



9th LuCE REPORT ON LUNG CANCER

Empowering voices:

Knowledge and decision-making among people impacted by lung cancer in Europe



Lung Cancer Europe (LuCE) has launched its 9th LuCE Report:
**Empowering voices: Knowledge and decision-making
among people impacted by lung cancer in Europe**

Lack of information and shared decision making: People impacted by lung cancer struggle with information barriers and demand more involvement in treatment decisions.

Online, November 28th, 2024 - Lung Cancer Europe (LuCE) today launched the 9th LuCE Report entitled 'Empowering voices: knowledge and decision-making among people impacted by lung cancer in Europe'. The event was hosted by Mr. Vytenis Povilas Andriukaitis (Member of the European Parliament and member of the MEP Lung Health Group). The LuCE Report is an annual initiative led by LuCE with the purpose of raising awareness relating to the main challenges faced by people impacted by this disease.

The 9th LuCE report explores the level of information, knowledge and decision-making involvement among those affected by lung cancer in Europe. Data collection was through a self-filled online survey (active from May 24th until July 7th, 2024). This survey was completed by 2,040 participants (1,432 people with lung cancer and 608 caregivers) from 34 WHO European Region countries.

This research reveals a concerning lack of awareness and understanding regarding lung cancer among those impacted by the disease. This report highlights the urgent need to raise awareness about lung cancer and empower individuals to actively participate in decision-making.

Anne-Marie Baird, President of LuCE commented:

"Shared-decision making is an important element in person centred cancer care, however from the data in this report we see that this is not the reality for many people living with lung cancer. The implementation of shared decision must be a key metric in determining quality cancer care for all."

Main findings

1. Knowledge about lung cancer

- Before their diagnosis, 55.3% of those diagnosed with lung cancer did not know they were at risk of developing the disease (*not at all/a little bit*).
- While 82.8% of all participants recognised smoking as a risk factor, only a minority were aware of other risk factors such as exposure to radon (17.1%), radiation (21.5%), asbestos (34.8%), and environmental pollutants (38.5%).
- A total of 65.1% delayed seeking medical advice after experiencing symptoms, with 4 out of 10 attributing this to not recognizing the symptoms associated with lung cancer (46.5%) or misattributing them to other conditions (42.9%).

- A quarter of participants admitted to having poor knowledge of the disease (28.8%), not being aware of biomarkers (22.2%) and not fully understanding the prognosis (24.2%).

2. Access to information

- Most participants (89.2%) believed that information was extremely important. However, 40.2% did not receive enough information and 28.9% stated that they did not fully understand the information received.
- One-third did not positively value their communication with their healthcare team, citing limited time for the consultation (50.9%) and poor communication skills (41.7%).
- Nine out of 10 sought health information outside of the healthcare system, but 1 in 4 either found no information or found it to be inaccurate.

3. Shared decision-making

- Almost all participants believed their opinions should be considered in the decision-making process (98.0% of people with lung cancer and 91.5% of caregivers).
- However, only 49.3% reported being highly involved in this process, and only 55.9% felt that their opinion was considered.
- As a result, only 59.5% positively valued their involvement in the decision-making process.
- Complex information (49.2%) was identified as the main obstacle to meaningful participation in decision-making.

Call to action

- **Raise awareness of lung cancer and early detection, and support risk reduction efforts.**
- **Enable shared decision making to help improve quality of life.**



REPORT

The full report and the executive summary are accessible here:
<https://www.lungcancereurope.eu/reports-and-position-papers/>

Lung Cancer Europe (LuCE)

Lung Cancer Europe (LuCE) is a not-for-profit umbrella organisation established in 2013 to provide a platform for lung cancer patient advocacy associations at a European level. Our vision is that all Europeans impacted by or at risk of lung cancer will have access to optimal care so that they have the best possible outcomes and quality of life. 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.

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