9th LuCE REPORT

# Empowering voices:

## Knowledge and decision-making among people impacted by lung cancer in the Netherlands

An initiative of: Lung Cancer Europe

With the support of: Longkanker Nederland

**Edited by:**
Lung Cancer Europe (LuCE)

**With the support of:**
Longkanker Nederland

**Coordinated by:**
Fundación MÁS QUE IDEAS (Spain)

**Graphic concept and design:**
Barcia Studio: **barciastudio.com**

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**info@lungcancereurope.eu**

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# INTRODUCTION

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

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

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

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

# DESCRIPTION AND METHODOLOGY

## DESCRIPTION:

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

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

## METHODOLOGY:

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

This Country Report includes results obtained from 153 participants from the Netherlands. This represented 7.5% of the total number of participants in the 9th LuCE Report[1]. All figures included in this report compare data collected from Dutch people with the average of all participants.

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[1] *153 responses from the Netherlands / 2,044 responses from the WHO European Region (including the Dutch responses)*

## Overview of Dutch participants characteristics:

**72.5%** People diagnosed with lung cancer (111)

**27.5%** Relatives (42)

**58.9%** People with (or their loved one) NSCLC - adenocarcinoma (89)

**80.4%** Women (123)

**19%** Men (29)

**25.2%** I don´t know if my tumour is positive for any marker (38)

**20.5%** EGFR (31)

**39.2%** 55-64 age group (60)

**32%** 65-74 age group (49)

**58.6%** Stage IV (89)

**20.4%** Stage III (31)

**51%** Upper secondary (78)

**46.4%** Tertiary education (71)

**58.6%** 1st level hospital (local) (89)

**44.1%** 3rd level hospital (university) (67)

# RESULTS

*The majority of Dutch participants stated that information about lung cancer was very important, but 4 in 10 did not receive all the information that they needed.*

Information about the disease is a key element to a better quality of life. Results from our research show high interest among people impacted by lung cancer in having access to medical and healthcare information. The majority of participants from the Netherlands (86.9%) considered this information was extremely important.

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

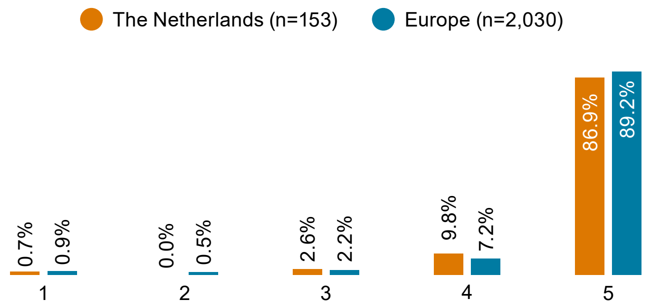
A total of 40.7% of participants highlighted that they did not receive enough information about their diagnosis, treatment and care. People impacted by lung cancer in the Netherlands reported receiving all the information they needed similar to the European average (59.3% *vs.* 59.8%).

> *I received incomplete information about the diagnosis and all treatment options.*

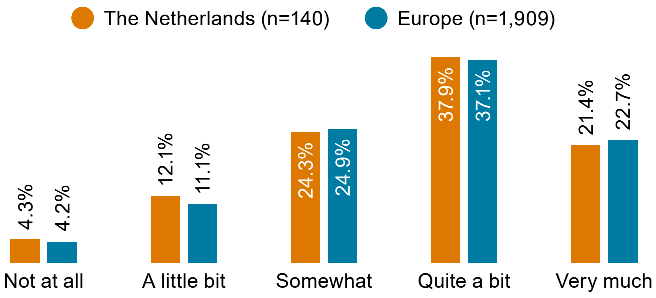
> *Consultations should be longer. Time is limited, which restricts the amount of information given and the opportunity to ask questions.*

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

*1 is 'not important at all' and 5 is 'extremely important´*



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



> *Doctor should be well-informed about the lung cancer subtype, so the patient receives clearer information.*

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

Approximately 50-60% received full diagnostic information and had good access to their healthcare team throughout the diagnostic pathway. Our data shows that almost half of Dutch participants reported having insufficient information or lack of access to the healthcare team during these challenging times.

*Almost half of Dutch participants reported having insufficient information about the diagnostic pathway.*

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

**The Netherlands (n=153)** *vs.* **European average (n=2,036)**

| | Not at all / A little bit | Somewhat | Quite a bit / Very much |
|---|---|---|---|
| We received information about the next steps along the diagnostic pathway | **17.9%** | **25.2%** | **57.0%** |
| | **17.4%** | **26.7%** | **56.0%** |
| We received information about the procedures relating to the diagnostic tests | **20.3%** | **25.5%** | **54.2%** |
| | **21.4%** | **26.1%** | **52.4%** |
| We were informed about the significance of the results | **25.5%** | **20.9%** | **53.6%** |
| | **17.5%** | **23.9%** | **58.6%** |
| We had proper access to the healthcare team during the diagnostic process | **22.9%** | **23.5%** | **53.6%** |
| | **20.4%** | **24.3%** | **55.3%** |
| We had the opportunity to receive answers to questions about the diagnostic process | **21.7%** | **17.8%** | **60.5%** |
| | **19.6%** | **23.8%** | **56.6%** |

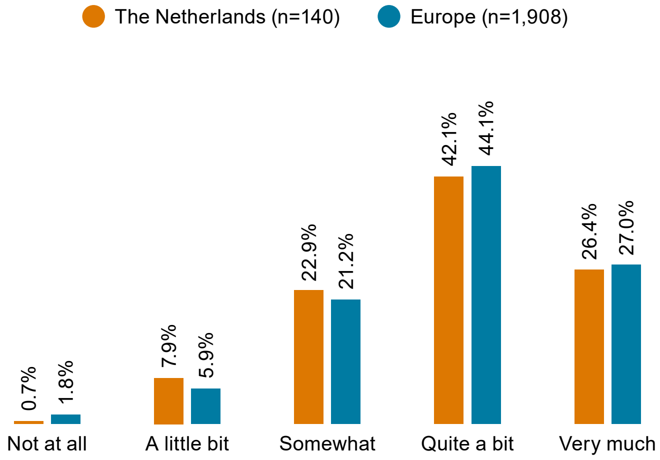
*One in three Dutch participants reported having difficulty understanding the information they received.*

Our research identifies challenges in understanding the information received throughout the disease journey. A total of 31.5% of participants from the Netherlands stated that they did not fully understand the information received about diagnosis, treatment and care. Only 26.4% of participants reported fully understanding all of the information received.

*One in three Dutch participants did not have a good level of knowledge about their disease.*

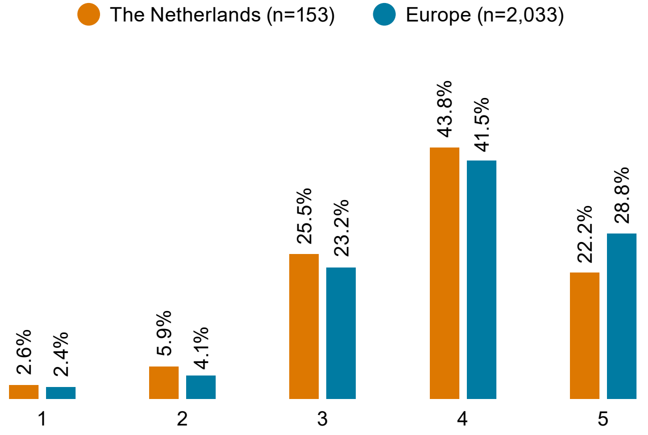
Our data suggest that the level of knowledge about lung cancer among those impacted by the disease in the Netherlands is slightly lower than the European average. Most participants from the Netherlands (66%) reported having good understanding of the disease. However, we still find a significant number of participants – 1 in 3 – who did not have a good level of knowledge about their disease.

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



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

*1 is ‘very limited understanding’ and 5 is ‘full understanding´*

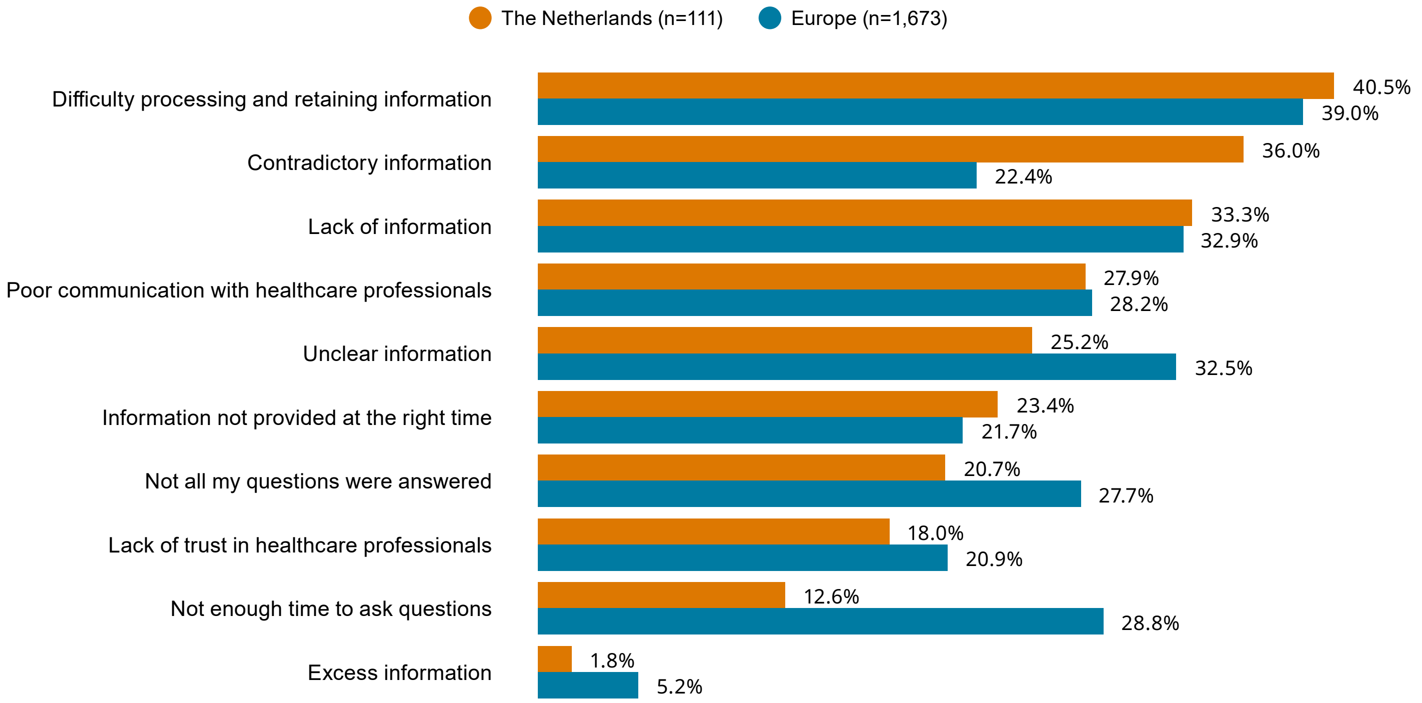


Dutch participants reported some barriers to information and communication. A significant number of survey respondents indicated difficulty processing and retaining information (40.5%), contradictory information (36%) and lack of information (33.3%).

*4 in 10 participants from The Netherlands reported difficulty processing and retaining information.*

Issues with communication with healthcare providers were also highlighted by a significant number of participants from the Netherlands: poor communication with healthcare professionals (27.9%), unclear information (25.2%), and information not provided at the right time (23.4%), among others. It is noteworthy that Dutch participants reported fewer barriers in terms of having time to ask questions and receive answers, compared to the European average.

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



*Side effects were reported as the main informational need by Dutch participants.*

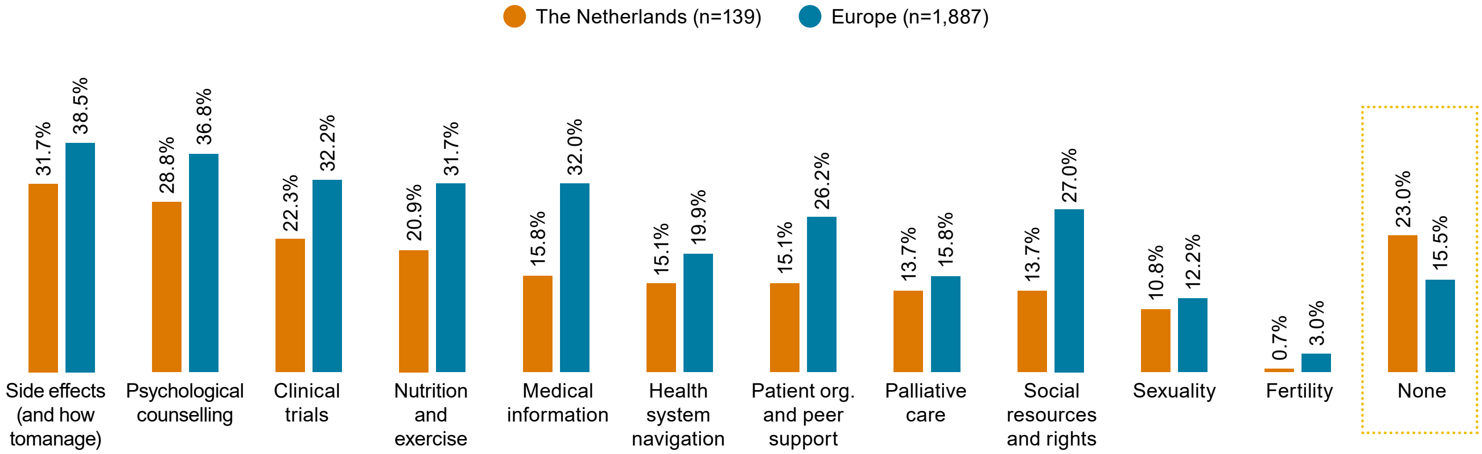
Information and support throughout the disease journey are crucial for appropriate care and well-being. However, 77% of respondents from the Netherlands impacted by lung cancer reported lacking some form of support or information. The most frequently reported informational gaps were related to side effects (31.7%), psychological counselling (28.8%) and clinical trials (22.3%).

> *I had symptoms for a long time, but due to a lack of information, I couldn't ask the right questions.*

> *Alongside talks with the oncologist, we also need conversations with psychological/social care professionals.*

> *Effects and side effects are never clear in advance.*

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



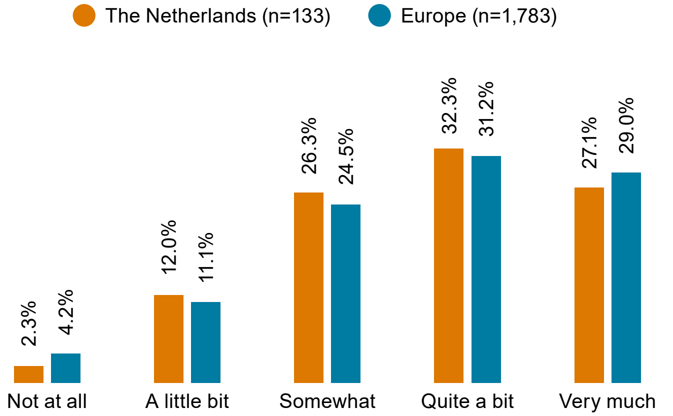
Physicians have traditionally held the decision-making responsibility. However, there is a growing emphasis on shared decision-making, where people living with a disease, or their loved ones, are more actively involved in their healthcare decisions. This approach respects patient autonomy and encourages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

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

Our research finds consensus on the importance of patient engagement in healthcare decisions. Almost all people surveyed in the Netherlands (97.7%) felt, to some extent, that their opinion must be considered in the decision-making process. A total of 59.4% of Dutch respondents felt that their opinions must `*very much*´ or `*quite a bit*´ be incorporated into the conversations.

The person diagnosed with lung cancer has the right to make decisions about their treatment and care. Therefore, it is important to explore the differences between patients and caregivers. Notably, 98% of Dutch people with lung cancer surveyed believed that their opinion should be taken into account, with 72.7% strongly supporting this (`*very much*´ or `*quite a bit*´). On the other hand, 97.1% of caregivers surveyed also felt that their opinions should be considered in treatment and care discussions, with most (76.5%) believing their voice should be taken into account to some extent (`*a little bit*´ or `*somewhat*´).

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



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

Responses collected in the Netherlands

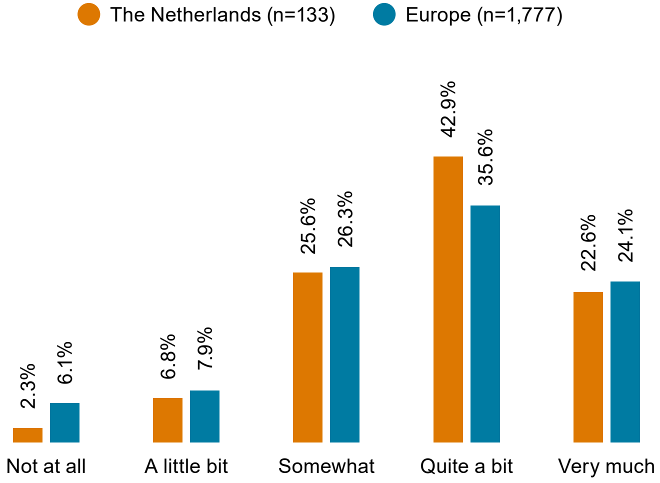
| | People with lung cancer | Caregivers |
|---|---|---|
| Not at all | 2.0% | 2.9% |
| A little bit | 5.1% | 32.4% |
| Somewhat | 20.2% | 44.1% |
| Quite a bit | 40.4% | 8.8% |
| Very much | 32.3% | 11.8% |

*Seven out of ten Dutch participants were satisfied with their level of involvement in shared decision-making, and 65.5% felt that treatment and care was aligned with their preferences.*

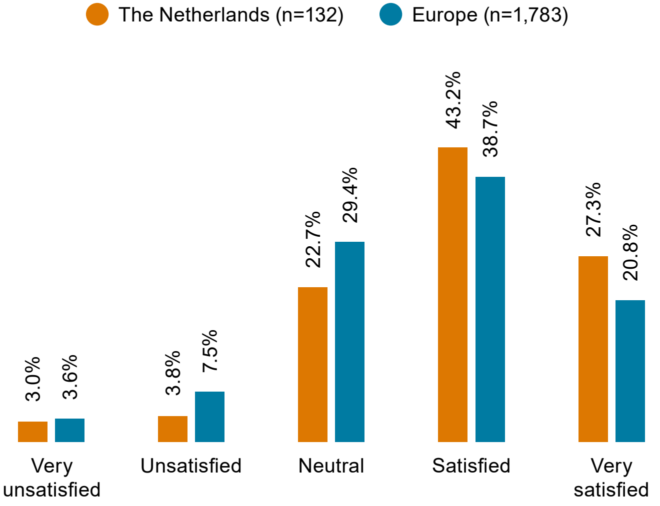
Despite the high interest of people impacted by lung cancer regarding shared decision-making, the data presented in this report highlights an insufficient involvement of patients and caregivers in this process. Consequently, only 65.5% of participants from the Netherlands felt that the treatment and care plan aligned with patient preferences by `*quite a bit*´ or `*very much*´[2].

Patient and caregiver satisfaction is an important factor in the healthcare journey. Out of all of the Dutch participants, 70.5% positively valued their involvement in the decision-making process, which was 11 percentage points higher that the European average (59.5%)[3].

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



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



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

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

*The main obstacle reported for participation in decision-making was the emotional difficulties in dealing with important decisions.*

It is crucial to have a good understanding of the disease and the various treatment and care options to effectively participate in decision-making. However, 1 in 3 participants from the Netherlands (35.6%) reported emotional difficulties in dealing with important decisions.

Complex information was selected as the second most common obstacle for meaningful participation in decision-making. Thus, there is an urgent need to improve the communication skills of physicians and facilitate open and honest dialogue with patients and caregivers.

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

| | The Netherlands (n=118) | Europe (1,701) |
|---|---|---|
| Emotional difficulties in dealing with important decisions | **35.6%** | **34.0%** |
| Complex information (difficult to understand) | **32.2%** | **49.2%** |
| Difficulties in finding trustworthy sources of information | **16.9%** | **27.5%** |
| Poor communication with the healthcare team | **16.1%** | **37.6%** |
| Barriers to access to a second opinion | **5.9%** | **20.0%** |
| Pressures and influence from family and friends | **4.2%** | **5.6%** |

> *Doctor should clearly explain everything and don’t hide anything. For doctors, some things are obvious, but that’s not the case for the layperson sitting across from them.*

> *At first, emotions often get in the way; later it’s easier to process information.*

> *Because my husband died young from lung cancer, emotions were very intense at the time of my diagnosis.*

> *We need more time with an oncology nurse or doctor to ask questions — or the option to ask questions via email.*

# CALL TO ACTION

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

Despite most participants considering health information to be very important, 1 in 3 reported having a poor understanding of lung cancer, and a similar proportion stated that they did not understand information about diagnosis and treatments.

## Clinicians should develop and implement a communication strategy to encourage and support shared decision-making.

Participation in decision-making is highly valued, but 1 in 3 did not feel that treatments were sufficiently aligned with their preferences. Emotional difficulties in dealing with important decisions and the complexity of the information have been identified as the main obstacles to effective participation in decision-making.

# ABOUT US

Lung Cancer Europe

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

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

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

## LuCE Member in the Netherlands

Longkanker Nederland

Longkanker Nederland
**www.longkankernederland.nl**

Longkanker Nederland is the professional patient organization that advocates for everyone affected by lung cancer: patients, family members and bereaved.

At Longkanker Nederland, you can turn to us with all your questions. We listen to you, offer support, and provide information and advice. We also connect you with others like you, so you can (online) share experiences.

Lung Cancer Europe

**Many Faces, One Voice**

www.lungcancereurope.eu

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

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