



## 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 24<sup>th</sup> until July 7<sup>th</sup>, 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.

With the collaboration in Norway of:



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