biopsy or aspiration	**46.5%**	**38.8%**	**14.7%**
Tissue biopsy or biopsy of a metastasis	**64.7%**	**26.8%**	**8.5%**
Molecular / Biomarker testing	**55.4%**	**17.8%**	**26.9%**

TABLE 2. Diagnostic tests undergone (n=987).

The diagnostic pathway is emotionally intense for people affected by lung cancer, especially in the moment of **receiving bad news,** such as a lung cancer diagnosis. What people valued the most in these moments are the information (51.0% mentioned a clear plan for next steps and 40.4% the clarity of the message) and the **empathy and sensitivity** of doctors (46.7%). The manner in which bad news is communicated, influences the physician-patient relationship and the care experience. Therefore, clinicians should plan how to deliver the information and evaluate the patient’s attitudes, knowledge, wishes, and needs[17].

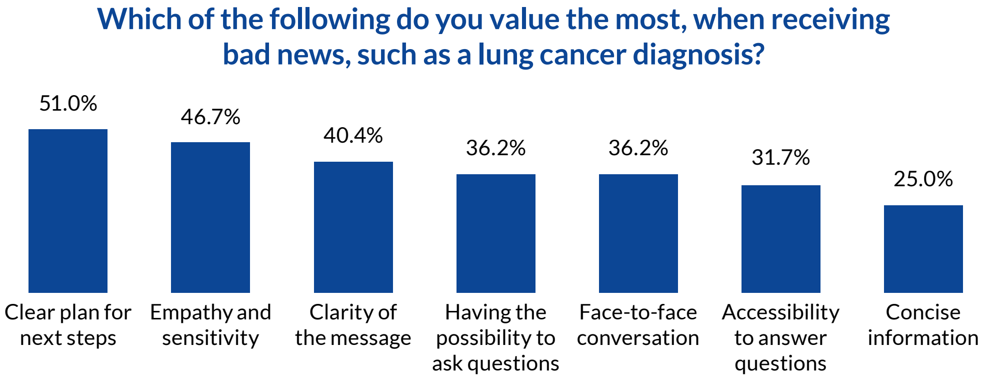

FIGURE 3. Most valued when receiving bad news (n=991).

> *We do not necessarily have all the questions when talking to our physicians. Questions often arise afterwards, and a second consultation is needed. (France)*

> *The patient should always be given hope to face the disease with better attitude, even when the diagnosis is very serious. (Spain)*

> *Honesty and transparency from the doctors. (The Netherlands)*

> *I was told I had incurable cancer and I didn't even have my husband or anyone with me. It was so devastating… (The United Kingdom)*

3.1.3. Experiences from diagnosis to treatment

People who have recently received a lung cancer diagnosis experience emotional distress and uncertainty about what to expect from treatment and are at risk of developing psychological distress. It can take weeks and even months to start a treatment after diagnosis and this time can be very frustrating and emotionally complex for people with lung cancer. Furthermore, their health may deteriorate while they are waiting for a treatment decision[18].

> *The time between diagnosis and treatment is too long. With an aggressive tumor, this time is of the essence. (Hungary)*

Speeding up the time interval from diagnosis to initiation of treatment is important not only from a clinical perspective, but it is also important to offer a better experience to people affected by lung cancer.

However, only **56.8% of participants received treatment within the first month from diagnosis** (Figure 4).

The period between diagnosis and treatment can be an opportunity to support and prepare (physically and psychologically) people with lung cancer for treatment[19]. According to the literature, the majority of interventions are implemented prior to surgery and show some of the following outcomes: less respiratory complications, reductions in the number of days spent in hospital post-operation, and reduction in hours spent in recovery from anesthesia[19].

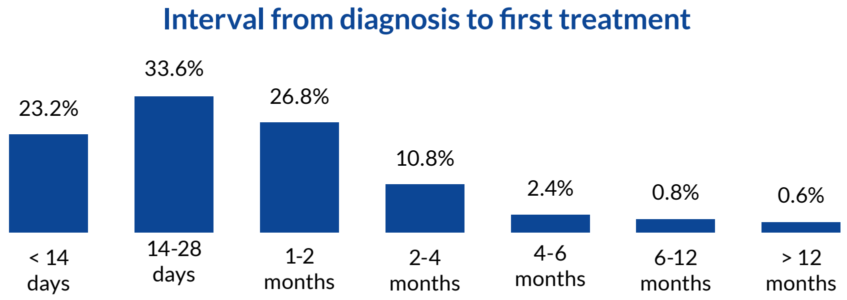

FIGURE 4. Time from diagnosis to treatment (n=976).

Figure 5 shows that **education about side effects and complications is valued as the most important in the time from diagnosis to treatment** (80.1% considered it as high priority – Table 3). Empowering people to manage these complications would be very helpful, considering the significant number of people who do not feel equipped to self-manage the side effects they experience (52.8% of people surveyed, according to our 2021 report)[20].

Three out of 4 participants (73.4%) also highlighted the importance of **having access to their medical treatment plan.** Once again, information is valued as very important to deal with lung cancer and treatments.

Six out of 10 participants (63.8%) suggested that smoking cessation support should be offered to people who smoke before starting treatment. Some national lung cancer guidelines cover both pharmacological and non-pharmacological interventions to achieve smoking cessation, as this can improve outcomes[21].

On the other hand, literature shows that pulmonary prehabilitation and physical exercise reduce the risk of complications and are associated with benefits of improved physical capacity, symptoms and quality of life[22-23]. This physical support has been valued as a high priority for supportive services, by half of participants.

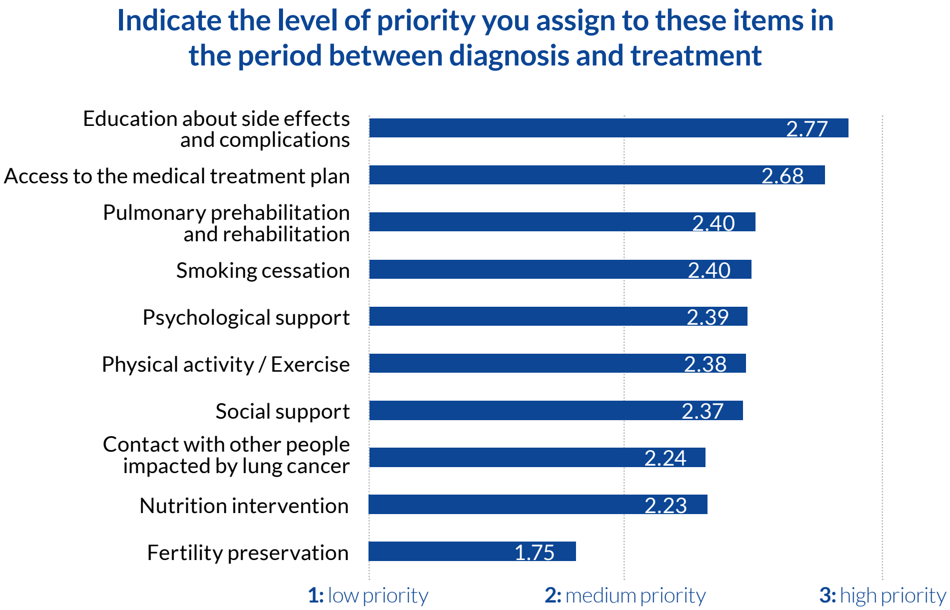

FIGURE 5. Priorities from diagnosis to treatment (n=929).

PRIORITIES IN THE PERIOD BETWEEN DIAGNOSIS AND TREATMENT*	HIGH PRIORITY	LEVEL OF AGREEMENT
Education about side effects and how to reduce the risk of complications	**80.1%**	**CONSENSOUS**
Access to the medical treatment plan	**73.4%**	**MAJORITY**
Smoking cessation	**63.8%**	**DISAGREEMENT**
Pulmonary prehabilitation and rehabilitation (i.e., exercises to manage shortness of breath)	**54.3%**	**DISAGREEMENT**
Psychological support	**52.6%**	**DISAGREEMENT**
Social support (work, finances, community resources)	**50.9%**	**DISAGREEMENT**
Physical activity / Exercise	**50.6%**	**DISAGREEMENT**
Contact with other people impacted by lung cancer	**42.6%**	**DISAGREEMENT**
Nutrition intervention	**41.6%**	**DISAGREEMENT**
Fertility preservation	**25.7%**	**DISAGREEMENT**

*Not all services may have been available to all people, and this may have influenced their response.

TABLE 3. High priorities from diagnosis to treatment (n=929).

GOOD PRACTICES IN THE DIAGNOSTIC PATHWAY, ACCORDING TO PARTICIPANTS

ACCELERATE THE DIAGNOSTIC PATHWAY

- The analysis of mutations took 6 weeks, and there was no therapy during that time, which was scary. (Germany)
- The waiting for marker testing to decide treatment options felt unbearable. (The United Kingdom)
- The waiting times are so long. I was in a state of high anxiety for months. (The United Kingdom)
- I waited five weeks between appointments. Scan results are available much quicker in other units. (Norway)

GUIDANCE ALONG THE DIAGNOSTIC PATHWAY

- We need better explanations on next steps and the meaning of results. (Sweden)
- I needed more contact. For many weeks I had no information about the results and treatment options. (Poland)
- Explanations of what they were looking for, how the tests would affect me, the implication of results, and how they would be carried out. (Spain)
- Clear outline of next steps, how to prepare and what to expect. (France)

SENSITIVITY AND EMPATHY

- Concise, specific information, but communicated in such a way that the patient leaves with the awareness that the disease is being effectively treated. (Poland)
- Having someone with empathy to talk to and get vital information from. (The United Kingdom)
- Discussion about my problem, with patience, without rushing and in a positive way. (Greece)
- Empathy, feeling that the follow-up activities are not a simple application of standard protocols, but personalized. (Italy)

CLEAR MEDICAL INFORMATION

- I needed more accurate and specific information about my medical condition, treatment prospects and recovery. (Poland)
- Quickly draw up a treatment plan with a clear explanation. (The Netherlands)
- Information on the possibilities of treatments, including experimental ones. (Italy)
- To provide information about the disease, diagnosis in a way that is understandable to a layman, without using specialized terms, providing exhaustive information, directing to asking questions, and not using laconic, short information. (Poland)

SECOND MEDICAL CONSULTATION

- To be able to have another appointment to ask questions and better understand the diagnosis. The day of the announcement of the diagnosis we do not record the data, we are stunned. (France)
- Possibility of a second consultation to ask questions. You are in shock when you receive the diagnosis. (Spain)
- You go home after the first conversation and then the questions come. (The Netherlands)
- Another meeting, one or two days later, with a professional to explain the diagnosis again. (France)

ACCESS TO MULTIDISCIPLINARY CARE

- I was diagnosed during a long hospital stay, and I could access to supportive care (physiotherapist, dietician, tobacco specialist, etc.) which was essential for me at the beginning of the process. (France)
- It would be nice if there was more contact with a care team during the period between diagnosis and the beginning of treatment. E.g., Psychological assistance for myself but also for the loved ones. (The Netherlands)
- As a family with children, we needed support. After the diagnosis, we could have been referred to a social worker. Instead, we were left alone with the diagnosis. (Finland)
- More support with the impact on mental health and how to cope with anxiety. (The United Kingdom)

CENTRAL POINT OF CONTACT

- I would suggest having a contact nurse and a phone number whom I could contact to ask questions. (Sweden)
- I was lucky to have a listening and accessible oncologist who answered all my questions and made himself available to my loved ones as well. (France)
- Having a contact to whom we can ask questions that we have not thought of during appointments and that end up stressing us out. (France)
- They helped by being available to take my phone calls and see me in clinic when new information was being given. (The United Kingdom)

PEER SUPPORT

- I felt like I was in a big bubble, alone without any psychological support. I have joined a patient association and shared my path with many other people. This is a very good exchange of experiences. (Germany)
- Healthcare team should pass on details of relevant patient support groups. (The United Kingdom)
- I needed the help of an expert and possibly a volunteer who had already been in the same situation. You need someone who can explain clearly. (Slovenia)

AVOIDING STIGMA

- Everyone thought I must have smoked, but I didn't. They made me feel ashamed by equating lung cancer with smoking and a deranged lifestyle. (Hungary)
- I needed help because I felt guilty for having smoked. (Spain)

3.2. TREATMENT PATHWAY

3.2.1. Treatment decision process

Changes in the therapeutic scenario in the last 15 years has emphasized the need for multiple specialists in the lung cancer treatment pathway. This can result in discontinuity and fragmentation of care[24]. Everyone needs to work together as a multi-disciplinary team with the person with lung cancer to decide on the best care plan.

In **multidisciplinary team meetings (MDTs/MTMs),** patients' cases and their care plans are discussed by a group of experts of different medical and healthcare disciplines and specialties. These MTDs/MTMs are vital to selecting the best strategy for local and advanced disease[25].

This is a common practice and, therefore, **72.5% of respondents stated that their diagnosis and treatment plans were discussed in these meetings** (Figure 6). However, some participants indicated that these meetings did not happen (9.6%) and others were not aware of them (17.9%).

It is important to ensure that each person's case is discussed in multidisciplinary teams, as well as to increase awareness of these teams. This information would help to better understand the diagnostic and treatment pathway.

Was your diagnosis and treatment plan discussed in lung cancer multidisciplinary meetings?

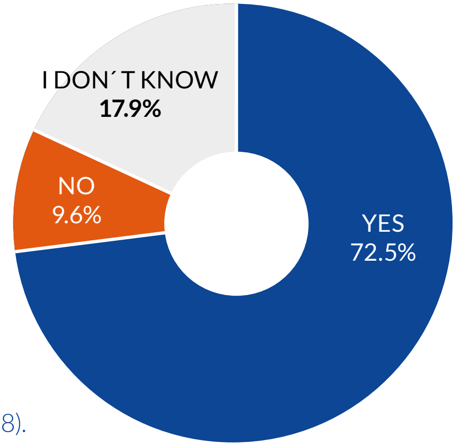

FIGURE 6. Multidisciplinary team meetings (n=928).

The MTMs inform about recommended treatment, but the final decision is made by the person with lung cancer, who usually follows the doctor recommendation. People need complete information for **decision-making** and participants reported three main types of information that may help in their treatment decision (Figure 7).

79.3% participants stated that having information about treatment options available is necessary for this decision, followed by data about **advantages and disadvantages of each treatment** option (73.8%) and information about **potential side effects and risks** (69.8%).

Clearly, what people most valued is the medical information associated with the different treatments available. Therefore, good communication between the clinical team and the person with the disease is necessary to offer understandable and complete information about the treatment options available.

Only 4.7% of people with lung cancer surveyed responded that only doctors should decide their treatments. This shows the importance of patient empowerment, so that they have an active role in the decisions taken to treat their disease.

What type of information do you think you need to help you be involved in treatment decisions?

79.3%
Treatment options available

73.8%
Advantages and disadvantages of treatment options

69.8%
Associated potential side effects and risks

53.2%
Information about clinical trials

50.5%
Likely repercussions on well-being and daily life

49.7%
Prognosis

40.7%
Supportive care available

39.1%
Treatment schedules and medical requirements

4.7%
None, I think only doctors should decide my treatment

FIGURE 7. Information needed for treatment decision (n=930).

Informed consent is crucial for treatment decisions. This is defined as the process of communication between doctors and individuals regarding treatment options, resulting in the individual's authorization or agreement to undergo a specific medical intervention[26].

People with lung cancer have the right to receive understandable information and ask questions about recommended treatments. However, only **52.7% confirmed they received and understood all of the information they needed before signing the informed consent document** (Figure 8).

Our research shows that only **29.2% of participants above 75 years of age had received and understood all the information** before signing the document (this is 52.7% for the overall participants). Therefore, more efforts should be made to ensure that older people understand the information that is being given to them before they consent to a medical intervention.

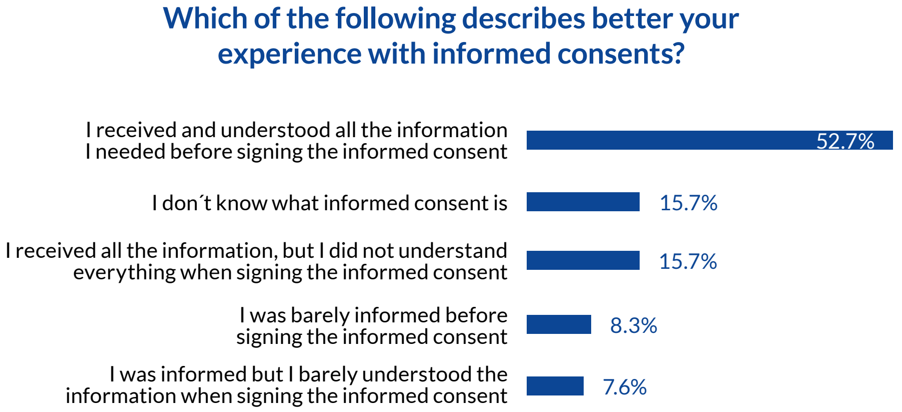

FIGURE 8. Experience with informed consents (n=923).

It is remarkable that 15.7% stated that they did not know what informed consent was. Our findings also show that the **information process around informed consent was not adequate for 31.6% of participants.**

Our data shows that the informed consent, as a process, is not working properly for many people affected by lung cancer. According to participants, there are two main suggestions that would improve this process. 56.0% stated that the use of **common words and terms** would help to better understand informed consent. In addition, around half of respondents (51.1%) also highlighted **the value of having a conversation with their specialist** (Figure 9).

1 out of 3 did not have enough knowledge
for shared decision making.

The age group who most selected `lay language´, `conversation with specialists´ and `more fluent communication´ were people over 75 (68.8%, 60.4% and 43.8%, respectively). This is important, considering that individuals over 75 are the group of participants that reported receiving less information and understanding the information before giving consent.

What would you suggest to improve the information process before signing the informed consent?

56.0%
Lay language: common words and terms, not medical jargon

51.1%
Conversation with specialist to be informed and understand the informed consent

29.8%	More fluent communication with healthcare professionals
28.5%	Shorter and friendlier documents
25.9%	Option to take it home, prior to signing the informed consent
18.8%	Glossary of medical terms in lay language

FIGURE 9. Suggestions to improve informed consent (n=903).

Clear information is needed for decision-making. People with lung cancer should be fully informed about their disease and recommended treatment options to make well-considered decisions about their disease and what is best for them. When participants were asked about the information they received before starting their treatment, we find that **most people stated they were well informed.**

However, as this report shows in the following sections, **there is a substantial number of participants who reported a lack of information prior to treatment, especially when receiving pharmacotherapy** (Figure 10). Clinicians should guide discussions to help people with lung cancer to make informed decisions about what is right for them.

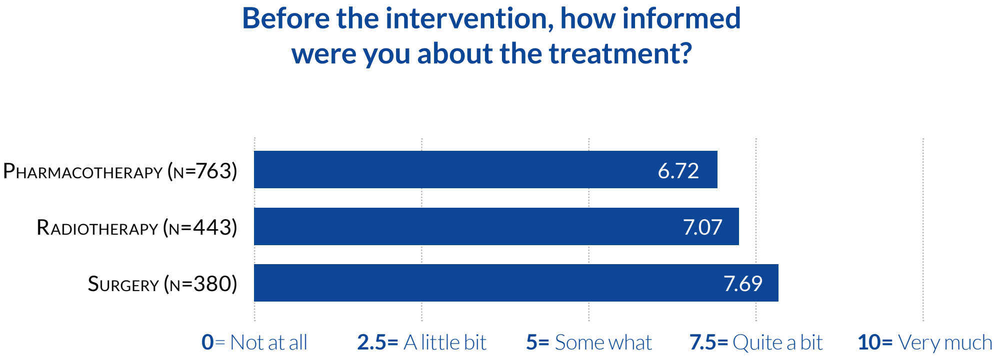

FIGURE 10. Information about treatments.

3.2.2. Surgery

41.5% of respondents (388 people) affirmed to have undergone surgery for their lung cancer. 46.5% of them had localized lung cancer, while 33.8% had Stage IV disease. Questions of this section were asked only to people who underwent surgery.

Figure 11 shows that **most people (77.9%) were very well informed about the surgery** before the intervention (very much / quite a bit). However, our findings suggest room for improvement: **1 out of 5 people with lung cancer affirmed not to have received enough information** about surgery.

Information and support are essential for dealing with the difficulties associated with surgery. Around half of the participants **(47.5%) mentioned how anxiety before surgery was one of the most difficult things to manage** (Figure 12). Appropriate information

Half of participants experienced
anxiety before surgery

could help to reduce these worries, as well as having access to psychological support. Information is also important for another top difficulty identified: doubts about life after surgery (43.0%).

Before the intervention, how informed were you about the surgery?

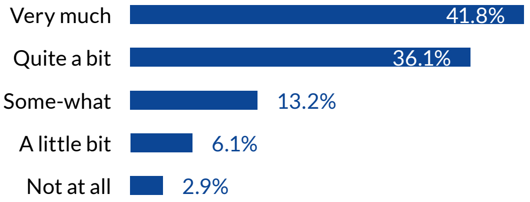

FIGURE 11. Information about surgery (n=380).

Side effects associated with surgery were also mentioned by a significant group of people, especially pain (44.9%), weakness / fatigue (39.6%) and breathlessness (30.5%).

> *I had a lot of pain after my lobectomy (rib spread), even at home. At a check up done 6 weeks la ter, they saw two ribs were broken. (The Netherlands)*

> *I was afraid of anesthesia because there were already problems with another operation and with the ventilation tube. (Germany)*

Talking about surgery, which of the following options did/do you find most difficult to manage?

47.5%
Anxiety before surgery

44.9%
Pain

43.0%
Doubts about life after surgery

39.6%
Weakness / Fatigue

30.5%
Breathlessness

22.3%
Life interrupted

19.4%
The time at the hospital

15.8%
Wound healing

14.2%
Constipation

12.3%
Lack of privacy during hospitalization

FIGURE 12. Issues most difficult to manage related to surgery (n=381).

When dealing with these difficulties, according to Figure 13 and Table 4, participants agreed that the highest priority when offering support to people undergoing surgery is to offer **information about surgery and what to expect (85.7% considered it as high priority).**

In the same way, around **3 out of 4 people identified pain management** (79.3%), **pulmonary training exercises** (78.1%), **support for side effects management** (76.2%) and **guidance about how to reduce the risks** of complications (73.4%) as high priorities. These results show the importance of offering supportive services before and after surgery to improve quality of life.

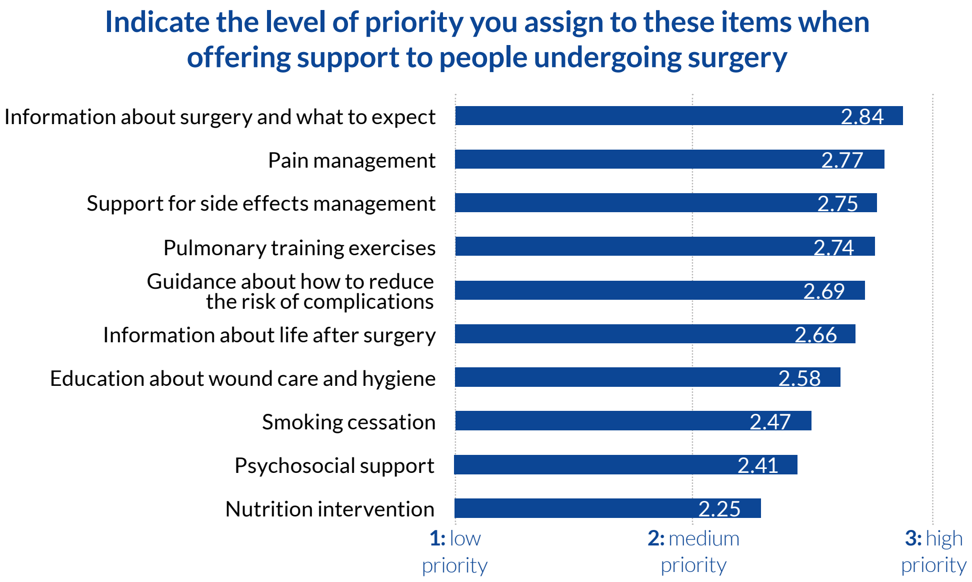

FIGURE 13. Priorities when offering support to people undergoing surgery (n=377).

PRIORITIES WHEN OFFERING SUPPORT TO PEOPLE UNDERGOING SURGERY*	HIGH PRIORITY	LEVEL OF AGREEMENT
Information about surgery and what to expect	**85.7%**	**CONSENSOUS**
Pain management	**79.3%**	**MAJORITY**
Pulmonary training exercises (prehabilitation / rehabilitation)	**78.1%**	**MAJORITY**
Support for side effects management	**76.2%**	**MAJORITY**
Guidance about how to reduce the risk of complications	**73.4%**	**MAJORITY**
Information about life after surgery (nutrition, rest, exercise, etc.)	**70.0%**	**MAJORITY**
Smoking cessation	**66.9%**	**DISAGREEMENT**
Education about wound care and hygiene	**63.7%**	**DISAGREEMENT**
Psychosocial support (emotions, finances, work, etc.)	**52.9%**	**DISAGREEMENT**
Nutrition intervention	**41.7%**	**DISAGREEMENT**

*Not all services may have been available to all people, and this may have influenced their response.

TABLE 4. High priorities when offering support to people undergoing surgery (n=377).

3.2.3. Radiotherapy

48.8% of participants (452 people) received radiotherapy as part of their treatment plan. Questions in this section were asked only to people who received this type of treatment.

Although the majority of participants (66.2%) responded that they were well informed about radiotherapy (very much / quite a bit), this is a much lower percentage than when asked about surgery (77.9%).

1 out of 3 respondents (33.9%) felt that they had not been informed enough about radiotherapy before starting treatment. This should be a priority as proper information influences the treatment decisions and has positive effects on patient satisfaction and quality of life[24].

Before starting the treatment, how informed were you about radiotherapy?

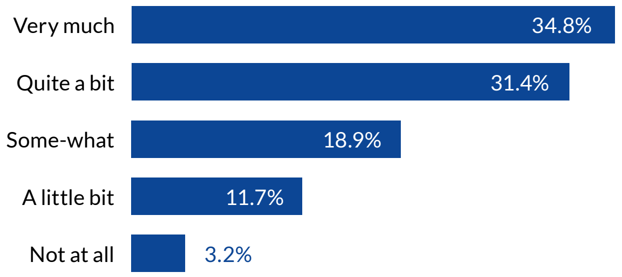

FIGURE 14. Information about radiotherapy (n=443).

Delivering high-quality integrated care when receiving radiotherapy must address difficulties associated with this treatment. According to those surveyed, **the most difficult issue to manage is the fatigue / weakness (45.8%)** (Figure 15). Fatigue is one of the most prevalent and distressing symptoms experienced by people living with cancer, during and after any cancer therapy[27]. This greatly affects quality of life, and it is commonly underreported and misevaluated by clinicians.

Participants who received radiotherapy also emphasized how difficult it is to live with the **stress and anxiety during the treatment** (29.8%), and the **logistical difficulties for visiting hospital frequently** (23.5%).

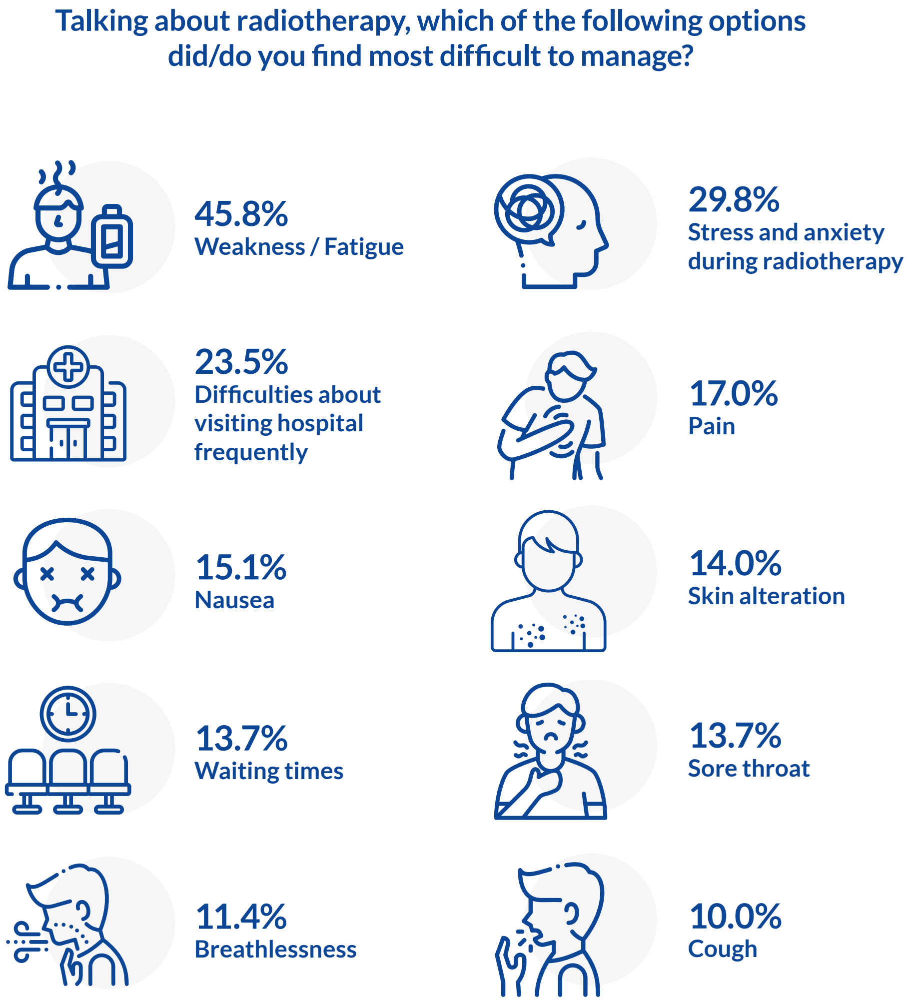

FIGURE 15. Issues most difficult to manage related to radiotherapy (n=430).

Priorities when supporting people during radiotherapy are similar to those observed for surgery. Looking at Figure 16 and Table 5, data shows that, once again, t**here is a consensus (84.6%) among people surveyed in the importance of information about the treatment and what to expect** as a high priority action.

The majority of people who received radiotherapy also identified, as a high priority, the importance of **supporting people to help manage side effects** (75.5%), **guidance about how to reduce the risk of complications** (73.8%) and **pain management** (72.3%).

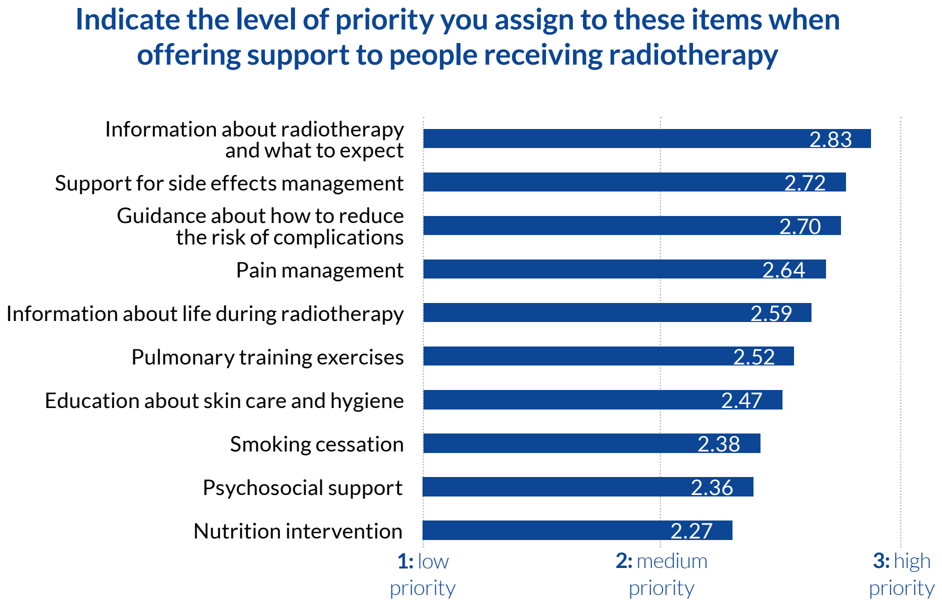

FIGURE 16. Priorities when offering support to people receiving radiotherapy (n=439).

PRIORITIES WHEN OFFERING SUPPORT TO PEOPLE RECEIVING RADIOTHERAPY*	HIGH PRIORITY	LEVEL OF AGREEMENT
Information about radiotherapy and what to expect	**84.6%**	**CONSENSOUS**
Support for side effects management	**75.5%**	**MAJORITY**
Guidance about how to reduce the risk of complications	**73.8%**	**MAJORITY**
Pain management	**72.3%**	**MAJORITY**
Information about life during radiotherapy (nutrition, rest, exercise, etc.)	**64.6%**	**DISAGREEMENT**
Smoking cessation	**63.5%**	**DISAGREEMENT**
Pulmonary training exercises (prehabilitation / rehabilitation)	**62.3%**	**DISAGREEMENT**
Education about skin care and hygiene	**56.6%**	**DISAGREEMENT**
Psychosocial support (emotions, finances, work, etc.)	**52.6%**	**DISAGREEMENT**
Nutrition intervention	**43.4%**	**DISAGREEMENT**

*Not all services may have been available to all people, and this may have influenced their response.

TABLE 5. High priorities when offering support to people receiving radiotherapy (n=439).

3.2.4. Pharmacotherapy

86.0% of people surveyed (788 individuals) responded that they had received pharmacotherapy, such as chemotherapy (63.3%), targeted therapy (45.9%) immunotherapy (39.7%) or antiangiogenics (2.0%). Six out of 10 participants who received a systemic treatment had Stage IV disease at diagnosis. Questions in this section were asked only to people who received pharmacotherapy.

In accordance with the results obtained with surgery and radiotherapy, most participants (62.1%) confirmed that they were well informed about pharmacotherapy before the treatment (quite a bit / very much). However, this percentage is lower compared with surgery (77.9%) and radiotherapy (66.2%). Almost **4 out of 10 people (37.8%) indicated that they had not received enough information about their pharmacotherapy.**

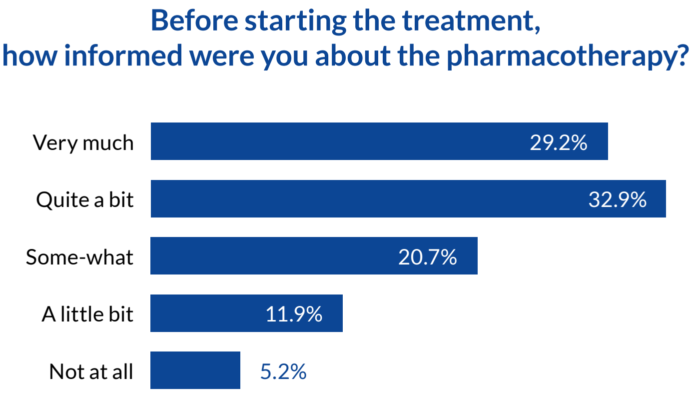

FIGURE 17. Information about pharmacotherapy (n=763).

72.0% of participants reported weakness / fatigue as the complication most difficult to manage during the treatment (Figure 18). This fatigue is usually defined in literature as more severe, more persistent, and more debilitating than `normal' fatigue caused by lack of sleep or over-exertion and is not relieved by adequate sleep or rest[28]. Fatigue is the main reason why people with lung cancer experience limitations in daily activities[20]. It is caused by multifactorial issues, such as comorbidities, nutritional status, medications, or reduction of physical activity[29].

Other significant difficulties reported by those surveyed were associated with **gastrointestinal repercussions:** nausea / vomiting (33.6%), constipation (31.6%), eating difficulties (27.6%) and diarrhea (24.0%). Specialized dietary advice and nutritional counselling should be offered to people receiving pharmacotherapy.

FIGURE 18. Issues most difficult to manage related to pharmacotherapy (n=753).

For supporting people receiving pharmacotherapy (Figure 19; Table 6), there is a consensus between participants about the **high need for information about the medical treatment and what to expect (88.5%).** People with lung cancer want to be informed about succeeding steps and possible expectations so that they can feel better prepared to face the difficulties associated with the treatments[30].

Participants also assigned a **high level of priority to the support for side effects management** (84.8%). Fitness is a crucial factor in whether people with lung cancer are able to undergo treatments[18], so care to deal with difficulties associated with side effects plays an important role in increasing quality of care.

Indicate the level of priority you assign to these items when offering support to people receiving pharmacotherapy.

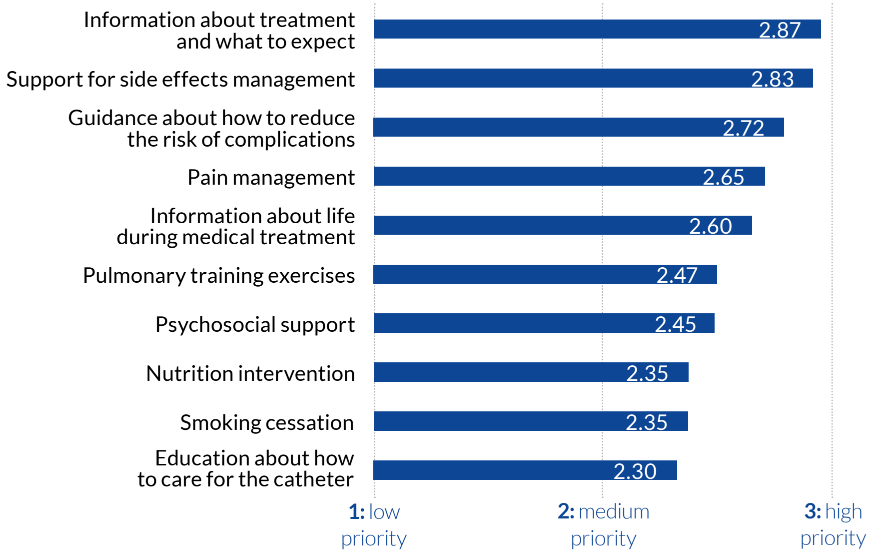

FIGURE 19. Priorities when offering support to people receiving pharmacotherapy (n=763).

PRIORITIES WHEN OFFERING SUPPORT TO PEOPLE RECEIVING PHARMACOTHERAPY*	HIGH PRIORITY	LEVEL OF AGREEMENT
Information about treatment and what to expect	**88.5%**	**CONSENSOUS**
Support for side effects management	**84.8%**	**CONSENSOUS**
Guidance about how to reduce the risk of complications	**74.5%**	**MAJORITY**
Pain management	**71.8%**	**MAJORITY**
Information about life during medical treatment (nutrition, rest, exercise, etc.)	**65.3%**	**DISAGREEMENT**
Smoking cessation	**61.6%**	**DISAGREEMENT**
Pulmonary training exercises (prehabilitation / rehabilitation)	**57.6%**	**DISAGREEMENT**
Psychosocial support (emotions, finances, work, etc.)	**55.2%**	**DISAGREEMENT**
Education about how to care for the catheter	**52.1%**	**DISAGREEMENT**
Nutrition intervention	**47.9%**	**DISAGREEMENT**

*Not all services may have been available to all people, and this may have influenced their response.

TABLE 6. High priorities when offering support to people receiving pharmacotherapy (n=763).

PRIORITIES ALONG THE TREATMENT PATHWAY
Summary

BEFORE TREATMENT

- Access to the medical treatment plan after diagnosis
- Education about side effects and how to reduce the risks of complications
- Information about treatments and what to expect
- Pulmonary training exercises for people undergoing surgery
- Smoking cessation for people undergoing surgery

DURING AND AFTER TREATMENT

- Support for side effects management, especially pain management
- Guidance to reduce risks of complications
- Information about life after surgery

TABLE 7. Priorities along the treatment pathway.

Data in Table 7 highlights the high importance of medical information and side effect management. Previous studies have highlighted that lung cancer is associated with higher disease burden, more physical hardships, and greater symptom distress than other cancer types[25]. The health of people with this disease declines both as a consequence of the illness itself, and because of side effects from the treatment they receive[31].

Participants suggested three main **strategies to improve the support given to manage symptoms and side effects** (Table 8):

- **Referral to allied health professionals (62.2%).** Other specialists should be involved in the pathway to address the multiple needs of people affected by lung cancer. Direct referrals to other specialists in a short period of time is highly important to manage symptoms and side effects.

- **Education about how to recognize and self-manage symptoms and side effects (58.8%).** Support to deal with symptoms and side effects is one of the highest unmet needs among those living with lung cancer, according to previous LuCE reports[20-32]. Individuals are increasingly playing a key role in their care, so self-management interventions are needed to empower them to manage their disease symptoms, including treatment, physical, social and lifestyle changes[33].

- **Improving accessibility to the medical and nursing team (43.7%).** Reducing waiting time across this care continuum is needed to improve easy access to healthcare. People with lung cancer live with the disease 24/7, so they need to have quick access to healthcare teams to solve the problems and difficulties they may experience.

HOW COULD HEALTHCARE TEAMS BETTER SUPPORT PEOPLE WITH LUNG CANCER TO MANAGE THEIR SYMPTOMS AND SIDE EFFECTS?

Referral to allied health professionals	**62.2%**	Provision of support at home	**29.1%**
Education about how to recognize and self-manage symptoms and side effects	**58.8%**	Informing people when to contact emergency services	**28.0%**
Improving accessibility to medical and nursing team	**43.7%**	Using telehealth services	**23.7%**
Coordination between the hospital and primary care	**30.1%**	Improving care follow-up through nursing and/or hospital pharmacy consultation	**21.6%**
Improving healthcare professionals' communication skills	**29.7%**	Referral to palliative care	**17.5%**

TABLE 8. Suggestion about support to manage side effects (n=835).

Even when **telemedicine** has been one of the less selected options (23.7%), it is remarkable that **39.0% of people from 35 to 44 years of age suggested telemedicine as a solution to offer better support.** This is an emerging model of communication that is having more support among people with lung cancer.

On the other hand, **palliative care was the least selected option.** The 5th LuCE Report (2020) highlighted that 76.3% of participants had not received palliative care and confirmed that they had not needed it. Palliative care is especially important in lung cancer, as around 80% have Stage IIIB or IV at the time of diagnosis and the burden of symptoms and side effects is higher compared to other cancers[25-31].

Our hypothesis is that society still associates the words `palliative care´ with `end-of-life care´. People should be informed that the focus of palliative care services is the reduction and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, such as physical, psychosocial and spiritual[34]. Clinicians should refer people with lung cancer who are experiencing high burden because of symptoms and side effects to these services at an early stage.

> *We need more time in consultation not only for the initial diagnosis, but also during treatment. Many questions only arise during therapy because side effects occur, because everything must settle first - it takes time. (Germany)*

> *We need better doctor-patient communication. The situation of patients is very delicate, and doctors must know how to answer their questions. (Spain)*

> *Better accessibility to care options for people in rural areas would help to deal with side effects. (Germany)*

> *Refer to patient support groups where we can interact with others going through a similar treatment pathway. (The United Kingdom)*

3.3. SUPPORTIVE CARE

Supportive care is multi professional attention to the person´s physical, psychosocial and spiritual needs, and should be available regardless of the treatment or the stage of the disease[35]. It is one of the key components in an optimal care pathway. This is so important because, as literature suggests, people with lung cancer are a neglected population in terms of physical and psychosocial needs compared with other cancers[25].

Our research shows that people with lung cancer continue to experience difficulties in their access to care, which needs to be addressed: **1 out of 3 people surveyed (35.4%) recognized that their overall needs were not addressed** enough.

Have your overall needs been addressed by healthcare along the disease journey?

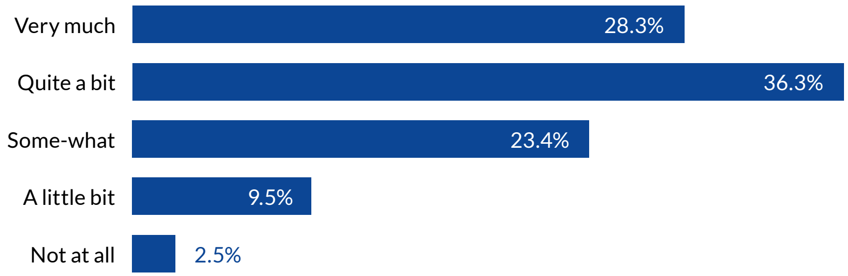

FIGURE 20. Needs addressed by healthcare (n=845).

64.6% stated that they were satisfied that their overall needs were met, however, when asked about the spheres of their lives not addressed by healthcare teams (Figure 21), people identified **emotional (52.5%), physical (39.7%) and social (31.3%) as unmet needs.**

What spheres of your life do you think have not been sufficiently addressed by healthcare teams?

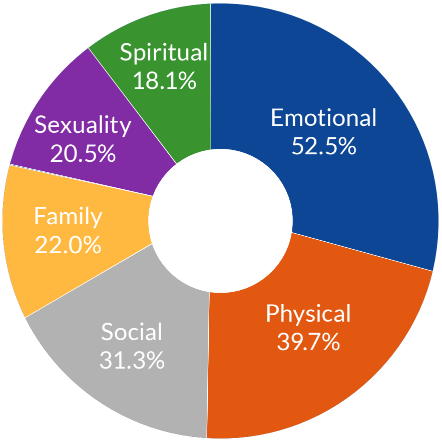

FIGURE 21. Life spheres not addressed by healthcare (n=796).

Access to psycho-oncologists, social workers and physiotherapists are needed to address difficulties in these spheres. However, the availability of multidisciplinary care varies across health facilities, so not many people with lung cancer have access to these allied health care professionals.

There are some differences depending on the age of participants. On the one hand, participants from 35 to 54 years reported that their needs were not sufficiently addressed in the social (work and finances) and sexuality spheres*. On the other hand, people over 65 reported higher needs in the physical sphere**.

A holistic approach to care, addressing the physical, psychosocial, and spiritual needs of people during their care pathway should be available. However, supportive services are not always accessible or even known by people with lung cancer. They should be informed about the healthcare services that are available, and professionals should encourage them to access services according to their individual needs and preferences[36].

> *I had no information on skin dryness, nail care, etc. from the medical team. I obtained this information thank to a patient association. (France)*

> *Stress of being alone at home after spending 3 weeks in hospital for the fear that the situation will get worse again at home. (France)*

> *I don't expect my medical team to address everything, just point me in the right direction in my area of need. (The United Kingdom)*

> *I have not discussed the areas of life with any doctor, I miss empathy. (Germany)*

> *I miss information about what I can do to improve my health. (Finland)*

According to 3 out of 4 participants (74.9%), healthcare teams should inform people about supportive services before starting treatment. 55.3% suggested that this should happen as soon as they receive a diagnosis and 19.6% at the time from diagnosis and treatment. There is a consensus among participants that **healthcare professionals should not wait until people explicitly report their needs before informing them about the support services** available.

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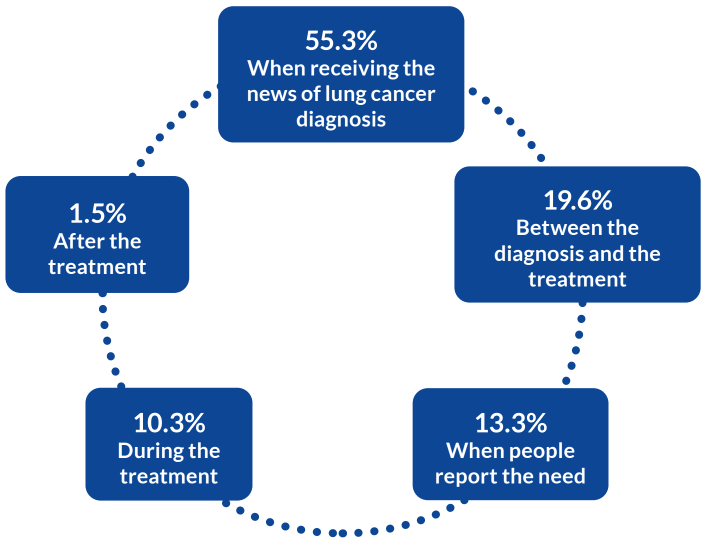
* Social: 35 – 44 (48.4%); 45 – 54 (44.6%) / Sexuality: 35 – 44 (29.7%); 45 – 54 (29.9%)

** Physical: 65 – 74 (44.2%); 75 or older (53.7%)



When should people with lung cancer be informed about the supportive services available?

FIGURE 22. Time points to inform about supportive services (n=945).

Accessibility is an important matter in the care pathway. **Half of respondents would prefer to obtain information from the healthcare team by phone** in non-urgent situations (Figure 23). However, 23.2% highlighted the importance of in-person consultations, and they stated they would be willing to wait 1 – 3 days for an in person appointment.

> *I´d liked having a telephone number where you can seek advice outside of consultations. For example, if I had a fever on weekends, the only solution for me was to go to the hospital emergency room. (France)*

Data from our research indicates that **only a minority of people (14.2%) prioritizes the use of telemedicine,** as a tool to solve practical questions from daily life issues related to the disease.

Communication between people with lung cancer and healthcare professionals is crucial for good supportive care along the disease pathway. Data obtained in our 2021 report showed that people diagnosed with lung cancer were highly satisfied with their communication with their healthcare team. 76.0% of participants from last year's research highlighted that the language used was more often easy to understand, and 70.7% felt they could usually express their preferences regarding treatment[20]. These numbers were similar to those obtained in our 2020 report: 78.1% of people diagnosed with lung cancer thought that communication was positive or very positive[32].

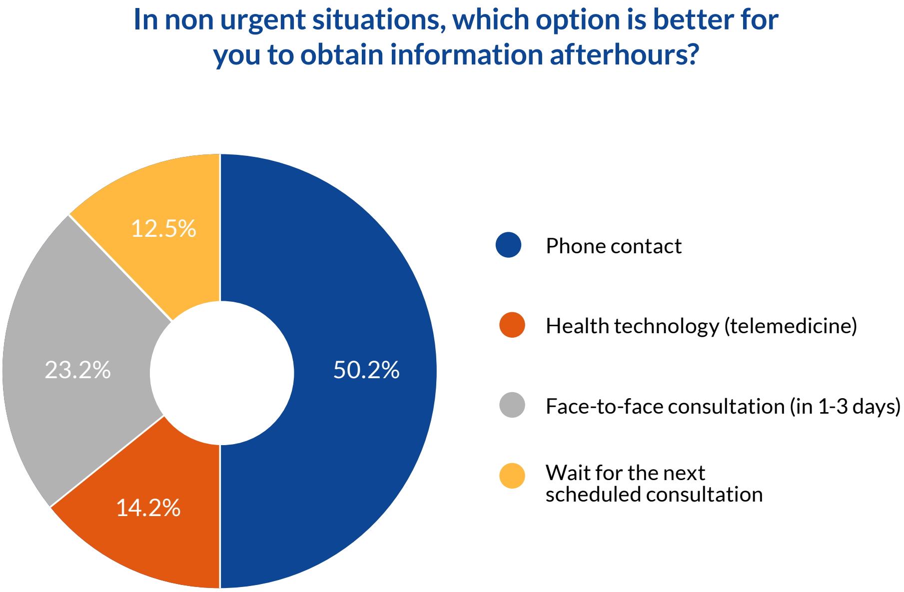


FIGURE 23. Options to contact in non-urgent situations (n=841).

However, as Figure 24 indicates, people with lung cancer who completed the survey from 2022 stated that they missed information along the care pathway. **Half of participants (48.2%) mentioned the lack of information about clinical trials.** Clinicians must be aware of clinical trials and inform people about the options available. The lack of knowledge and awareness of trials is a significant barrier to participation[37]. Our 2018 report showed some concerning data: 22% of people surveyed had never heard about clinical trials and only 47% were made aware about trials by their physicians[38].

Another significant issue is that **4 out of 10 people surveyed have missed information about emotional and social issues.** As Figure 21 details, the emotional sphere was not sufficiently addressed by healthcare teams, according to half of participants. Therefore, psychosocial factors of illness should be discussed in more depth with people with lung cancer.

Advanced care planning is important for people with lung cancer. This refers to the process of reflection and communication about a person's values and wishes concerning future health issues and personal care preferences in the event that one becomes incapable of consenting to treatment or other care[39]. **38.6% stated that they had missed talking about future care** in the event they become unable to communicate their wishes. Clinicians and other healthcare professionals should be aware that these sensitive issues are unlikely to be raised in the clinic. They should be prepared to start the conversation and explore preferences and values.

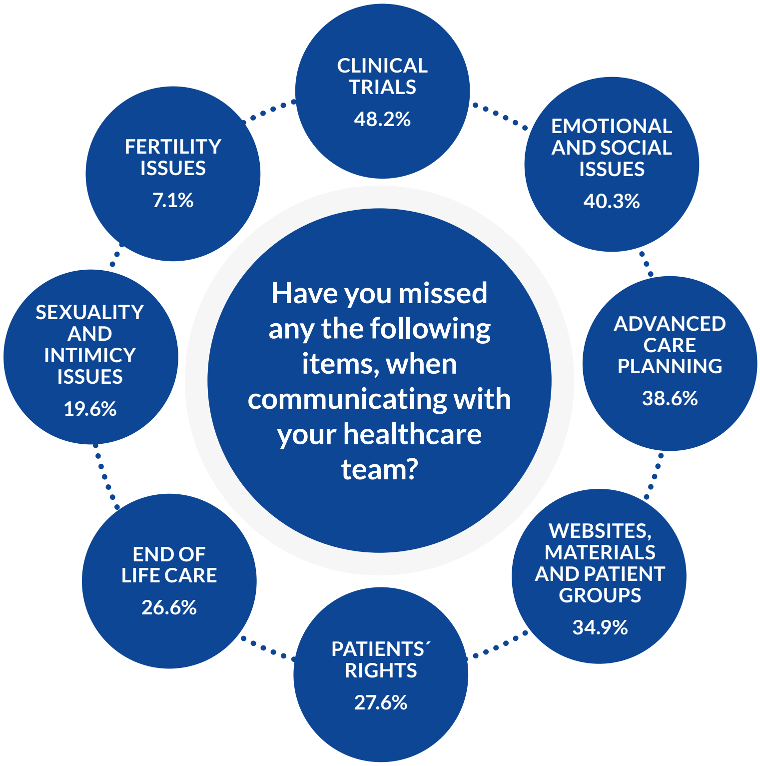


FIGURE 24. Missing information from healthcare (n=787).

People with lung cancer need more information about clinical trials, emotional issues, and advanced care planning

Communication is much more than informing people about their disease, treatment and care. Assessment and discussion between healthcare professionals and people with lung cancer about their needs for physical, psychological, social and spiritual support should be undertaken along the disease pathway[40]. However, our research shows that **half of participants (49.2%) stated not to have shared all aspects of their health status with their healthcare team.**

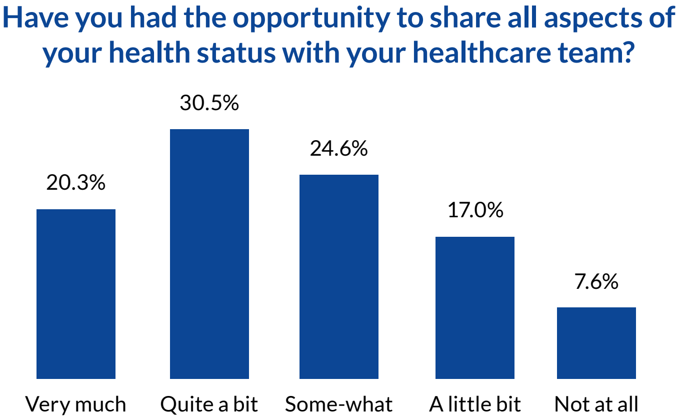


FIGURE 25. Opportunity to share all aspects of health status with healthcare (n=846).

The value of Patient Reported Outcomes (PROs) along the care pathway

Healthcare professionals cannot address patient´s needs if these do not inform all aspects of their health status. This can compromise patient care and safety. Collection of patient-reported outcomes (PROs) is highly recommended for this matter and **should be integrated into routine cancer care.**

PROs is **data directly reported by the patients** about their health status such as symptoms, quality of life, functional status or needs. Instruments used to measure PROs tend to be self-completed questionnaires, providing valuable information that helps to determine the type and level of support each person requires. This data collection lets healthcare team to better understand their concerns, worries and difficulties, improving the communication with people with lung cancer.

Respondents suggested some measures to improve the communication and relationship between people with lung cancer and healthcare professionals (Figure 26). The most selected option was having the possibility to **access to specialised cancer nurse consultations (44.1%).** According to literature, specialised nurses may help to identify and effectively help manage people's needs[41]. Their role is becoming more important in a clinical setting as they provide advanced clinical practice, effective communication and complex navigation and brokering for people with cancer[42].

Around 4 out of 10 participants highlighted the importance of **longer medical consultations** and having a **central point of contact.** As multiple specialists are involved in the pathway, people with lung cancer are sometimes confused and do not know who to refer to for questions[30]. It can feel burdensome to have to seek care from different professionals[30]. This is a consequence of fragmented pathways and lack of continuity of care, so it is a priority to have someone who can coordinate all the points of the pathway and for people to have a specific person to contact when they need help.

Two other measures that obtained similar percentages were: better communication skills among the healthcare team (42.9%) and the use of lay language (40.0%). Participants valued the sensitivity of providers as important and the comprehensive information when communicating with people affected by lung cancer.

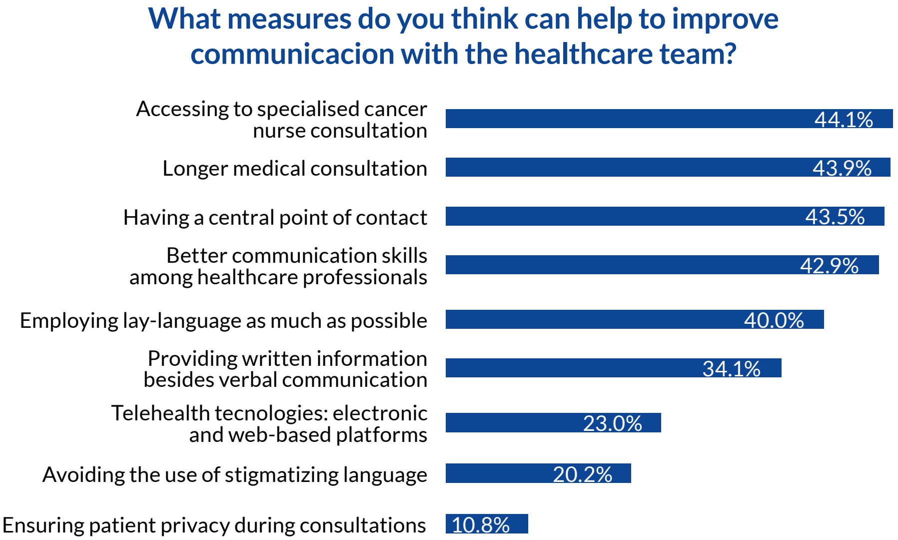


FIGURE 26. Measures to improve communication with healthcare (n=830).

> *Patients should have a contact person they can turn to with questions. For example, a specialized nurse who can filter questions for the doctor or can help right away. Patients need a lot more care and contact. (Germany)*

> *I have been very annoyed with the focus on smokers. I've never been a smoker. I feel we are being overlooked. People forget we all can get lung cancer. (Denmark)*

> *We need just one person as contact. Until I switched to a resident oncologist for this reason, I had different face-to-face consultations with almost every doctor at the hospital. (Germany)*

> *After 3 years and getting to know the team, communication is now good but that reflects good continuity of care without which I wouldn't feel as well looked after and supported as I do. (The United Kingdom)*

What is patient-centred supportive care?

Personalize the best treatment for each patient and a lot of empathy from the healthcare staff. (Spain)

Listening and taking the patient's opinion into account when planning care and treatments. (Finland)

Consider, as a starting point, the fact that patients are different and may have different needs. (Denmark)

Patient centred supportive care is allowing the patient to decide what is best for themselves. (Ireland)

That I don't have to look for all the information myself, but that everything is available, and I can then choose what's relevant to me. (Germany)

A relationship with my team where I feel they know my treatment plan, are up to date with scans and the need for results and when I know I can contact them with any queries. (The United Kingdom)

That there is 1 point of contact who is also the case manager and who provides everything you might need. (The Netherlands)

To consider the patient in his uniqueness and integrity as a person, and not just the disease. (Italy)

To look at the patient holistically, not just the lungs, and to ensure full support considering all possibilities. (Germany)

Communication in a language that the patient can understand, and tests are performed in a short time. (Hungarian)

Patients being aware of the support available, and this support being tailored to the individual needs. (The United Kingdom)

Honesty and empathy, responding to questions and concerns in a timely manner. (The United Kingdom)

To feel that someone with experience can understand and support you, and freely express your feelings. (Greece)

Make sure you are heard, where you can express your concerns, where you are listened to and where you are involved in the search for answers. (The Netherlands)

Care that considers the actual problems reported by the patient and support him. (Slovenia)

Individual needs are heard and addressed by a multidisciplinary team of health care professionals. (Sweden)

Putting the patient first, being aware of their emotional as well as physical needs, providing clear information and contact with healthcare team so patients can make informed decisions about their care and treatment. (Ireland)

3.4. FOLLOW-UP CARE

When active treatment is completed, people with lung cancer need to receive regular follow-up care. 261 people surveyed (30.7%) said that they were in follow-up care at the time of completing the survey. 47.1% had Stage I-II at diagnosis, 24.1% Stage III and 26.1% Stage IV.

As Figure 28 shows, **most participants stated that they were satisfied or very satisfied with the follow-up care** received (69.2%). Around 1 out of 3 were not satisfied with the support received in the follow-up.

Have you completed your active treatment and are you currently in follow-up?

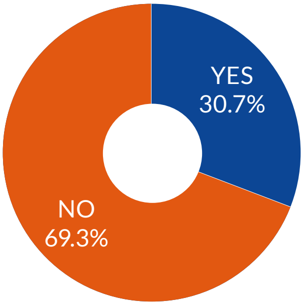


FIGURE 27.
Active treatment completed (n=851).

How satisfied are you with your follow-up care?

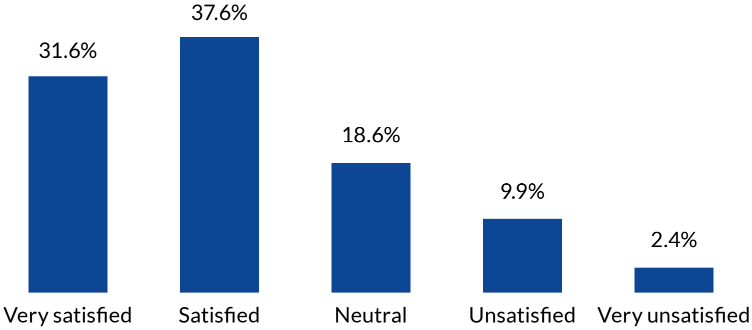


FIGURE 28. Satisfaction with follow-up care (n=253).

Even when most participants reported high satisfaction with their follow-up care, our findings suggest some lack of information and support. 85.3% of participants who completed their active treatment acknowledged to have missed information and support (Figure 29).

Information about the symptoms of recurrence was reported as the main need in follow-up care (44.2%). Prognostic risk factors in lung cancer include an effective follow up regimen to identify disease relapse and offer the best support as possible to people with lung cancer[21]. It is essential to educate people about how to recognize symptoms and when to contact their doctors.

The second priority is to offer more information about difficulties associated with lung cancer and treatments. 39.0% stated that they had missed support for the **management of the consequences of lung cancer and treatments.** This is not only about the side effects that remain even after finishing acute treatment. Late effects may occur months or years later, so support and educational interventions are required to manage these issues.

> *After all the treatments you fall into a hole. Little information about where you can go for rehabilitation or a coach who guides you to get back to the 'normal' world. (The Netherlands)*

The number of people who complete active treatment is increasing, and they need rapid access to health services when required. However, **1 out of 3 (31.1%) highlighted that they did not have faster access to healthcare** once their active treatment was completed. Speeding up this access is required, as survivors have also the risk of primary recurrence or a second primary cancer.

People with lung cancer should be involved in the care plan after active treatment. However, **29.1% of participants stated that they did not have a follow up care plan designed with them.** This plan should cover issues, such as a follow-up schedule, supportive care services and recommendations for post-treatment care, among others[43].

Finally, **28.7% of participants mentioned psychosocial support** as an unmet need in the follow-up phase. People need guidance and support about how to manage the psychological and emotional issues associated with living with lung cancer after active treatment.

What type of information / support have you missed in the follow-up?

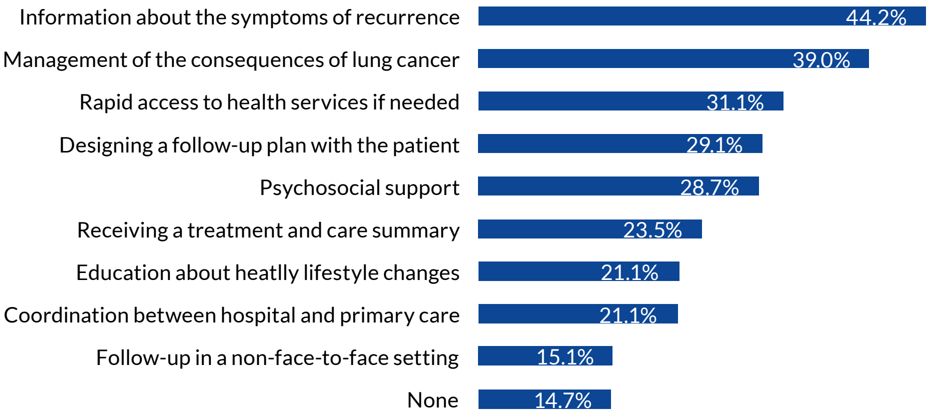


FIGURE 29. Missed support in the follow-up (n=251).

4. CASE STUDIES - Lung cancer pathway in two european countries: The Netherlands and Romania

Data presented in the previous section shows the experiences and preferences reported by people with lung cancer from 25 European countries. In addition, to the survey completed by 991 participants, we also collected preliminary data to explore the current status of the lung cancer care pathway in two European countries, as case examples. The countries selected were: The Netherlands and Romania.

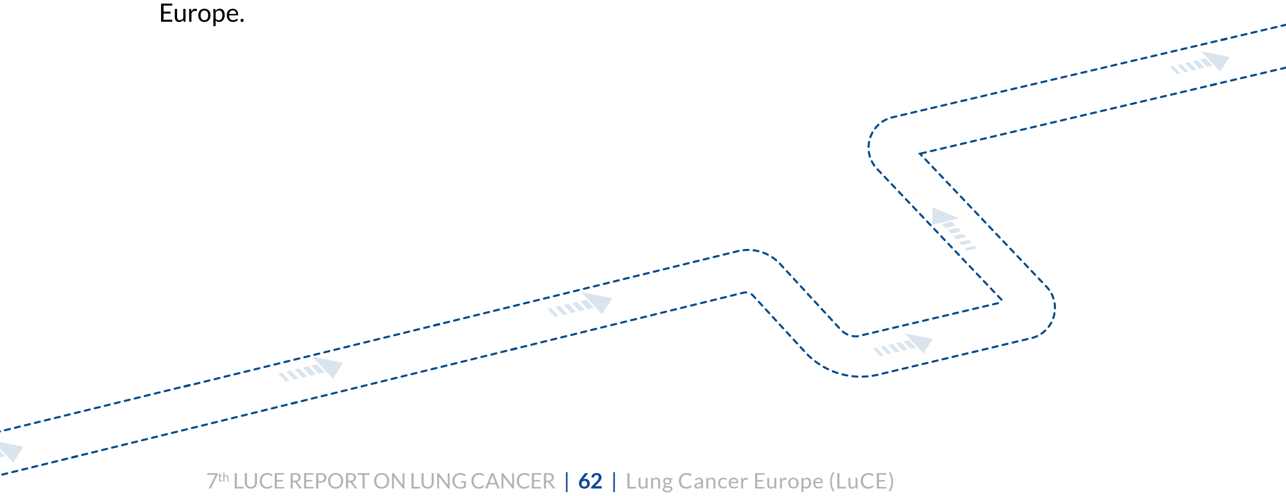
The purpose of this section was to provide additional data about the care pathway in these countries, based on the experiences of national experts, physicians, healthcare professionals and patient advocates (see the section `Report collaborators´).

The country selection was made according to the following criteria:

- **LuCE representation:** Both countries have LuCE representation and were willing to participate in this research.

- **Different geographical location:** The countries selected had to be in different geographical regions in Europe.

- **Differences in disease outcomes:** Romania and The Netherlands were selected as potential differences in the care pathways of both countries were expected. This was according to previous research, such as the LuCE Position Paper (2020)[44]. As LuCE advocates for equity in access to optimal care, this research also aims to highlight the significant inequities in terms of access to care across Europe.



4.1. DIAGNOSTIC PATHWAY

Our research finds relevant differences when comparing data obtained from experts from The Netherlands and Romania. According to experts from The Netherlands, the main challenges to speed up access to diagnostics are associated with self-recognition of disease risk and accessibility to health care (Figure 30). Data obtained in relation to these issues are similar in both countries. However, experts from Romania valued, as a higher priority, to reduce the diagnostic time interval when the person is already attending a lung cancer specialist, and the time from diagnosis to treatment.

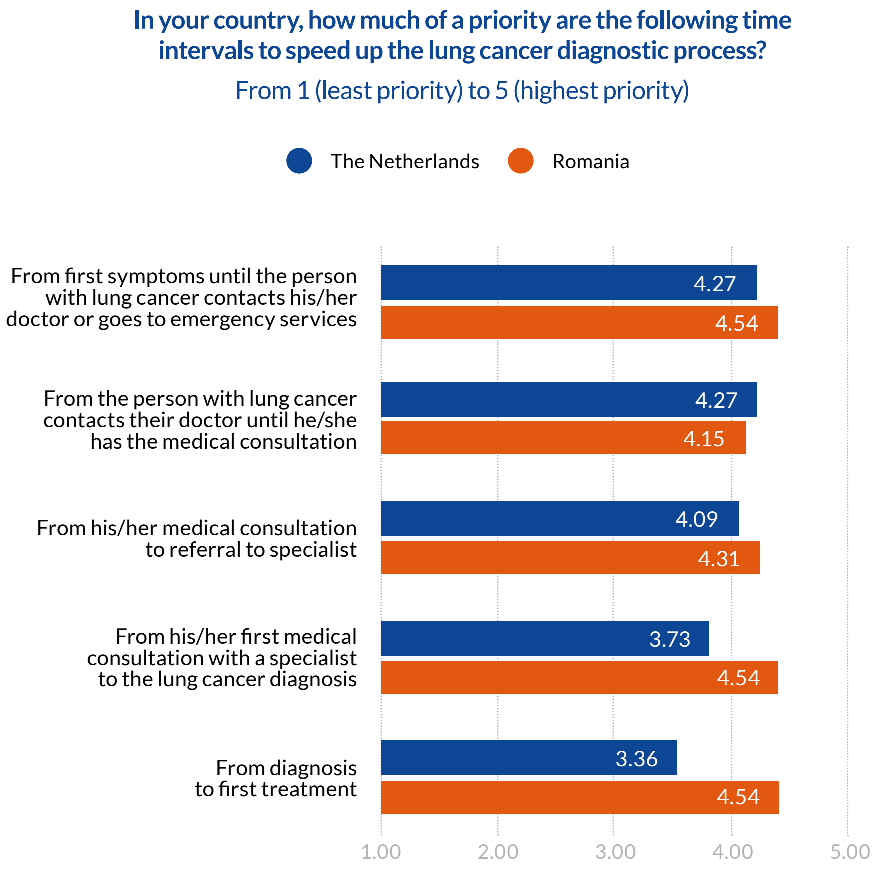


FIGURE 30. Priority intervals to speed up the diagnostic process (The Netherlands and Romania).

As Figure 30 shows, experts from The Netherlands (n= 11) stated that the time of reporting symptoms is one of the two priority issues to hasten the diagnostic pathway. People consulted from this country answered that the main reason for the delay in reporting symptoms is because people do not know anyone can get this disease, so they do not suspect lung cancer (Figure 31).

This was selected by 81.8% of experts from The Netherlands (9 / 11), while only 46.2% (6 / 13) of experts from Romania considered that this is a clear reason to explain delays in reporting. According to Romanian participants (n= 13), the main reasons are normalization of symptoms (low risk perception of symptoms) and lack of knowledge about symptoms (76.9%: 10 / 13).

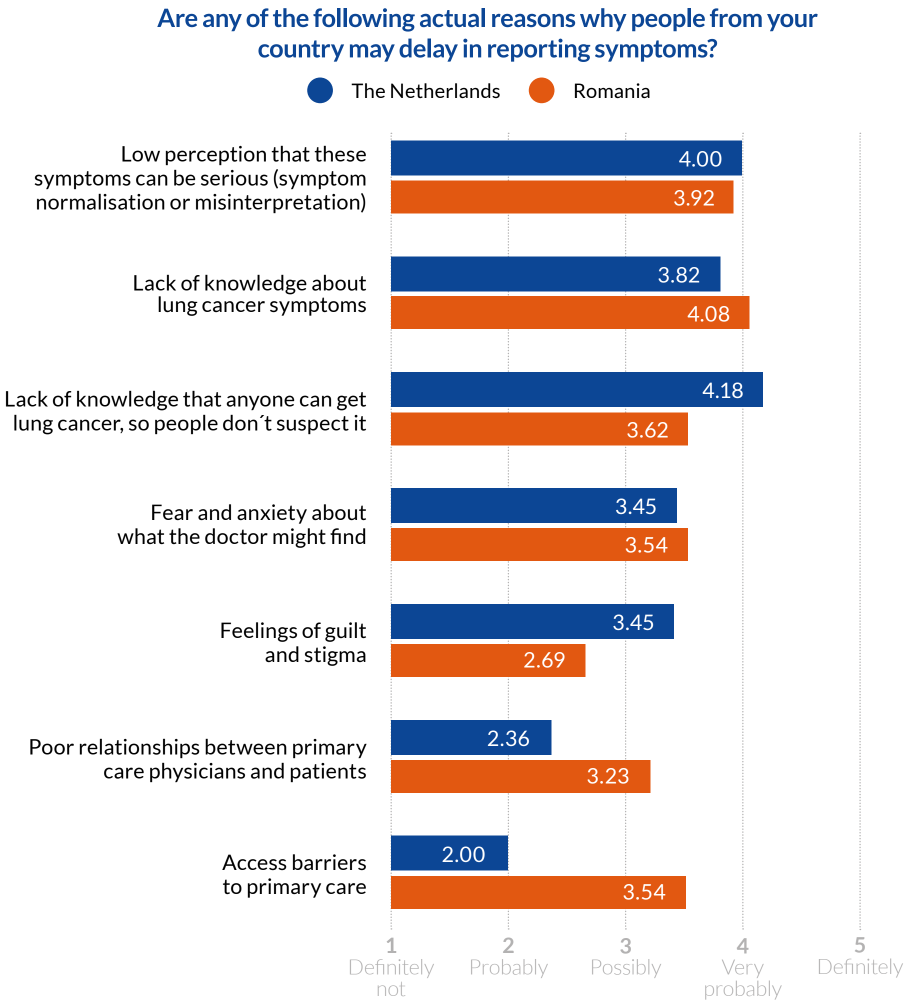


FIGURE 31. Reasons for delays on reporting symptoms (The Netherlands and Romania).

Challenges associated with the diagnostic pathway were also reported by experts from both countries. The main issue reported by experts from Romania and The Netherlands is the lack of screening programmes (Figure 32).

Our research identifies significant differences between the high priority values of the experts from these countries. Romania reported much higher healthcare challenges than those from The Netherlands. Our data suggests that coordination and communication across specialties and long times for diagnostic procedures are relevant barriers in the diagnostic pathway in Romania (11 / 13). In contrast, The Netherlands reported a higher impact of misinterpretation and misattribution of symptoms by primary care physicians, but only 3 out of 11 experts valued this as highly significant.

Are any of the following issues associated with a delay in accessing the lung cancer diagnostic pathway?

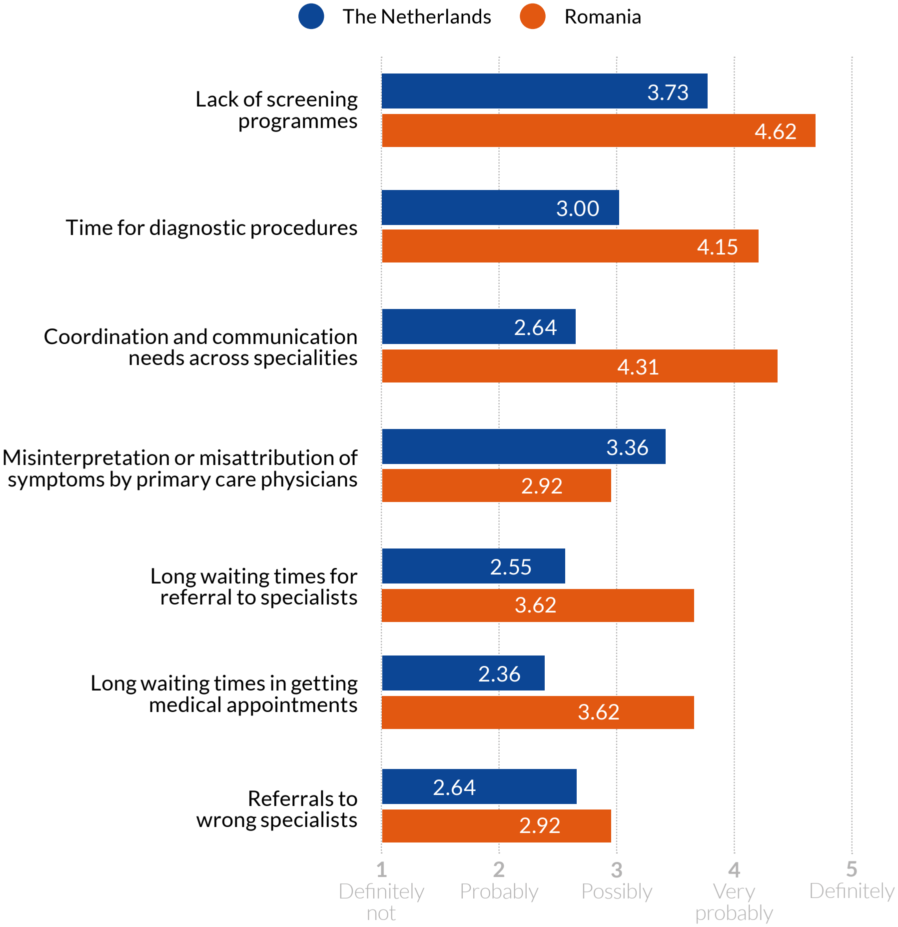
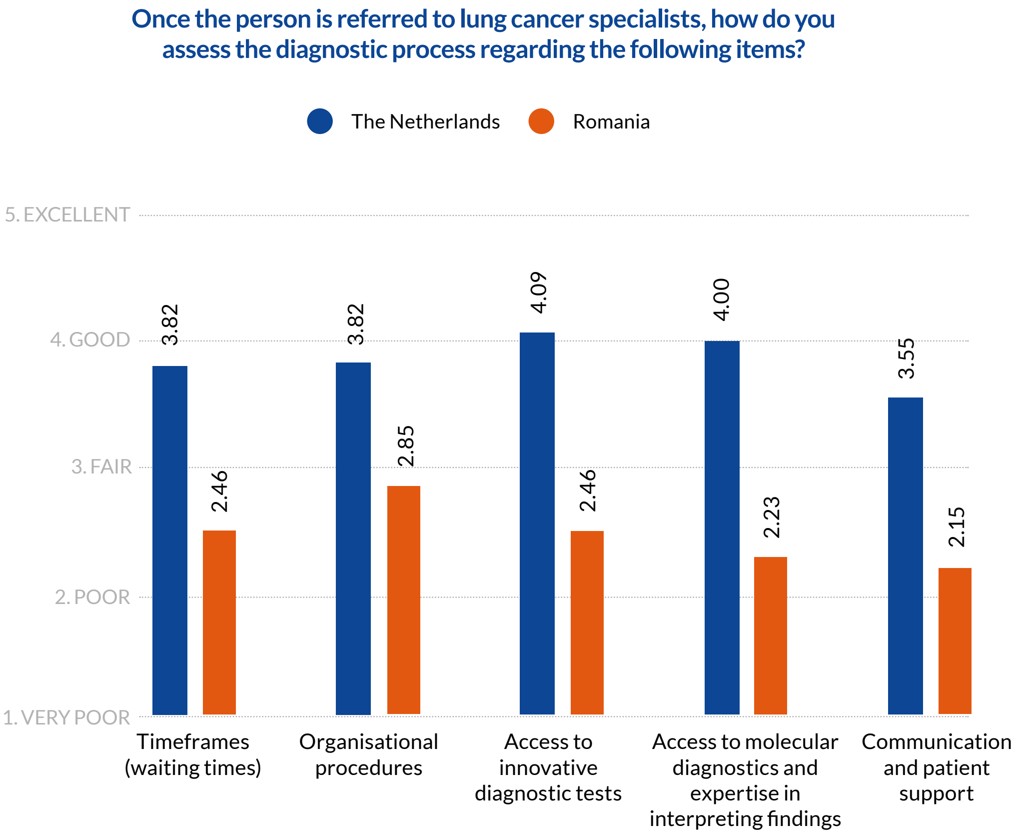


FIGURE 32. Reasons for delays on accessing to diagnostic pathway (The Netherlands and Romania).

Even when the person is referred to a lung specialist, some barriers in the diagnostic process remain, especially in Romania (Figure 33).

Data shows that experts rated the diagnostic process as good in The Netherlands when patients are already attending a lung specialist unit. The worst rated issue was communication and patient support (4 out of 11 said this was poor / fair).

In contrast, those from Romania valued this pathway as poor / fair. It is remarkable that 9 out of 13 experts rated the communication and support to patients along this pathway as very poor / poor, as well as the access to molecular diagnostics (7 / 13).



Once the person is referred to lung cancer specialists, how do you assess the diagnostic process regarding the following items?

FIGURE 33. Assessment of the diagnostic process after referral (The Netherlands and Romania).

4.2. PATHWAY AFTER DIAGNOSIS

Experts' assessment about the lung cancer pathway was structured into the following quality care indicators:

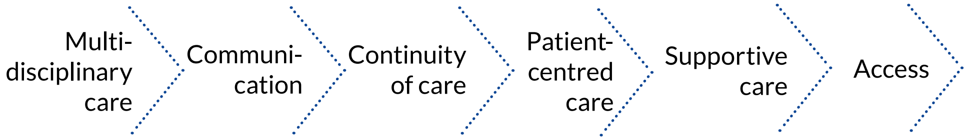


Figure 34 suggests that there is insufficient **multidisciplinary care** in both countries. Looking at the data reported by experts from Romania, 11 out of 13 agreed that there is a lack of good communication and coordination across healthcare professionals and the absence of coordinated multidisciplinary care. Information sharing and communication among healthcare professionals are associated with patient satisfaction, psychological and physical outcomes, and continuity of care[45]. However, processes for communication and coordination between services are not always optimized.

Most from The Netherlands (8/11) agreed that multidisciplinary meetings existed. However, 6 out of 11 stated that care is not always integrated across different specialties and not all people with lung cancer have access to coordinated multidisciplinary care.

MULTIDISCIPLINARY CARE

Indicate your level of agreement with the following statements regarding the multidisciplinary care that people with lung cancer receive in your country.

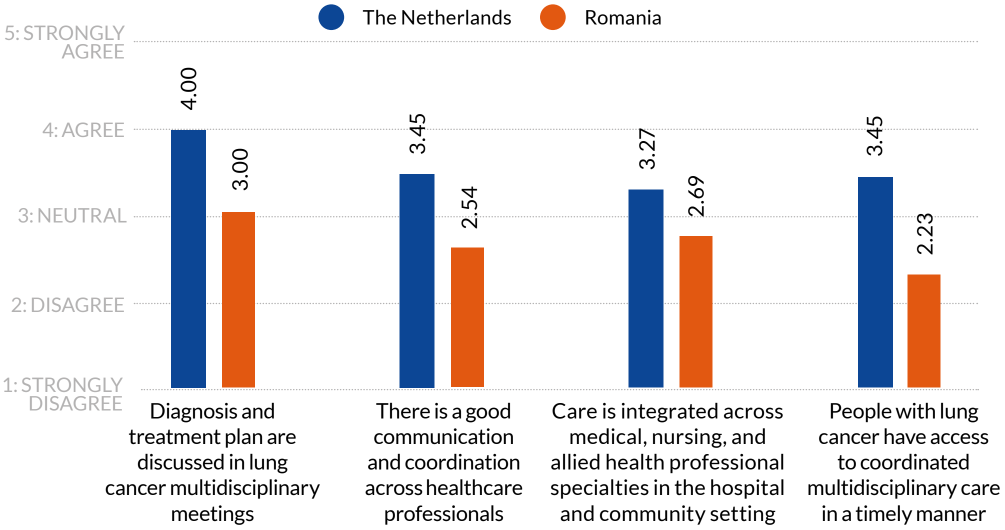


FIGURE 34. Multidisciplinary care: level of agreement (The Netherlands and Romania).

Regarding multidisciplinary care, Table 9 shows that the level of access to different healthcare disciplines is much lower in Romania than in The Netherlands.

The most severely underrepresented disciplines reported by experts from Romania are occupational therapy (12 / 13), psycho-oncologists (10 / 13) and rehabilitation / physiotherapists (10 / 13). On the other hand, access needs in The Netherlands are mainly related to psychologist, psycho-oncologists and primary care nurses (reported as no access or low access by 6 out of 11).

Data reported by experts suggest that both countries have low access to geriatric oncologists and psycho-oncologists, and high access to primary care doctors. On the contrary, the most significant differences are the access to primary care nurses (much higher in Romania) and to rehabilitation / physiotherapists (much higher in The Netherlands).

How do you value the overall level of access of people with lung cancer to the following professionals in your country?

THE NETHERLANDS		ROMANIA	
0 (NO ACCESS) 1 (LOW ACCESS) 2 (MEDIUM ACCESS) 3 (HIGH ACCESS)			
Primary care doctors	**2.73**	Primary care doctors	**2.31**
Rehabilitation / Physiotherapists	**2.27**	Primary care nurses	**1.92**
Specialist lung cancer nurses	**2.27**	Palliative care specialists	**1.77**
Dietitians / Nutritionists	**1.91**	Pain specialists	**1.62**
Pain specialists	**1.82**	Psychologists	**1.46**
Palliative care specialists	**1.73**	Social workers	**1.31**
Psychologists	**1.55**	Dietitians / Nutritionists	**1.15**
Occupational therapists	**1.45**	Rehabilitation / Physiotherapists	**1.15**
Social workers	**1.27**	Specialist lung cancer nurses	**1.08**
Psycho-oncologists	**1.18**	Psycho-oncologists	**1.00**
Geriatric oncologists	**1.00**	Occupational therapists	**0.77**
Primary care nurses	**0.73**	Geriatric oncologists	**0.69**

TABLE 9. Access to healthcare professionals (The Netherlands and Romania).

Communication challenges remain in both countries. Experts from Romania and The Netherlands agreed that patient reported outcomes are not integrated into routine cancer care yet (Figure 35). Overall, just 20.8% of experts surveyed (5 / 24) stated that these measures were routinely captured.

The lowest rating received was in relation to the time with the healthcare team in Romania. Only 3 out of 13 experts from this country thought that this time is enough to provide information and answer people's questions.

COMMUNICATION

Indicate your level of agreement with the following statements regarding the communication between the healthcare teams and people impacted by lung cancer in your country.

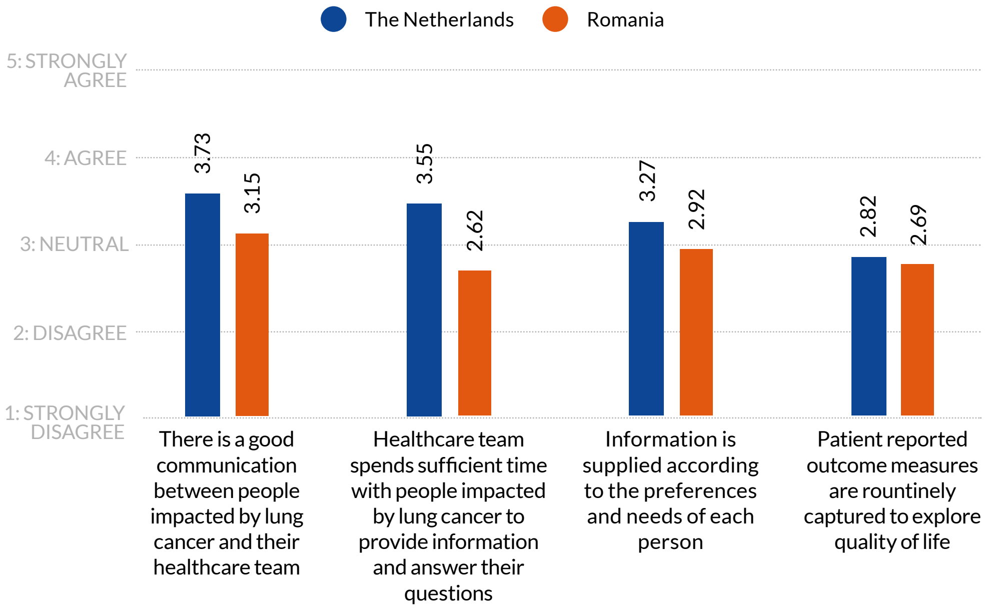


FIGURE 35. Communication: level of agreement (The Netherlands and Romania).

Our findings show that there is room for improvement in both countries regarding the information given to people with lung cancer. This statement is also corroborated in Figure 36: 9 out of 13 experts from Romania (69.2%) and 4 out of 10 from The Netherlands (40.0%) stated that people with lung cancer are not sufficiently informed by healthcare professionals (56.5% of total responses).

In this sense, according to data collected from the larger survey, the information that people with lung cancer from Romania missed the most is about end-of-life care (75.0%) and patient rights (75.0%). Instead, what people from The Netherlands missed the most is information about clinical trials (45.7%) and about how to deal with emotional and social issues (45.7%).

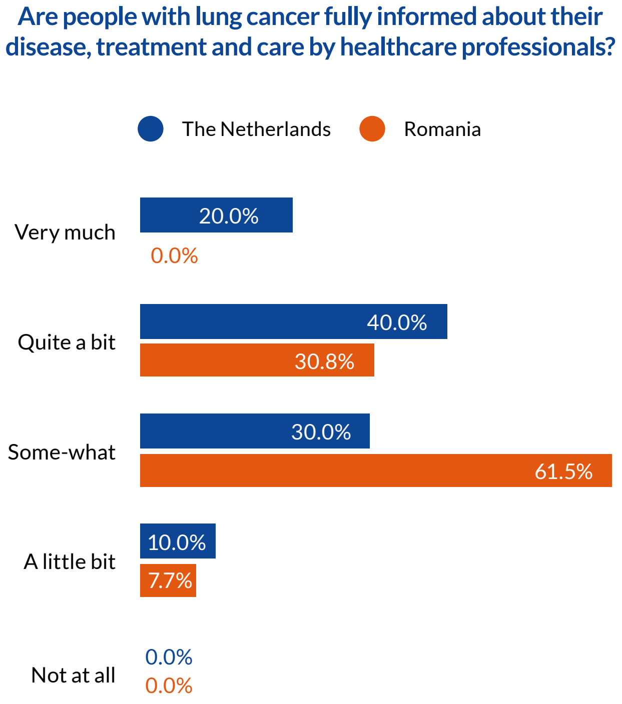


FIGURE 36. Level of information provided by healthcare professionals (The Netherlands and Romania).

People with lung cancer frequently experience fragmented pathways and lack of **continuity of care**[46]. Less than half of the experts from both countries considered that there is continuity of care (Figure 37). A lack of coordination can result in poor quality of care, inefficient resource use and dissatisfaction of patients[47].

Only 2 out of 13 participants from Romania and 4 out of 11 from The Netherlands agreed that there is cooperation between primary care and hospital care. Furthermore, access to patient navigators and allocated key workers to contact was only reported by around half of experts from The Netherlands and around one third from Romania.

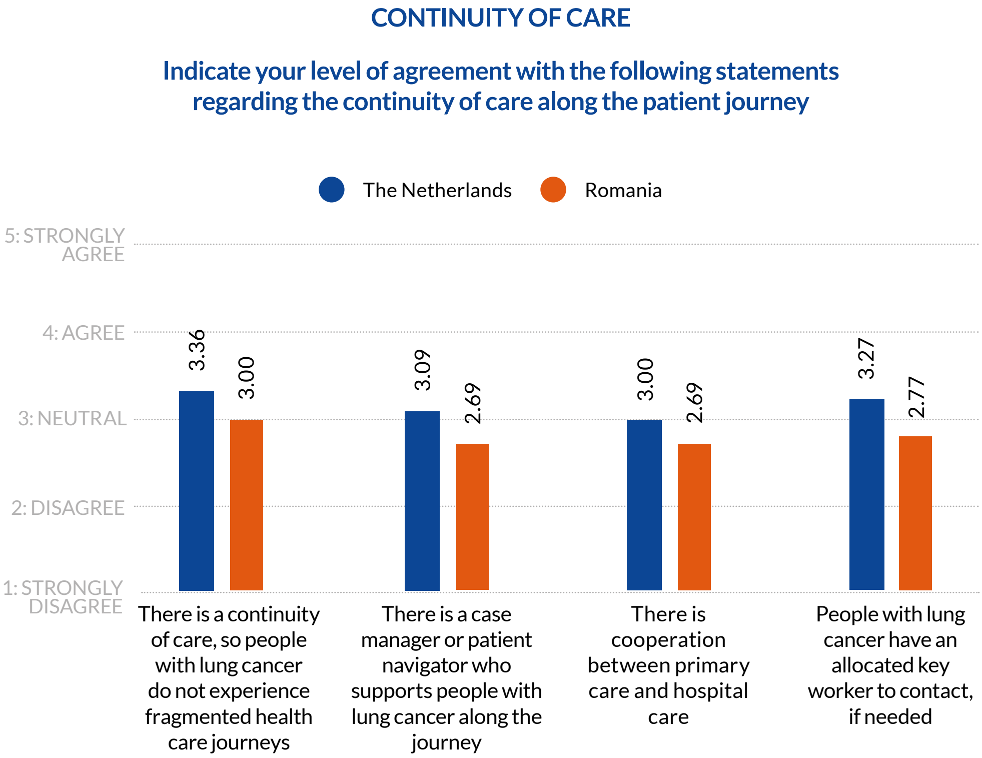


FIGURE 37. Continuity of care: level of agreement (The Netherlands and Romania).

Continuity of care often needs to extend to social services, such as housing and employment. Guidance from social workers is needed for people with lung cancer who face work or financial difficulties. Data from our 5th LuCE Report (2020) showed that 38.0% of people with lung cancer surveyed stated that there had been a negative impact on their household's financial situation with less income reported by 82.1% of respondents. At the same time, 38.1% of participants reported a negative impact on the work situation of someone in their house as well, mainly due to the inability to work (55.7%)[32].

However, our findings suggest a lack of coordination between health and social services in The Netherlands and Romania (Figure 38). Only 5 out of 11 experts from The Netherlands and 2 out of 13 from Romania mentioned that these are well coordinated (by very much / quite a bit).

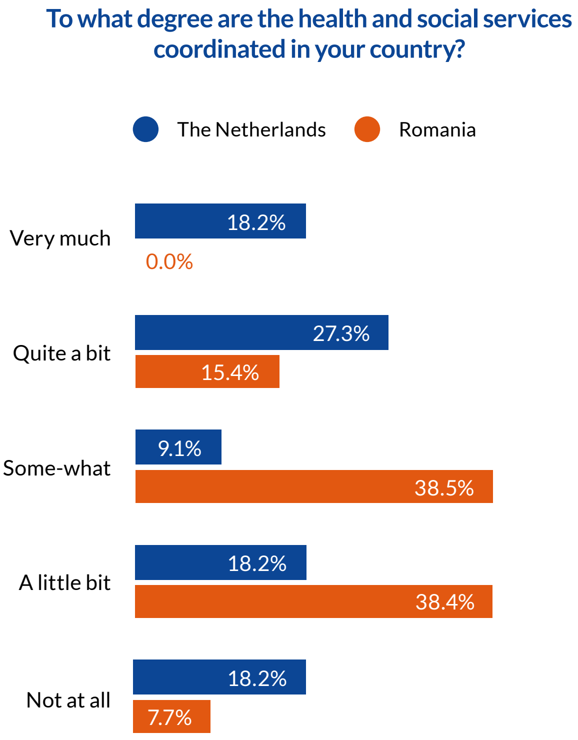
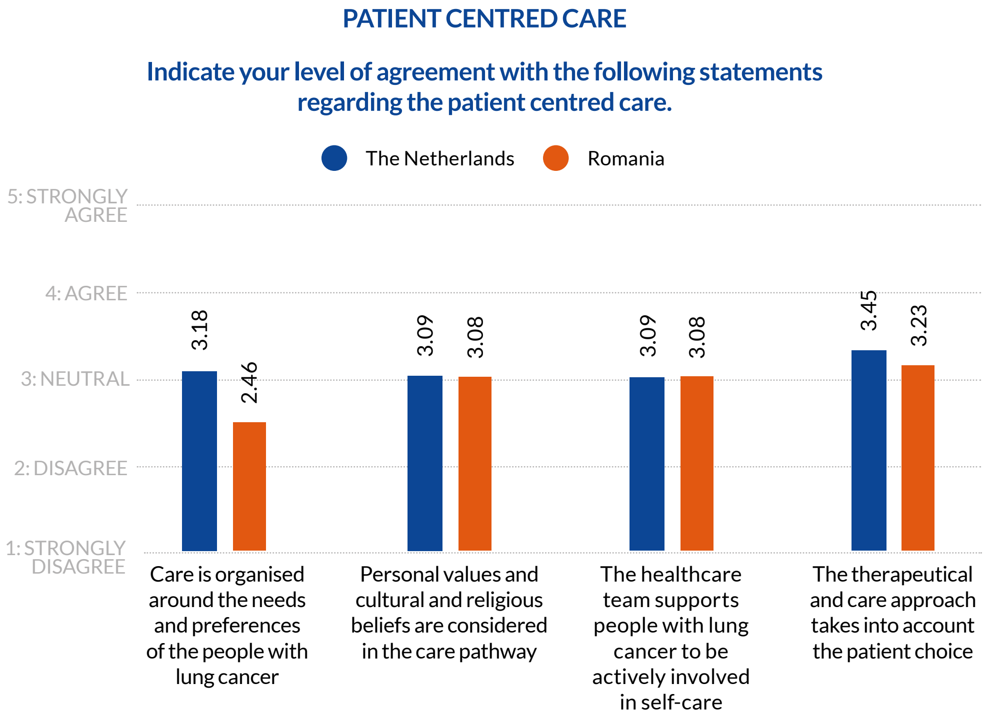


FIGURE 38. Level of coordination of health and social services (The Netherlands and Romania).

Good quality care can only be provided if care is organized around the needs and preferences of patients[48]. However, **patient-centred care** is far away from being a reality, according to experts from both countries. Only 4 out of 11 participants from The Netherlands and none from Romania agreed that care is organised around the needs and preferences of the people affected by lung cancer (Figure 39).

There is also a significant need in both countries to offer more individualised healthcare that considers the personal values and beliefs of people and supports them in active self-care.


PATIENT CENTRED CARE

Indicate your level of agreement with the following statements regarding the patient centred care.

FIGURE 39. Patient-centred care: level of agreement (The Netherlands and Romania).

Patient-centred care requires the consideration of all the personal values of each individual and offer an individualized care plan according to their needs. However, the level of education and place of residence seems to have a greater influence in healthcare accessibility in both countries (Figure 40).

The most significant personal variable that influences the lung cancer pathway in Romania is personal finances. 11 out of 12 experts from this country considered that finances influence this by “quite a bit / very much”.

Do the following personal variables influence the diagnosis, treatment and care?

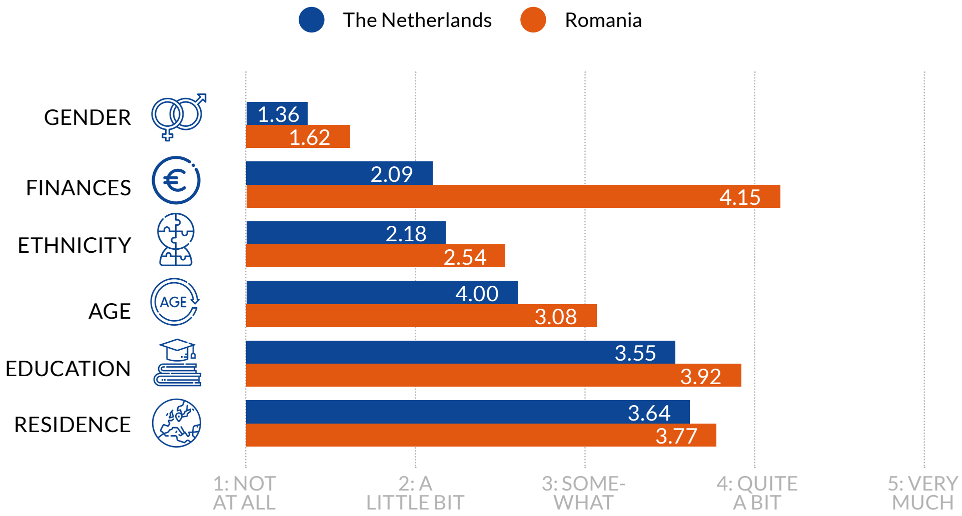


FIGURE 40. Personal variables influencing healthcare (The Netherlands and Romania)..

Supportive care is the quality care indicator rated the worst by experts from The Netherlands. Only one 1 out of 11 experts from this country considered that care needs are periodically assessed. Additionally, Figure 41 suggests that geriatric assessment is lowly implemented in Romania and there is a lack of information about patient associations given by healthcare teams.

Experts from both countries agreed that much more can be done in healthcare to actively involve people with lung cancer in their own care. Only 3 out of 11 from The Netherlands and 6 out of 13 from Romania considered that healthcare professionals empower patients to self-care.

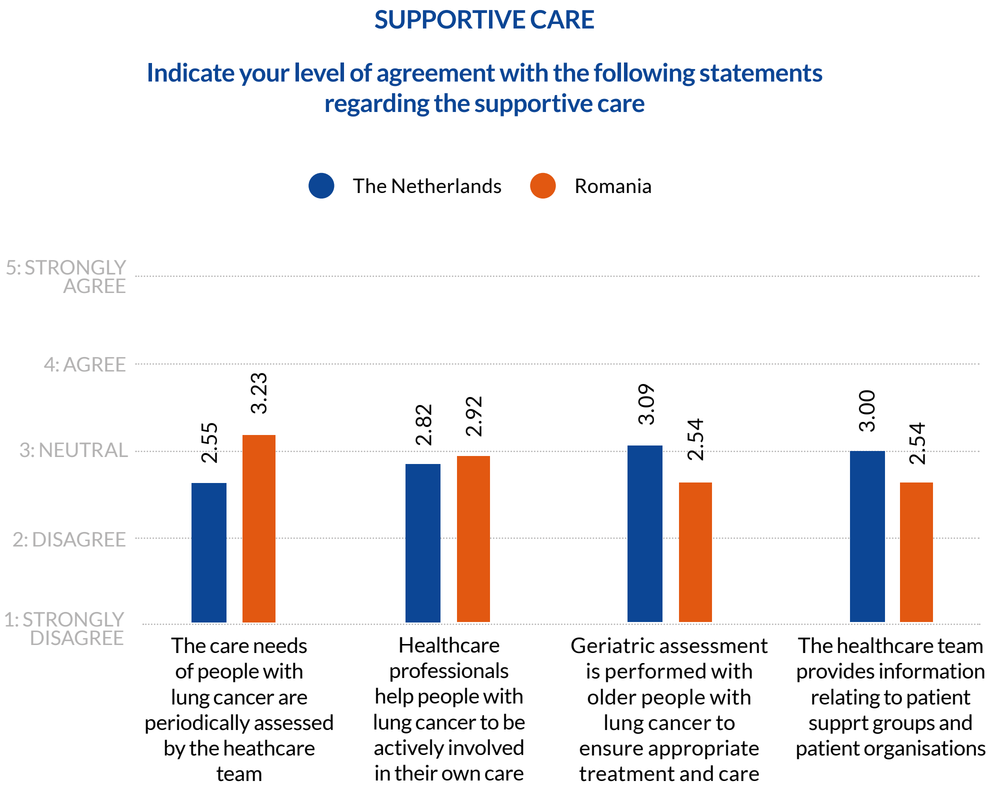
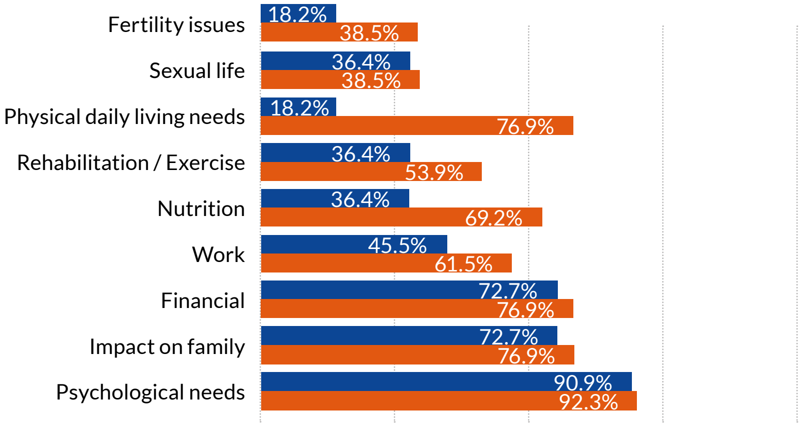


FIGURE 41. Supportive care: level of agreement (The Netherlands and Romania).

Insufficient supportive care contributes to the prevalence of unmet needs. There are three main areas reported by experts from both countries: psychological, family and financial needs (Figure 42).

Our data suggests significant differences regarding physical daily living needs and nutritional needs, which was much more frequently reported by experts from Romania.

This is probably a consequence of higher access to rehabilitation / physiotherapists and to dietitians / nutritionists in The Netherlands (Table 9).

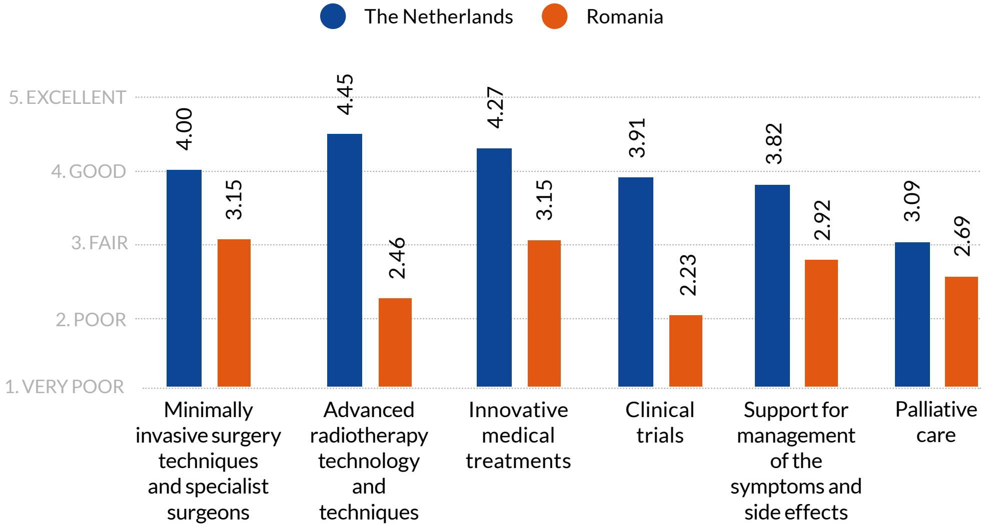


What are the most prevalent unmet supportive care needs experienced by people with lung cancer?

FIGURE 42. Unmet supportive care needs (The Netherlands and Romania).

The last quality care indicator assessed is **access.** Experts from The Netherlands valued positively the patient access to medical innovation: surgery, radiotherapy, medical treatments and clinical trials (Figure 43). However, 5 out of 11 responded that access to palliative care is poor / fair in their country.

ACCESS



How do you value the level of access to the following items by people with lung cancer from your country?

FIGURE 43. Access: level of agreement (The Netherlands and Romania).

In contrast, the access situation in Romania is one of the main challenges in the lung cancer pathway, according to experts consulted. Access to advanced radiotherapy technologies (8 / 13) and to clinical trials (9 / 13) is low, and there is room for improvement also in all the other issues assessed, especially in palliative care access

Figure 44 emphasizes again that the level of access to innovation is high in The Netherlands and moderate in Romania.

Only 4 out of 13 experts from Romania considered that people with lung cancer have access to professionals with high expertise in this disease. This proportion is much higher in The Netherlands (10 / 11).

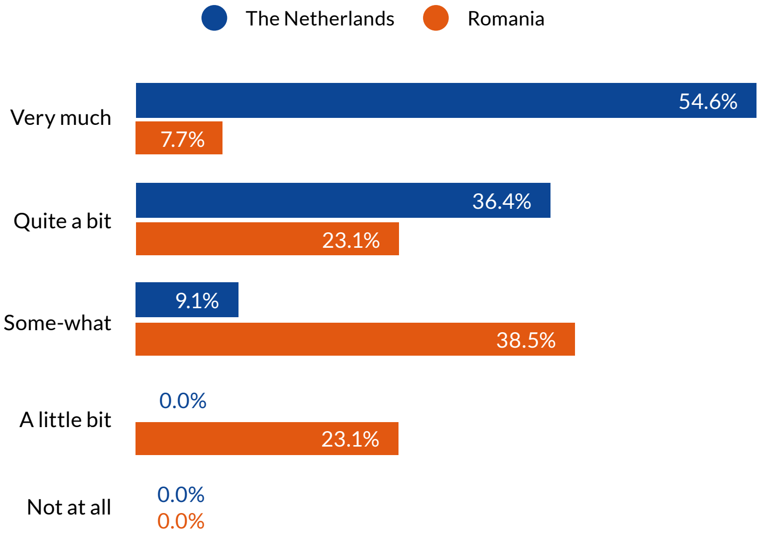

To what degree do you think people with lung cancer have access to clinicans and healthcare professionals with a high expertise in lung cancer?

FIGURE 44. Access to high expertise (The Netherlands and Romania).

5. CALL TO ACTION

Implement rapid referral pathways to reduce the time between diagnosis and treatment for people with suspected lung cancer.

National programs should be implemented to organize access to coordinated and comprehensive diagnostic services. This pathway needs to be focused on the milestones of the diagnostic process and ensure rapid access to diagnostic pathways and specialists.

Develop targeted screening programs to aid in the earlier diagnosis of lung cancer.

We urge everyone in the lung cancer community to come together to lobby for lung cancer screening to be included in the EU Council Recommendation on Cancer Screening; and in parallel work collectively to promote education and awareness of lung cancer screening across Europe. Now it is more important than ever, as the Europe´s Beating Cancer Plan has committed the European Commission to update their recommendations on cancer screening.

Provide more information to people impacted by lung cancer to enable shared decision making and improve their quality of life.

Healthcare teams should offer complete and comprehensive information about lung cancer and the treatments available. Additionally, people with lung cancer require further information and support for managing side effects and guidance to reduce the risk of complications.

6. ACKNOWLEDGMENTS

We want to start by expressing our sincere gratitude to the **991 people who completed our survey.** Thank you for sharing your experiences and preferences with us. We hope that this report reflects your priorities as accurately as possible.

Thank you to the **24 experts from The Netherlands and Romania** who also participated in this research. We really appreciate your time sharing your thoughts and knowledge to better understand the lung cancer pathway in your country.

A special thanks goes out to **our members.** This report was possible thanks to all the LuCE members, who provided their insights and disseminated the surveys across Europe. We are very grateful that our members recognise the value of working together at the European level, to face the challenges that we all share.

Our thanks to the **members of the LuCE Report Working Group** for their great support: Anne-Marie Baird, Karen Clayton, Alina Comanescu, Nicoline Ehrhard, Merel Hennink, Annette Hans, Sandra Karabatic, Leslie Manot, Debra Montague, Korina Pateli-Bell, Shani Shilo and Diego Villalón. Thank you for your generosity and time.

We also want to give a special thank you to **MÁS QUE IDEAS Foundation** for their continued support, especially Diego Villalón. This report would not have been possible without the key role they played in bringing this to fruition.

Lastly, we would like to thank all of the **organisations that provide support to LuCE.** Thank you for your commitment to people impacted by lung cancer: Amgen, AstraZeneca, Bayer, Blueprint Medicines, Bristol-Myers Squibb, Boehringer Ingelheim, Daiichi Sankyo, Janssen, Lilly, Merck, MSD, Novartis, NovoCure, Regeneron, Roche, Sanofi, Takeda and Thermo Fisher.

Teamwork has made this report possible.

Let´s continue working together and bring true meaning to the phrase

`Alone we can do so little, together we can do so much´.

7. LUNG CANCER EUROPE (LuCE)

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

Our vision

All Europeans (patients, families and caregivers) impacted by lung cancer will have equity in 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 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.

Meet our team:

Anne-Marie Baird
(Ireland)
President

Ewelina Szmytke
(Poland)
Vice-President

Korina Pateli-Bell
(Greece)
Treasurer

Marjo Forsbloom
(Finland)
Board member

Lavinia Magee
(UK)
Board member

Alfonso Aguarón
(Spain)
Project Manager

Tammy Cruickshank
(Spain)
Administrator

Maeve O'Sullivan
(Ireland)
Executive Officer

David Sepúlveda
(Spain)
Project Manager
at Máxima Web

About our members

LuCE provides a platform for organisations and individuals working for people impacted by lung cancer. As of November 2022, there are 16 full members, 15 associate members and 5 individual members, representing 24 countries. We encourage you to learn more and support LuCE and our member organisations.

www.lungcancereurope.eu/our-members

FULL MEMBERS

Patientforeningen Lungekræft
www.lungekraeft.com

Lélek-zet Egyesület
www.lelekzetegyesulet.hu

ALK Positive Deutschland
www.alkpositiv-deutschland.org/

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

Women Against Lung Cancer in Europe
www.womenagainstlungcancer.eu

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

Israel Lung Cancer Foundation
www.ilcf.org.il

Longkanker Nederland
www.longkankernederland.nl

Lungekreftforeningen
www.lungekreftforeningen.no

Stowarzyszenie Walki z Rakiem Pluca
www.rakpluca.org.pl

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

Lungcancerförening
www.lungcancerforeningen.se

Pulmonale
www.pulmonale.pt

Leben mit Lungenkrebs
www.krebsinformationsdienst.de

Fairlife Lung Cancer Care
fairlifelcc.com

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

ASSOCIATE MEMBERS

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

Jedra
jedra.toraks.hr

SuomenSyöpäpotilaat
www.syopapotilaat.fi

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

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

European School of Oncology (ESO)
www.eso.net

Dzivibas Koks
www.dzivibaskoks.lv

De L'air
www.assodelair.fr

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

Community Health Association
www.facebook.com/pg
SanatatepentruComunitate

Društvo onkoloških bolnikov Slovenije
www.onkologija.org

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www.fundacionmasqueideas.org

European Thoracic Oncology Platform (ETOP)
www.etop-eu.org

Pembe Hanim
www.pembehanim.com.tr

Athena Women against Cancer
www.athena-wac.com

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REGENERON

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8. ANNEX I. Detailed breakdown of participant characteristics

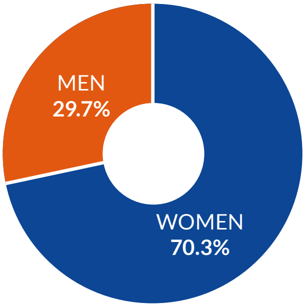


FIGURE 43.
GENDER
(n= 981)

FIGURE 44. **AGE** (n= 988)

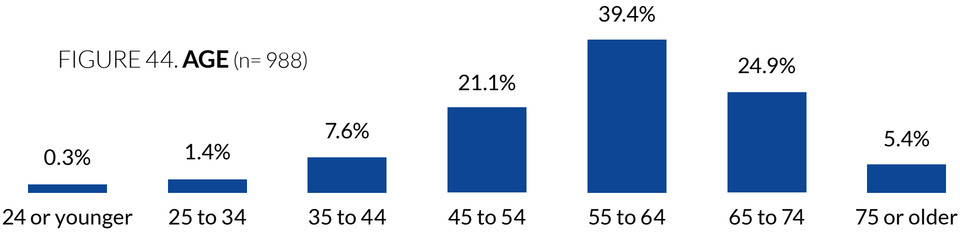


FIGURE 45.
LEVEL OF EDUCATION
(n= 988)

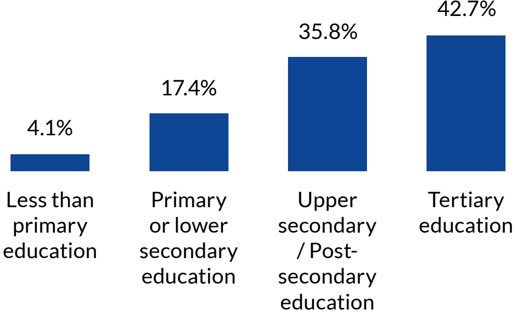


FIGURE 46.
AREA OF RESIDENCE (n= 989)

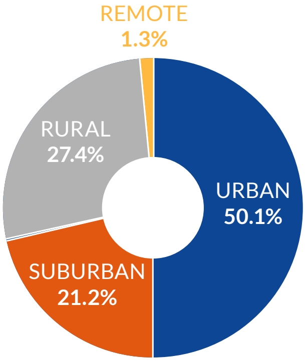


TABLE 12: **Country of residence** (n= 987)

	Country	%	n
1	France	21.1%	208
2	Germany	17.9%	177
3	The United Kingdom	8.2%	81
4	Poland	6.8%	67
5	Greece	6.3%	62
6	Spain	5.2%	51
7	Italy	5.0%	49
8	The Netherlands	4.8%	47
9	Israel	4.5%	44
10	Denmark	3.8%	37
11	Finland	3.4%	34
12	Romania	2.4%	24
13	Sweden	1.6%	16
14	Belgium	1.5%	15
15	Croatia	1.4%	14
16	Slovenia	1.4%	14
17	Ireland	1.0%	10
18	Austria	0.8%	8
19	Norway	0.8%	8
20	Switzerland	0.8%	8
21	Hungary	0.5%	5
22	Portugal	0.4%	4
23	Latvia	0.2%	2
24	Kosovo	0.1%	1
25	Malta	0.1%	1

TYPE OF LUNG CANCER	%	n
Non-small cell lung cancer (adenocarcinoma)	75.2%	743
Non-small cell lung cancer (squamous)	6.3%	62
Non-small cell lung cancer (other subtype)	6.1%	60
Small cell lung cancer	6.2%	61
Another type of lung cancer	3.1%	31
I don´t know	3.1%	31

TABLE 13: **Type of lung cancer** (n= 988)

FIGURE 47 : **Is your tumour positive for any marker?** (n= 981)

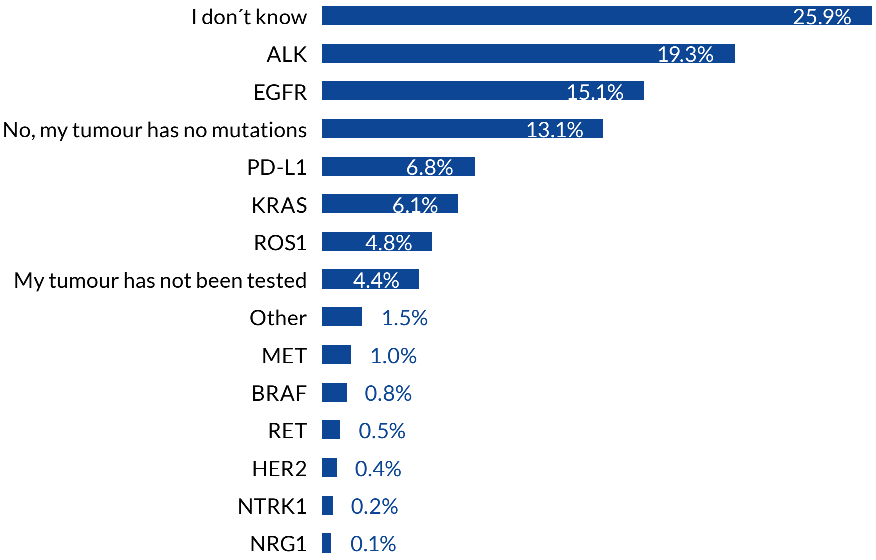
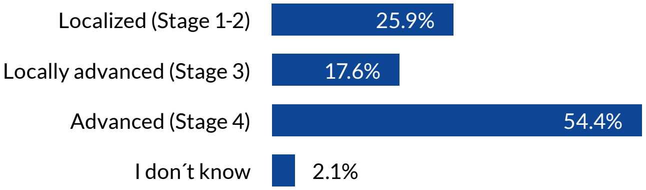


FIGURE 48 : : **Clinical situation at diagnosis** (n= 988)



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Lung Cancer Europe

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