Patients' experiences of lung cancer

Insights from the United States

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 States

Demographics

50 lung cancer patients responded

78% identified as male; **22%** as female

36% had non-small cell lung cancer

86% 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

90% of eligible respondents **had been spoken to about** biomarker testing

56% 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

66% get **help** from **healthcare professionals**; **60%** from **family and friends**; **26%** from **social media communities**

28% would like to get help through **counselling/therapy**, but only **14%** reported **getting help** that way

The respondents sought help from a variety of places. Their **preferences largely matched where they were already getting help**, except for a **greater need for counselling/ therapy**.

Involvement with treatment teams

98% of respondents said that they felt **involved** in decisions about their treatment and care

Less than half of respondents felt **fully involved**, while **48%** wanted to be **more involved**

While patient involvement was high, **treatment teams need to ensure** patients have the opportunity to be **involved in decision-making as much as they would like** to be.

Preferred methods of receiving information

Throughout the patient journey, **face-to-face interactions** were preferred, especially for **regular check ups** or if patients were **worried about something**

Cancer support hotlines (52%) were the most popular format for receiving information, followed by **print materials (14%)**

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 improved involvement in treatment and care decisions** when compared to last year's results. 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 their preferred support options.

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 States are:

- **Cancer Care**: www.cancercare.org
- **Go2 for Lung Cancer:** www.go2.org
- **Lung Cancer Research Foundation:** lungcancerresearchfoundation.org
- **Prevent Cancer Foundation:** preventcancer.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