Patients' experiences of lung cancer

Insights from the United Kingdom

GLOBAL LUNG CANCER COALITION

Introduction

The Global Lung Cancer Coalition (GLCC), an alliance of 41 patient organisations from 29 countries across the world, wanted to understand the challenges patients are currently facing to inform its patient advocacy work and the work of its member organisations.

In March 2024, the GLCC commissioned Censuswide to conduct a survey of lung cancer patients.

The survey received **905 responses** from patients across **18 countries**. For more information about the global findings, please visit www.lungcancercoalition.org/surveys.

Key findings from the United Kingdom

Demographics

50 lung cancer patients responded

68% identified as male; **32%** as female

26% had non-small cell lung cancer

92% were diagnosed in the last **five years**

** Survey respondents were predominantly male, younger, and included a higher proportion of those with small cell lung cancer than the general lung cancer population.*

Experiences of biomarker testing

All eligible respondents **had been spoken to about** biomarker testing

44% did **not understand** what biomarker testing was when they were first spoken to about it

These results suggest a clear need for **improved communication around the topic of biomarker testing**.

Support preferences in coping with lung cancer

76% said they **would like to** get help from **healthcare professionals**, but only **60%** reported **getting help** that way

56% get help from **family and friends**; **34%** from **in-person support groups**; **26%** from **online support groups** and **social media communities**

The respondents sought help from a variety of places. Their **preferences mostly matched where they were already getting help**, except for a **greater desire** for **support from healthcare professionals.**

Involvement with treatment teams

90% of respondents said that they felt **involved** in decisions about their treatment and care (compared to 94% in 2023)

Only **30%** of respondents felt **fully involved** while **54%** wanted to be **more involved** (compared to 39% in 2023)

While overall patient involvement was still high, it was down compared to last year's survey. **Treatment teams need to ensure** all patients have the opportunity to be **involved in decision-making as much as they would like** to be.

Preferred methods of receiving information

Across the patient journey, **face-to-face (f2f) interactions** were preferred. When **finding out the diagnosis** patients preferred **both f2f and video**; **when worried**, patients preferred **f2f and telephone**.

Cancer support hotlines (62%) were the most popular format for receiving information, followed by **print materials (22%)**

Whilst the results indicate a **preference for direct interaction** when receiving information, it remains crucial that treatment teams **understand and accommodate individual patient preferences**.

Call to action

This year's Patient Experience Survey highlighted **encouraging trends, including a high number of indiviuals being spoken to about biomarker testing, and a large majority of respondents who felt involved in decision-making** (despite being slightly down compared to last year's survey). The results, however, also showed that more needs to be done to ensure all patients feel as involved as they would like in decision-making, that treatment teams clearly communicate to patients on topics relevant to their condition, such as biomarker testing, and that patients can access the support options of their preference.

The GLCC is therefore calling for the **implementation of the rights set out in its Patient Charter**, to ensure 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 members in the United Kingdom are:

- **Asthma + Lung UK**: www.blf.org.uk
- **Lung Cancer Nursing UK:** www.lcnuk.org
- **Roy Castle Lung Cancer Foundation:** https://roycastle.org/

For more information about this survey and the work of the GLCC, please visit our website: https://www.lungcancercoalition.org/ or email our secretariat at: glcc@roycastle.org