Patients' experiences of lung cancer during COVID-19

Insights from Portugal

GLOBAL LUNG CANCER COALITION

Introduction

The COVID-19 pandemic has had a profound impact on patients, including those living with lung cancer, and healthcare systems around the world.

The Global Lung Cancer Coalition (GLCC), an alliance of 42 patient organisations from 30 countries across the world, wanted to understand if COVID-19 is still impacting the care patients receive, and to compare the experiences of patients in different countries.

In December 2021, the GLCC shared a **global online patient experience survey**.

The survey ran for eight weeks and received **555 responses** from patients across **21 countries**.

Key findings from Portugal

Demographics

17 lung cancer patients or their carers responded

59% of respondents identified as female, **41%** identified as male

82% were diagnosed in the last **five years**

88% have non-small cell lung cancer

Treatment

82% of responding patients are currently **having treatment**. **12%** had **finished treatment**, and **one patient** had **just been diagnosed**

Involvement in decisions

82% felt involved in decisions about their treatment and care. **6%** said they **were not** involved but would like to have been

Accessing information

Almost 70% said they got the **information they needed** at the right time. Some patients had to look for more information, or said that what they received wasn't helpful or was given too late

Screening

82% of responding patients said they **would attend** a screening appointment if invited

Two patients said they were **not sure** if they would attend a screening appointment

Emotional impact

Getting the diagnosis had the biggest emotional impact for **57%** of patients, followed by **telling family and friends (50%)** and **waiting to see if treatment was working** (36%)

57% of responding patients said they are **fearful of relapse. 43%** are **worried about the impact on their family** and **36%** are **worried about the financial impact**

38% of patients stated that either **speaking to their treatment team or to family and friends** was the most helpful in dealing with their emotions

Impact of COVID-19

100% of responding patients **have been vaccinated** against COVID-19

69% of patients said there was **no difference** in how easy it has been to contact their treatment team during COVID-19. **62%** said their **treatment has continued** as normal. Just one patient said that their face-to-face appointments had been **swapped to telephone or video**

A large **majority** (92%) of patients **prefer face-to-face appointments** in most situations, particularly when finding out their diagnosis, for the first consultation, and if there is a change to treatment. A third (31%) would like to telephone if they are worried about something

Call to action

The members of the GLCC are calling for the implementation of the rights outlined in its patient charter, namely ensuring that all lung cancer patients have access to quality healthcare; informed self-determination, which includes involvement in decision-making; and physical and mental integrity.

More information

The GLCC's member in Portugal is **Pulmonale**: https://pulmonale.pt

For more information about this survey and the work of the GLCC, please visit our website: https://www.lungcancercoalition.org/

You can email our secretariat at: glcc@roycastle.org