



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

· Executive Summary ·

Introduction and methodology

This report is a descriptive research analysis that 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.

Results

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*). Similarly, 58.3% of caregivers were also unaware of the risk of their loved one developing lung cancer.

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 to the chest (21.5%), asbestos (34.8%), and environmental pollutants (38.5%).

Possible lung cancer symptoms were largely unknown to people impacted by lung cancer before their diagnosis. 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%) or not fully understanding the prognosis (24.2%).

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. The main barriers cited were difficulties in processing the information (39.0%), insufficient information (32.9%), and unclear information (32.5%). The most frequently identified information needs related to side effects (38.5%), followed by psychological counselling (36.8%).

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 the healthcare system, but 1 in 4 either found no information or found it to be inaccurate.

Shared decision-making

Almost all participants believed their opinions should be considered in the decision-making process (98.0% of patients 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, followed by poor communication with their healthcare team (37.6%).

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.

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