



Lung Cancer Europe



REPORT ON LUNG CANCER EARLY DIAGNOSIS AND SCREENING CHALLENGES

· Executive Summary ·

Introduction

Since its establishment in 2013, one of the key goals of Lung Cancer Europe (LuCE) has been to generate evidence on the main challenges faced by the lung cancer community. For our fourth report, we explored issues and challenges around two main topics: early diagnosis and screening. The data provided by this report gives a better understanding around these issues

in the community and thus a call to action in order to remove barriers to early diagnosis as well as lung cancer screening. By undertaking these actions, we will ensure better outcomes for people impacted by this disease. This report includes the results of a patient survey developed in conjunction with Fundación MÁS QUE IDEAS from 368 patients across 18 European countries.

General Characteristics

A total of 368 people with lung cancer completed the online patient survey. This consisted of 246 females and 122 males, with over half in the 55-74 age bracket.

Over three quarters of patients were diagnosed with non-small cell lung cancer, with adenocarcinoma the most common sub-type (81% of all NSCLC diagnoses). Over two thirds were diagnosed with either Stage IV (48.9%), or Stage III (15.2%) disease, underscoring late presentation as a huge issue for the community. In terms of molecular testing, a number of respondents had mutation positive lung cancer tumours.

Worryingly, we did identify that 6% of respondents did not know what type of lung cancer they had been diagnosed with; 1 in every 7 (15.76%) did not know the stage of their disease; and almost one third did not know if their tumour was tested for any of the common mutations or PD-L1. There is a need for better communication between clinicians and people impacted by lung cancer. This lack of clarity in the most basic of information, could lead to further patient stress and uncertainty, and most importantly serve as an obstacle to take part in shared decision making in their lung cancer journey.

Delays in early diagnosis

Around half of the respondents of the survey stated it took more than 2 weeks to contact their doctor when they first experienced some symptoms. Lack of awareness was the main contributory factor, as the main two causes for this delay seemed to be that patients didn't know they were experiencing a symptom of lung cancer and/or they didn't realise the symptom was serious.

Regarding healthcare system challenges, it was distressing that almost half of the patients who reported worrisome symptoms had 3 or more visits with a primary care doctor before being referred to a

specialist. This is alarming, given that any delays can mean a greater chance of presenting with late stage disease, and thus result in less treatment options. Over half of all respondents, felt that their diagnosis could have been made earlier.

The report identified a great need for improved education and awareness of lung cancer, both in terms of risk factors and symptom awareness for both the public and HCPs. This is in light of over 70% of patients stating that they had no or slight knowledge regarding lung cancer symptoms. Additionally, adequate funding is required to ensure that patients have access to primary health care, specialists, diagnostic scans and biopsies in a timely manner.

Lung cancer screening

Although there are some pilot lung cancer screening programmes being undertaken in a number of European countries, it is not something that is part of the standard of care or has been implemented widely in any part of Europe at the time of this report.

The results gathered from the patients' survey have shown that there is a lack of understanding of not only what defines lung cancer screening but also of general awareness around it in the vast majority of respondents. This has a great impact on how patient's understand benefits, harms and screening expectations.

There is a need for a proper screening information campaign throughout Europe in order to increase the awareness and understanding of lung cancer screening. Nearly 9 out of every 10 of those surveyed believe that lung cancer screening can save lives and ultimately 90% felt that lung cancer screening should be available in their country. This provides evidence to advocate for screening at an individual, organisational and political level.

Call to action

Given the findings of this report, we now ask you to work with us as we make the following Call to Action.

1. Early diagnosis

We call on all stakeholders to work together as a community to design and drive an education and awareness campaign around lung cancer risk factors and symptoms recognition; with unified messaging in non-stigmatising language that can be translated into multiple languages and used across Europe.

2. Lung Cancer Screening

We urge everyone in the lung cancer community to come together to lobby for lung cancer screening to be included in the EU cancer screening guidelines; and in parallel work collectively to promote education and awareness of screening across Europe.

Additional information

If you would like to get the full IV LuCE Report on lung cancer early diagnosis and screening challenges you can download it by accessing

<http://www.lungcancereurope.eu/wp-content/uploads/2019/11/WEB-VERSION-IV-LuCE-Report.pdf>

Get in touch:



Lung Cancer Europe

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