

· 2022 ·

7th LuCE REPORT ON LUNG CANCER

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

· Executive Summary ·

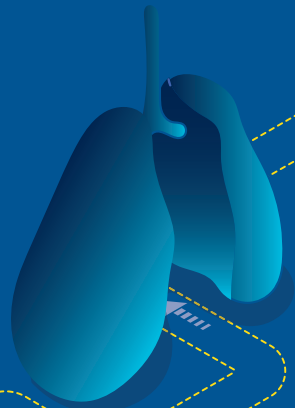
| Background

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. LuCE promotes a person-centered and multidisciplinary approach to healthcare delivery across the entire lung cancer pathway.

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. Data was collected through a self-filled online survey and was open to those diagnosed with lung cancer in the WHO European Region.

| Survey Participants

The survey was completed by 991 participants across 25 European countries. The majority were women (70.3%) between 55-64 years of age (39.4%). A total of 75.2% were diagnosed with 'non-small cell lung cancer – adenocarcinoma', 54.4% had Stage IV disease and 57.7% confirmed that their tumor was positive for a molecular marker.



Results

Diagnostic pathway

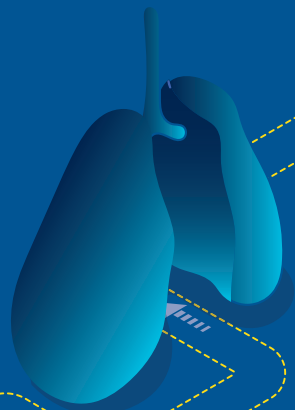
A substantial number of participants experienced significant delays from the first signs and suspicion of lung cancer to the diagnosis of the disease and start of treatment.

- 40.3% waited more than one month since they experienced their first symptoms until they contacted their doctor
- 1 out of 5 participants 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

According to survey participants, the measure that would help the most to obtain an earlier diagnosis of lung cancer is to implement screening programmes (64.0%). Additionally, more than 1 out of 3 people surveyed highlighted the necessity of improving education for primary care doctors for early recognition, and the importance of shortening waiting times in the diagnostic pathway.

Key priority measures to improve the experience along the diagnostic pathway were: fast tracking services that reduce waiting times (83.5%), providing a name from the healthcare team and number of a direct contact if needed (73.4%), and providing a roadmap and clear information about the diagnostic process (72.1%).

Education about side effects and complications is valued as the most priority measure in the time from diagnosis to treatment (80.1% considered it as a high priority).



Results

Treatment pathway

Participants reported three main types of information that might help in their treatment decision making: treatment options available (79.3%), advantages and disadvantages of each treatment option (73.8%) and potential side effects and risks (69.8%).

Receiving understandable information is crucial for making a treatment decision. However, only 52.7% confirmed they received and understood all of the information they needed before signing the informed consent document. There was a substantial number of participants who reported a lack of information prior to treatment, especially when receiving pharmacotherapy (i.e. targeted therapy).

Half of the participants suggested the use of common words and terms (56.0%) and the value of having a conversation with their specialist (51.1%) to better understand the informed consent document and to improve the treatment decision process.

The main priority reported along the treatment pathway was to improve the 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.

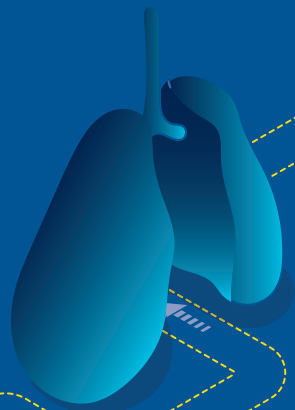
Supportive care

Supportive care is one of the key components in an optimal care pathway. However, 35.4% recognized that their overall needs were not addressed enough by their healthcare teams. When asked about the spheres of their lives not addressed by healthcare teams, participants identified emotional (52.5%), physical (39.7%) and social (31.3%) spheres as unmet needs.

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

Accessibility is an important matter in the care pathway. Half of respondents would have preferred to obtain information from the healthcare team by phone in non-urgent situations, followed by an in person appointment in 1 – 3 days (23.2%). Communication between people with lung cancer and healthcare professionals is crucial for good supportive care along the disease pathway, but significant number of participants stated that they missed information and guidance. The type of information they missed the most was about clinical trials (48.2%), followed by emotional and social issues (40.3%) and advanced care planning (38.6%).

Half of participants (49.2%) stated not to have shared all aspects of their health status with their healthcare team. Access to specialised cancer nurse consultations (44.1%), longer medical consultations (43.9%) and having a central point of contact (43.5%) were selected as the most important measures to improve the communication between people with lung cancer and healthcare professionals.



Call to action

- Implement rapid referral pathways to reduce the time between diagnosis and treatment for people with suspected lung cancer
- Develop targeted screening programs to aid in the earlier diagnosis of lung cancer
- Provide more information to people impacted by lung cancer to enable shared decision making and improve their quality of life

Full Report

Access the full 7th LuCE Report:
www.lungcancereurope.eu

Get in touch: